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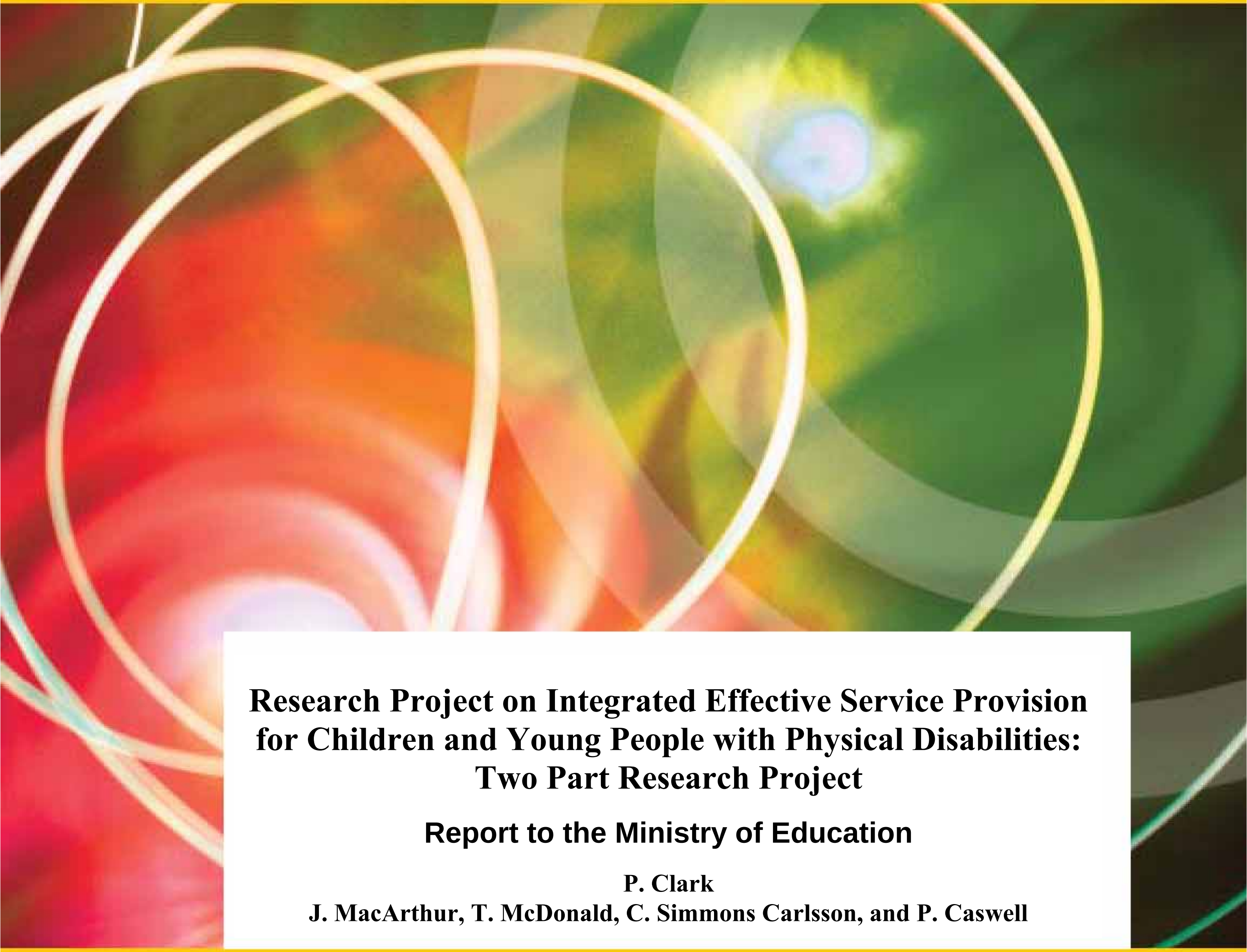

Research Project on Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Two Part Research Project

Report to the Ministry of Education

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Research Project on Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Two Part Research Project

Part 1: Database Project

Phillipa Clark

Part 2: Case Studies

Jude MacArthur, Trevor McDonald, Carolyn Simmons Carlsson, and Pat Caswell

Preface to reports of research into integrated effective service provision for children and young people with physical disabilities

We, the Ministry of Education Advisory Reference Group for Students with Physical Disabilities, are pleased to introduce you to this report of a two year research programme about integrated effective services for children and young people with physical disabilities.

With the implementation of Special Education 2000 (SE2000) we saw significant opportunities for providing more effective services but we were aware that there was much debate about what these effective services could and should look like. Recognising that young people with physical disabilities had a range of support needs and were learning in a number of different settings, we wanted to build a solid base of evidence information that covered a range of effective practices and approaches. With the many perspectives represented in our group, we were well placed to understand the diverse views, hopes and experiences of families, educators and specialist services.

We used a collaborative approach that brought together the experiences of the young people themselves, their families and whānau, their therapists and their teachers. We were determined that the research would take a holistic approach which illustrated the central role of families and the importance of the young person as a person, rather than just a recipient of resourcing and services.

In 2001–2002 we commissioned a scoping study into the characteristics of integrated effective practice. The resulting indicators are contained in the scoping study report - www.educationcounts.govt.nz/publications/special_education/integrated_effective_service

Building on the findings of the scoping study, in 2003 we went on to commission a comprehensive, two part research project. One part focused on getting a better picture of the numbers of students with physical disabilities and the resources these students were drawing on across a number of relevant government agencies. The other consisted of case studies which illustrated approaches to education and therapy for students in a range of different school settings and locations. Together, the two parts of the research provide a rich picture of the experiences of young people with physical disabilities, their families, schools and therapists.

This was the first time statistical and administrative data was used in Aotearoa New Zealand to understand the numbers of young people with physical disabilities, and their situation. Through assembling information from Work and Income, ACC, and the Ministries of Health and Education, the researchers discovered some patterns and gaps in access to resources. This data was supplemented with a survey of schools which were providing therapy services.

The case studies component of the research was conducted by a second team of researchers who accompanied a small number of students throughout one or more typical school days. This layering of approaches and sources of data has created very rich information about the young people in and across all their usual settings and activities.

We acknowledge that the research was ambitious and the resulting information was extensive and complex. Although it has taken time to do justice to the wealth of detail in the reports, the resulting information is still real and relevant.

We are confident that the research reports from both projects will be valuable for everyone involved in striving towards integrated effective practice for students with physical disabilities. The research captures day-to-day challenges and achievements. It does not gloss over the difficulties but reveals potential for improvements across a number of the systems that support these students, and their families and whānau.

This report highlights the aspects of the research which we see as being particularly important for policy, planning and practice, including the:

- importance of collaboration – between families, schools and specialist services, and between different government agencies;
- complexity of needs and ways to address these – requires flexibility and a range of options, rather than a single recipe for services;
- significant contribution made by families, parents, whānau and fono;
- significant contribution made by teachers, teacher aides, therapists and communities;
- the need for professional learning and development;
- value of communicating and sharing information – everyone needs to know what is possible and how to make it happen.

As a group, our vision is for students to engage in learning and participate in their communities to their fullest. For that we all need access – to information, knowledge and quality services. From the research it is clear that there is a marked need for building the knowledge, skills and confidence of all those who support the young people. We can all contribute to this development, as we all have some of the skills, knowledge and information that are needed to provide truly integrated and effective support.

Whether you are involved in developing policy, planning services or providing day-to-day support for young people with physical disabilities, you will find these reports contain information that will help you and improve outcomes for the young people.

A summary of this report is available at www.educationcounts.govt.nz/publications/15361

Authors and Acknowledgements

Part 1, the database research project, was prepared by Phillipa Clark, Department of Paediatrics, University of Auckland. Phillipa would like to offer grateful thanks to Ministry of Education officials for their invaluable help and advice in putting together the document for this part of the project.

Part 2, the case studies, was written by Jude MacArthur, Donald Beasley Institute; Trevor McDonald, Education Associates Ltd; Carolyn Simmons Carlsson, Ministry of Education, Special Education (GSE); and Pat Caswell, GSE. This project was made possible through the willing participation of children, families, school personnel and the staff of GSE and Child Development Services (CDS) teams. The researchers would like to thank the children and families who welcomed the researchers into their homes and shared their experiences with them. Special thanks go to the children who happily agreed to have a researcher 'hang around' with them for two days. Thanks go also to the boards of trustees, principals, teachers, teacher aides, and therapists of the 12 schools visited, for supporting the research and for making the researchers feel welcome. In particular, the researchers wish to record their appreciation of the way they were accommodated in classrooms, and the readiness of school staff to answer questions. The researchers spoke in depth with therapists on GSE and CDS teams about their approaches to integrated effective practice, and about their experiences supporting children with physical disabilities. The researchers appreciate the time and effort therapists devoted to these discussions, and hope that the research will contribute to an improved understanding of integrated effective practice, and ultimately to enhanced services that support the lives of children with physical disabilities and their families.

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A Quick Guide to Navigating the Document

This is a substantial document. To make it easier for readers to access material of interest we have provided this quick guide, which describes the basic structure of the document and briefly summarises the contents.

Part 1

Part 1 is the database research project, which set out to gather and synthesise the available information on the distribution of resources and funding streams for children and young people with physical disabilities, and the amount of resourcing on a national and regional basis. The data was extracted and collected over the period 2001 – 2003.

Section 1.1 is an introduction to the database research. It looks at who provides physiotherapy and occupational therapy to school-age children and young people, and at the data sources used to find out more about these services and the children and young people they provide for. It describes the definition of disability used by each service. It also covers how key agencies have agreed to work together.

Section 1.2 estimates how many children (aged 0 to 14 years) in New Zealand have physical disabilities, thereby providing a context in which to view the more detailed data on service provision. It describes how the researchers for this project used data from the 2001 Household Disability Survey, conducted by Statistics New Zealand, to make their estimates. They also looked at aspects of the reported experiences of children with physical disabilities, based on the responses of the representative sample of children taking part in the 2001 Household Disability Survey.

Section 1.3 considers the Child Disability Allowance, a benefit administered by Work and Income, Ministry of Social Development, which is not means-tested. It looks at the proportion of children and young people in different parts of New Zealand who receive this allowance, and at the available information on the likely disabilities or underlying medical diagnoses of recipients.

Sections 1.4 and 1.5 focus on children and young people who receive services from ACC. Children and young people whose disability is due to an accident are not entitled to the Child Disability Allowance. Those who receive lump sums or the Independence Allowance (an ACC allowance similar to the Child Disability Allowance), not all of whom have physical disabilities, are described in Section 1.4. Section 1.5 moves to a more specific focus on those children and young people who receive ongoing support from ACC and who are believed to have physical disabilities.

Section 1.6 examines data relating to the Education-funded Ongoing and Reviewable Resourcing Schemes (ORRS), as well as data from those who provide therapy to these students – specialist service providers and the Ministry of Education, Special Education (GSE). It looks at the rates for ORRS applications, uptake over time and geographically (including rural and urban comparisons), and the ethnicity of recipients. It includes estimates of how many recipients have a physical disability contributing to their eligibility for such funding. It considers data from specialist service providers on how they apportioned their ORRS funding.

Section 1.7 describes the provision of therapy through the ‘moderate contract’, which is the Education funding stream for students with moderate physical needs.

Section 1.8 looks at the available information on physiotherapy and occupational therapy provided to students through Health-funded services.

In **Section 1.9** describes a survey of New Zealand special schools, schools with attached units for students with physical disabilities, and schools receiving central funding for therapy provision. It looks particularly at the provision of physiotherapy, occupational therapy, and speech-language therapy in these schools.

Part 2

Part 2 describes and discusses a series of case studies that set out to see what the models of therapy and other service provision for students with physical disabilities in the compulsory school sector look like across different services, settings and locations; the extent to which these models reflect the components and principles of effective integrated practice; and the effect that therapy and services provided by the support team has on the life and quality of life of the student with physical disabilities and his or her family.

Section 2.1 is the introduction, with a brief review of the literature on integrated effective practice that has been used to guide the case study research.

Section 2.2 outlines the methods used to identify the case study sites and to guide the data gathering and analysis phases of the research. The project generated a large amount of observational, interview and archival data. As the analysis proceeded, it became clear that data from settings with on-site therapy shared common elements, while those with itinerant therapy shared other common elements. To manage the data and to explore these common themes, discussion in this report distinguishes settings with on-site therapy from those with itinerant therapy. In organising the data in this way there is no intention to evaluate or draw comparisons between these two settings.

Sections 2.3 to 2.6 present the data from the case studies. They describe what models of integrated effective practice look like and consider the different ways in which teams work to support children and young people with physical disabilities and their families across a range of settings. **Section 2.3** describes the case studies in schools with on-site therapy, **Section 2.4** describes the models of therapy used in schools with on-site therapy, **Section 2.5** describes the case studies in schools with itinerant therapy, and finally **Section 2.6** describes the models of therapy used in schools with itinerant therapy.

The final three sections discuss the previous findings. **Section 2.7** discusses the extent to which the models described in Sections 2.1 to 2.6 reflect the components and principles of effective integrated practice as described in the scoping report which preceded the present study.

Section 2.8 describes the effect of therapy and service provision on the quality of life of the focus students and their families.

Section 2.9 addresses some of the key findings from the case studies within the context of the relevant research literature.

List of Terms and Abbreviations

ACC	Accident Compensation Corporation
ADHD	Attention Deficit Hyperactivity Disorder
Alphasmart	An electronic notetaker or word processor – essentially a simple computer for writing.
Additional central resourcing	Initially provided as transitional funding for three years to 26 schools and units to help them make the transition to the new Special Education 2000 (SE2000) framework so they would not be disadvantaged. The term 'transitional funding' is no longer used but some schools and units still receive additional centrally funded physiotherapy and occupational therapy positions.
CCS	New Zealand CCS provides support and services to people with physical disabilities and advocates for the rights of disabled people. The organisation was formerly known as the New Zealand Crippled Children Society, and adopted the name of CCS in 1989.
CDA	Child Disability Allowance
Consultative service model	In the consultative service model, the therapist works collaboratively with the classroom and specialist teachers; providers of other services; parents; and, where appropriate, the student to jointly assess, problem-solve, plan and devise a programme that is incorporated into the student's typical daily activities. The therapist usually models the interventions and coaches the team most directly involved with the student. This team then carries out the programme.
Ecological assessment	An approach to assessment that recognises that surroundings and context also have an effect on abilities and needs. Ecological assessments include a study of the student's physical environment and their interactions with the people in close contact with them.
FTE/FTTE	Full-time equivalent/full-time teacher equivalent
GSE	The term GSE is the standard abbreviation used for Ministry of Education, Special Education.
HDS 2001	The 2001 Household Disability Survey
HOD	Head of department

IA	Independence Allowance
IEP	Individual Education Programme
Moderate contract	Education-funded contract for provision of therapy for services for students with moderate physical disabilities
NACS	Needs Assessment and Co-ordination Services
ORRS	Ongoing and Reviewable Resourcing Schemes
OT	Occupational therapy
PT	Physiotherapy
RTLB	Resource Teacher/s: Learning and Behaviour
SE2000	Special Education 2000. Introduced in 1996, Special Education 2000 was a major new policy for special education. It instigated a range of changes relating to resourcing and service provision approaches for learners with special educational needs, and was implemented over three years.
SEG	Special Education Grant
SLT	Speech-language therapy/therapist
Specialist service provider	The Ministry of Education, Special Education (GSE) is the overall fundholder for all types of education funding for students with physical disabilities. But GSE allocates some of the money to particular schools approved by the Ministry as specialist service providers. In some instances, a specialist service provider might hold the money for just itself; in other instances, a specialist service provider holds the money on behalf of a cluster of schools. Specialist service providers were formerly known as fundholder schools.
Transitional funding	Additional central resourcing provided for three years to 26 schools and units to help the schools make the transition to the new Special Education 2000 (SE2000) framework so they would not be disadvantaged. The term ‘transitional funding’ is no longer used but some schools and units still receive additional centrally resourced physiotherapy and occupational therapy positions.
TLA	Territorial local authority
‘Unders and overs’	A term used to describe a method for allocating resources. Funding for ORRS-verified students is managed at the local level by a range of specialist service providers. Each provider pools all the funds for the students and allocates according to changing student needs.

Part 1: Database Project

Phillipa Clark

Section 1.1: Introduction to Database Research Project

Purpose

The purpose of this research project was to obtain and synthesise the available information on the distribution of resources and funding streams for children and young people with physical disabilities, and the quantum of resourcing on a national and regional basis. This section gives an overview of the project's aims and methods, including data sources.

The aims of the research were to:

1. identify the number of New Zealand children and young people with physical disabilities
2. identify how many school-age children and young people were receiving therapy and through which funding streams
3. examine the quantum of therapy provided
4. find out how easy or difficult it is to extract data from local therapy provider databases
5. look for evidence of unmet need
6. relate the findings to the outcomes of the case study research (see Part 2).

Background

When it comes to the provision of therapy to school-age children and young people, two different but overlapping questions arise:

1. Who provides physiotherapy and occupational therapy to school-age students?
2. What sources of information were used in this research to find out more about each funding stream?

The questions are answered in order below.

Who provides therapy to school-age students?

School-age students can receive therapy from the following funding streams or services (with the source of the funding for each indicated in brackets):

- the Ongoing and Reviewable Resourcing Schemes (ORRS). These schemes provide additional teachers, funding for specialists such as speech-language therapists, physiotherapists and occupational therapists, and funding for teacher aides for students verified as having very high or high needs (Ministry of Education)
- the contract for children and young people with moderate physical disabilities. The Ministry of Education funds a number of providers to provide occupational therapy and physiotherapy services to schools with students who meet the criteria for moderate contract funding (Ministry of Education)

- additional resourcing for therapy provision (now called ‘centrally funded therapy support’ and also known formerly as ‘transitional funding’ (Ministry of Education)
- Health-funded Child Development Services (CDS) teams (Ministry of Health, Disability Support Services)
- Independence Allowance, lump sum payments, and ACC-funded services (Accident Compensation Corporation)
- Child Disability Allowance (Work and Income, Ministry of Social Development)
- privately provided therapy (usually funded by parents and caregivers).

What sources were used to find out more about each funding stream?

Table 1.1 shows the sources of information about children and young people with physical disabilities, and the services that they received, that were used in this research project. There was sometimes more than one source of information about each funding stream. Information from a number of different sources was combined in order to answer particular research questions, as shown in the table.

Table 1.1.: Databases used to answer research questions

	Focus of research question					
Database	**Number of children and young people**	**Intensity of provision**	**Cost**	**Gaps**	**National information**	**Regional information**
2001 Household Disability Survey[1]	√			√	√	Limited
Child Disability Allowance[2]	√				√	√
ACC[3]	√		√		√	√
ORRS[4]	√			√	√	Urban/rural
Moderate contract[4,5]	√				√	√
Health-funded occupational therapy and physiotherapy[6]	√				√	Auckland
Special schools[7]	√	√			√	
Specialist service providers			√		√	

Note: Each number refers to the source of the information in each database, namely:

[1] Statistics New Zealand

[2] Work and Income, Ministry of Social Development

[3] Accident Compensation Corporation: Independence Allowance and lump sum, and ongoing claims

[4] Ministry of Education, Special Education

[5] School-based providers

[6] Ministry of Health Disability Support Services and two services based in Auckland

[7] Survey of special schools and schools receiving additional centrally funded therapy support

How agencies have agreed to work together

Given that there are a number of potential sources of therapy provision for students, key providers have written protocols for working together and dividing up responsibilities. Two key agreements are between the Ministry of

Education and the then Health Funding Authority,[1] and between the Ministry of Education and ACC. An overview of each agreement is given below (see Appendix A for the full documents).

Ministry of Education and the Health Funding Authority

The *Operational Protocol on Occupational Therapy and Physiotherapy Services for School Students with Disabilities* (November 1999) was drawn up by the Ministry of Education and the then Health Funding Authority (see Appendix A). It was intended for both Health- and Education-funded providers of therapy services, as well as for school boards of trustees, school staff, specialist service providers,[2] families and whānau. It identifies the funding and service provision responsibilities of both Health and Education for occupational therapy and physiotherapy for school students.
Some key points of the protocol are as follows.

- School students will be eligible for Education-funded occupational therapy and physiotherapy if they are either verified in the Ongoing and Transitional Resourcing Schemes (now ORRS) or meet the criteria for the contract for students with moderate physical disabilities (the moderate contract).
- Health-funded services are available to those who satisfy the Ministry of Health definition of disability (see 'How disability is defined in this report' below) and on the basis of individually assessed needs and service co-ordination.
- Health will not fund therapy for children and young people who are eligible for Education funding.
- Health retains the responsibility for funding those children and young people who do not meet the criteria for Education funding.
- In addition, Health has funding responsibility for intensive pre-operative and post-operative rehabilitation, orthotics services and orthoses.
- The fact that both Health- and Education-funded therapies come from a capped budget is noted. Thus, while all referrals must meet the criteria set out by Health and Education, available funding and relative priority for access will determine which individual referrals can be accepted.
- The classroom teacher is the centre of the learning programme for all students, including those with disabilities and special educational needs.

Some further points are made in relation to Education-funded occupational therapy and physiotherapy. It is interesting that they are described under Education, even though the criteria would generally also apply to many parts of Health-funded services. Thus Education-funded occupational therapy and physiotherapy:

- occur within the context of the New Zealand Curriculum framework
- focus on removing, reducing or overcoming barriers to educational achievement
- assist in meeting identified achievement objectives and learning outcomes
- support the students in the context of their classroom/learning environment
- derive from the goals identified through the Individual Education Programme (IEP) process

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[1] The Health Funding Authority was disbanded on 31 December 2000 and its functions distributed between the Ministry of Health and district health boards.

[2] The Ministry of Education, Special Education (GSE) is the overall fundholder for all types of education funding for students with physical disabilities. But GSE delegates some of the money to particular schools approved by the Ministry as specialist service providers. In some instances, a specialist service provider might hold the money for just itself; in other instances, a specialist service provider holds the money on behalf of a cluster of schools. Specialist service providers were formerly known as fundholder schools.

- are ethically sound
- are based on current research evidence about effective practice
- are cost efficient.

The need for a seamless transition into and out of school is also identified.

Ministry of Education and Accident Compensation Corporation (2000)

The *Operational Protocol Between the Ministry of Education and ACC* (2000) (see Appendix A) states that it:

- applies to school students aged five or over who are enrolled in a school and who, as a results of an accident, have cover under ACC legislation and have special educational needs
- encourages and promotes co-operation, collaboration and co-ordination by all those working with the student
- clarifies funding and service provision responsibilities
- fosters effective support through an emphasis on identifying and overcoming barriers to achievement

This protocol provides:

> *… a framework for effective use of resources by bringing the two sectors together … Those closest to the student best know their needs and the resources available to meet them. The protocol gives a greater sense of working together for a shared goal – the learning and rehabilitation of the student.*

The overall aim is to achieve the best possible outcomes for students.

For each student, an identified key school contact person and the ACC case manager should liaise closely. Where other sectors, such as health and welfare, also have funding responsibility for a student, 'there should be an attempt to co-ordinate assessment amongst all agencies, in order to minimise disruption for the student'. Any further agency with responsibility for a student's needs (other than ACC or the Ministry of Education):

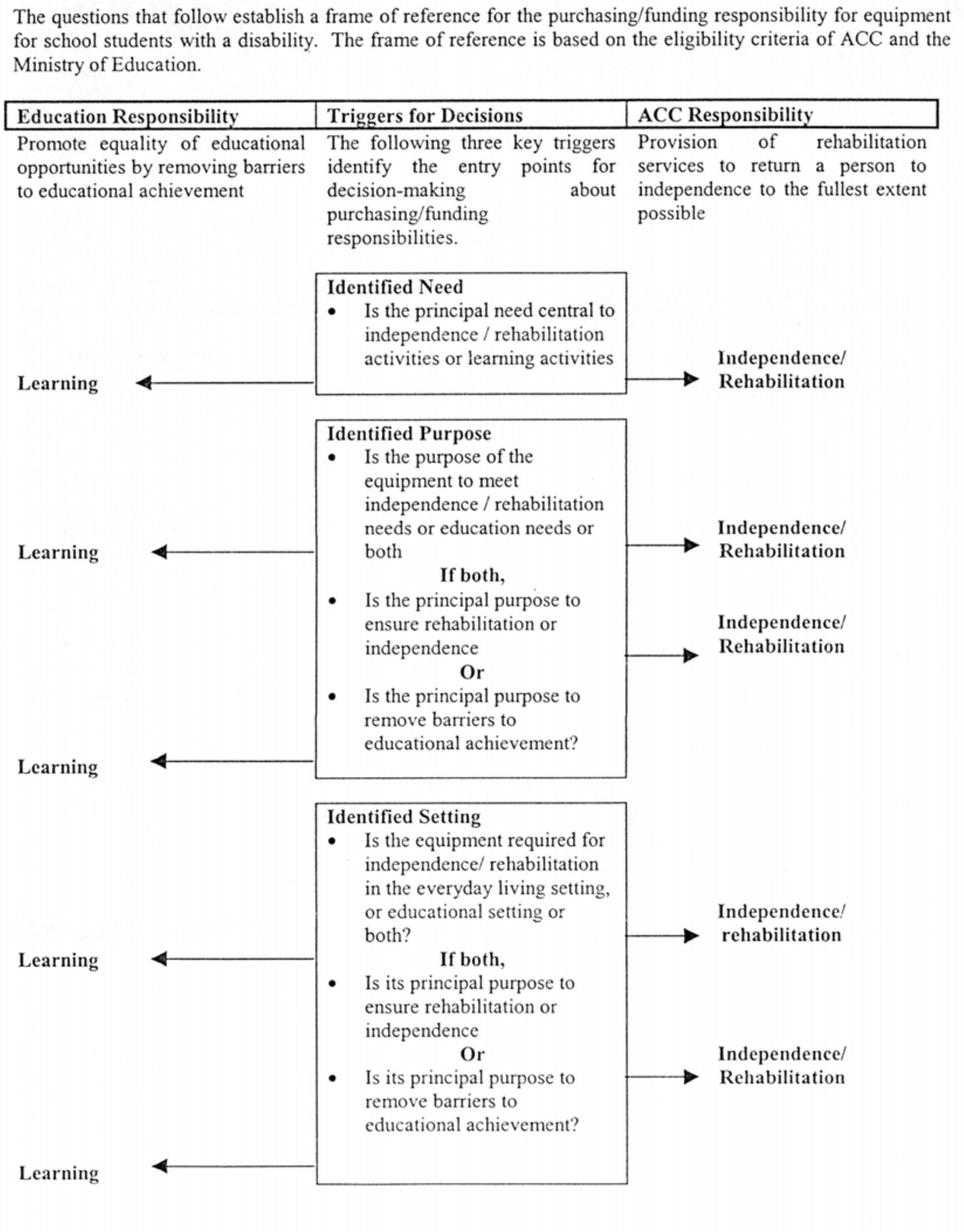
> *… should be invited to participate in the joint planning process from the outset. This is in line with the Strengthening Families approach, which involves networking between agencies and collaborative case-management to ensure there are no gaps or overlaps in service provision.*

Elsewhere the protocol notes that children and young people will still have access to Special Education 2000 (SE2000) initiatives such as ORRS.

The division of responsibilities in relation to purchasing assistive equipment, as established by this protocol, is depicted in Figure 1.1.

Guidelines have also been developed to aid teachers in deciding whether to refer a student to the team providing services for students with moderate physical disabilities, to the local Child Development Services team or to the Resource Teachers: Learning and Behaviour (RTLB). Figure 1.2 provides an example of a flow chart that can assist decision-making at a local level.

Figure 1.1.: ACC and Ministry of Education responsibilities in relation to the purchase of assistive equipment



The questions that follow establish a frame of reference for the purchasing/funding responsibility for equipment for school students with a disability. The frame of reference is based on the eligibility criteria of ACC and the Ministry of Education.

Education Responsibility	Triggers for Decisions	ACC Responsibility
Promote equality of educational opportunities by removing barriers to educational achievement	The following three key triggers identify the entry points for decision-making about purchasing/funding responsibilities.	Provision of rehabilitation services to return a person to independence to the fullest extent possible

Identified Need
- Is the principal need central to independence / rehabilitation activities or learning activities

Learning ← → **Independence/ Rehabilitation**

Identified Purpose
- Is the purpose of the equipment to meet independence / rehabilitation needs or education needs or both

Learning ← → **Independence/ Rehabilitation**

If both,
- Is the principal purpose to ensure rehabilitation or independence → **Independence/ Rehabilitation**

Or
- Is the principal purpose to remove barriers to educational achievement? → **Learning**

Identified Setting
- Is the equipment required for independence/ rehabilitation in the everyday living setting, or educational setting or both?

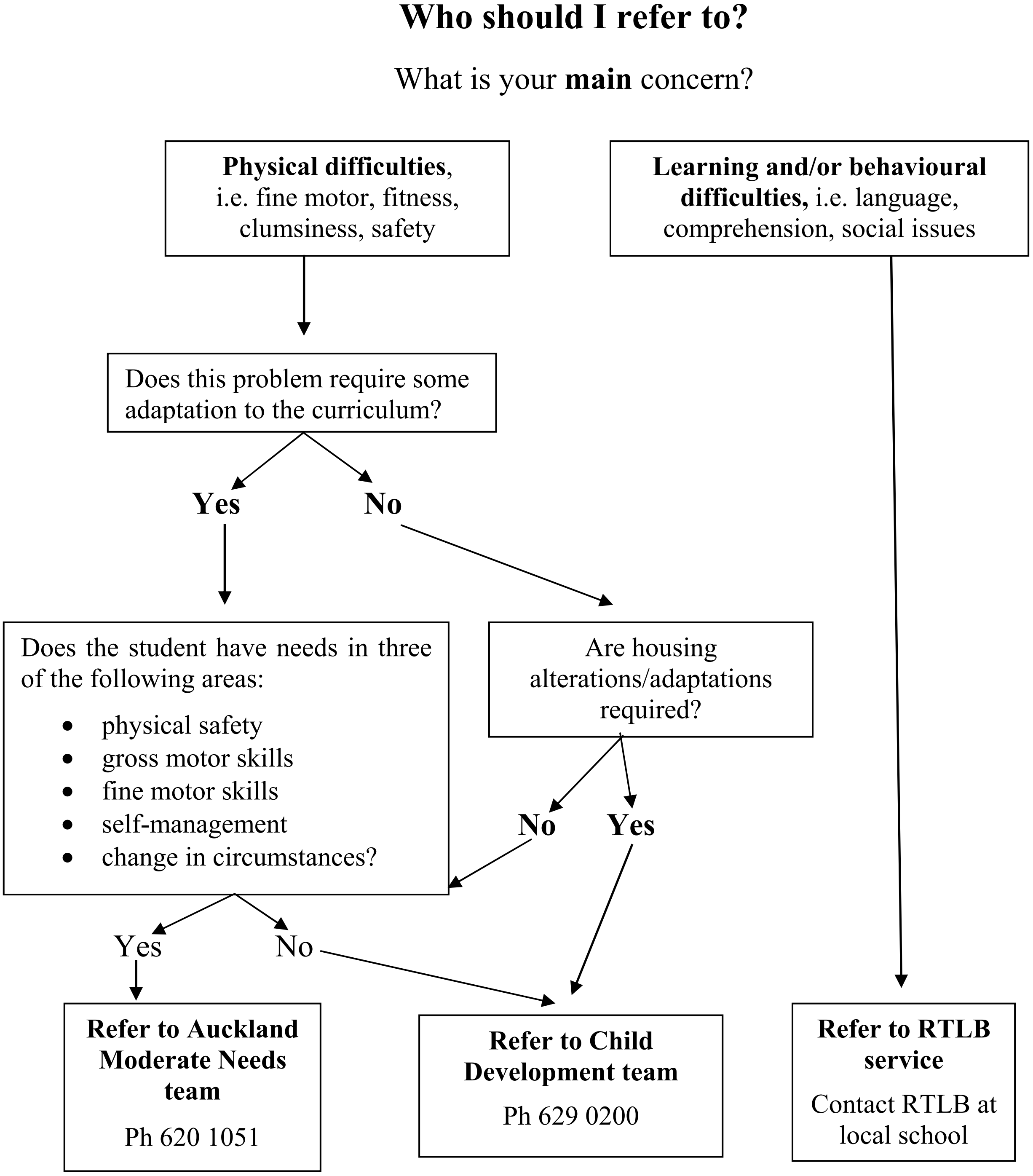
Learning ← → **Independence/ rehabilitation**

If both,
- Is its principal purpose to ensure rehabilitation or independence → **Independence/ Rehabilitation**

Or
- Is its principal purpose to remove barriers to educational achievement? → **Learning**

Source: Operational Protocol Between the Ministry of Education and ACC (2000)

Figure 1.2.: **Sample flow chart to assist a decision over where to refer a student with physical difficulties**



Source: Developed by the Central Auckland team providing services for students with moderate physical disabilities in close collaboration with the Health-funded Central Auckland Child Development Services Team. Used with permission.

Accessing therapy services

The means of accessing Education-, Health- and ACC-funded therapy services are outlined below:

- Education-funded services are accessed through
  - schools.
- Health-funded services are accessed through
  - Needs Assessment and Co-ordination Services (NACS), with application initiated by schools, families or other health professionals. In practice, many services accept referrals that are not submitted via NACS.
- ACC services are accessed through
  - notification of accident forms
  - assessment of impairment
  - case management decision-making.

Clearly, if children and young people are to get the therapy services they are entitled to, those around them need knowledge of the services that provide therapy, how they work together, and how they are accessed.

How disability is defined in this report

The agencies or funding bodies that provided information for this research have their own definitions of disability (or, in the case of Education, a definition of special education), each of which differs from that of the scoping project (McDonald et al., 2001). None of these definitions consider the way that attitudes or environment affect an individual's experience of disability. The qualifying period for which someone must have a condition or illness before they are deemed to have a disability is either six months or one year. In some situations, this report uses aspects of available information to define a subgroup of children and young people with physical disabilities.

The definition from the Ministry of Health describes those individuals who are eligible for Health-funded disability services such as Health-funded occupational therapy and physiotherapy. The Ministry of Health definition of disability is:

> *A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.*

ACC provides services on the basis of assessed need.

Statistics New Zealand's definition of disability (Statistics New Zealand, 2001, p. 130) is:

> *A disability is any self-perceived limitations in activity resulting from a long-term condition or health problem; lasting or expected to last six months or more and not completely eliminated by an assistive device.*

The Child Disability Allowance is available to children and young people with a physical or mental disability that has endured or is expected to endure for more than one year. The full definition of disability in relation to the allowance (which provides the criteria for eligibility for this allowance) is described in Section 1.3.

The Ministry of Education's definition of special education is 'the provision of extra assistance, adapted programmes or learning environments, specialised equipment or materials to support children and young people with accessing the curriculum in a range of settings' (Special Education Policy Guidelines).[3]

Approaches used in this research to examine how many New Zealand children and young people have a presumed physical disability were to:

- define those with physical disabilities on the basis of data collected by the agency in question – which sometimes involved a heavy emphasis on the use of equipment (e.g. in the use of ACC data and, to some extent, with the information abstracted from the 2001 Household Disability Survey)
- estimate numbers using categories already in use by an agency (e.g. the assumption of physical disability in those children and young people who are defined as receiving ORRS resourcing because of a predominantly physical problem; in contrast, 'physical' as used with the Child Disability Allowance was not helpful as it included by definition children and young people with a number of chronic illnesses)
- assume that children and young people receiving occupational therapy or physiotherapy have physical disabilities
- specify a definition, which was only possible in the survey of special schools, schools with special units and other schools receiving extra funding for therapy provision. The definition in this case concerned physical disability that has an effect on learning or access to the curriculum.

For the purposes of this project, the *research* definition of physical disability that impacts on learning or access to the curriculum is:

> *Difficulties with physical activities, which involve sitting, standing, positioning, moving, communicating, writing, manipulating school tools/materials, and self-care, that impact on learning or access to the curriculum.*

Detailed methodology on how the researchers dealt with the above definitions in working with the databases to which they applied is provided in what follows.

However, the variety of definitions of disability, and the variation in the age range covered, mean that care needs to be taken when combining or comparing data from different sources.

Aspects of integrated effective practice that could be examined in this research project

The database research was seen as complementary to the case study research project. Together the two projects were to examine integrated effective service provision for school-age children and young people with physical disabilities.

In contrast to the qualitative case study research, the database research was envisaged as being predominantly quantitative in nature. The database research was seen as answering different questions (such as how many children and young people are receiving occupational therapy and physiotherapy, and through which funding streams). Equally, however, it was seen as complementing the work of the case study research on integrated effective service provision. The components of integrated effective service provision were considered when designing the methodology used in this database research project.

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[3] The Special Education Policy Guidelines can be accessed at http://www.minedu.govt.nz/goto/7327

Summary

The above information covers the aims of the database research project, and the data sources used to answer its research questions. The different funding streams for therapy provision, and how such services are accessed and have agreed to work together, have been outlined.

To address the questions of the database research project, it has been necessary to obtain information from a variety of sources. However, as noted above, this means care is needed in comparing data from different sources.

Section 1.2: The 2001 Household Disability Survey

This section examines the estimated prevalence of physical disability in New Zealand children aged up to 14 years, using data collected by Statistics New Zealand as part of the 2001 Household Disability Survey (HDS 2001).

Statistics New Zealand, using HDS 2001 data, estimated there were 90,000 children aged up to 14 years with disabilities. The database project estimated the number of a subgroup of these children – children with physical disabilities – using a definition developed for this project in conjunction with Statistics New Zealand (based on questions asked during the HDS 2001).

This section presents detailed data requested specifically from Statistics New Zealand to estimate the nature, cause and severity of the disabilities experienced by these children with physical disabilities. It also looks at the estimated patterns of service use by these children.

All data in this section are based on information collected from the representative sample of children aged up to 14 years and their parents and caregivers who took part in the HDS 2001. Because a representative sample was interviewed for the survey, rather than all children with disabilities, all data are presented as estimates.

In this section, the terms ‘estimate’ and ‘estimated’ relate directly to numbers or proportions estimated from the responses obtained from the representative sample of parents and caregivers of New Zealand children aged up to 14 years who took part in the HDS 2001.

Background

The key objective of the HDS 2001, conducted by Statistics New Zealand, was to measure the prevalence of disability among the resident New Zealand population living in households. The focus was on measuring disability among children, adults and older people at the national and regional levels (that is, for the four Transitional Health Authority areas that were in place in 1996–97) and for Māori and Pasifika peoples at the national level. The survey aimed to:

> *… provide information on the nature, duration, severity and cause of disabilities amongst New Zealanders. Secondary objectives of this survey were to examine disability-related expenses incurred by individuals and families, and to examine the current and unmet needs for services and assistance. (Statistics New Zealand, 2001, p. 126)*

In part this aim was achieved, as described below, by surveying a representative sample of children up to 14 years old. Many of the results of this survey are available in *Disability Counts 2001* (Statistics New Zealand, 2001).

The following text describes the HDS 2001 in more detail. The results of this survey show that an estimated 90,000 New Zealand children aged up to 14 years had a disabling condition or chronic illness. The discussion shows how the responses to questions contained within the survey were used to identify a subgroup of an estimated 14,500 children with physical disabilities. It then describes how detailed estimates were obtained from Statistics New Zealand on the characteristics of this subgroup, and on the experience of these children and their families. As will be explained, information had been collected on the use of services, provision of aids, and aspects of estimated met and unmet need for assistance as reported by parents and caregivers.

These data complement the experiences of children and those around them that are described in the case study research project. Furthermore, the estimated number of New Zealand children who could be described as having physical disabilities will be relevant to the later focus on particular funding streams. The HDS 2001 is a unique source of such New Zealand-wide information.

Methods

Statistics New Zealand's approach to the 2001 Household Disability Survey

The target population for the HDS 2001 was the usually resident population of New Zealand, comprising those who were resident in private households and group homes on the night of the 2001 Census of Population and Dwellings. Statistics New Zealand considers everyone aged 15 years and over to be an adult. While long-term residents in institutions such as prisons, hospitals and homes for the elderly were excluded from the survey, this criterion would not have excluded many children under the age of 15 (Melville, 2003, p. 21).

Statistics New Zealand included two general questions on disability in the 2001 Census of Population and Dwellings. The response to these questions was taken into account when selecting 38,508 people to invite to participate in the HDS 2001. Those invited to take part included children and adults, including some who had made a positive response to questions about disability and some who had not. The invitation had a 73% response rate; this figure is not elaborated further by Statistics New Zealand (2001).

The total number of respondents with disabilities included 2,055 children aged up to 14 and 3,483 adults aged 15 to 64 years. Results are available in these age bands. For the purposes of this research, the focus is on information relating to those aged 0–14 years, as the questions posed in the adult questionnaires were different from those in the child questionnaires.

The Child Screening and the Child Content Questionnaires

The HDS 2001 used four questionnaires: two for adults and two for children. All young people aged 15 years and over were deemed adults and filled in the adult questionnaires. A parent or caregiver of all those aged 14 years and under completed a face-to-face Child Screening Questionnaire. The parent or caregiver of any child identified as having a disability by the criteria described below was then asked further questions relating to services and assistance, education, equipment, transport and accommodation. This second questionnaire was the Child Content Questionnaire. Its wording suggests that questions were always directed to the parent or caregiver rather than to the child. However, Statistics New Zealand is aware that some older children took part. (See Appendix B for both questionnaires.)

How did the Child Screening Questionnaire identify children with disabilities?

Children with disabilities were identified by Statistics New Zealand as follows. The Child Screening Questionnaire contained a series of questions asked of a parent, a caregiver or an alternative 'responsible adult'. Those answering 'Yes' to the specific screening questions were selected to respond to the Child Content Questionnaire and by definition made up the disability survey population of the HDS 2001.

These screening questions resulted in the selection of any child who had long-term difficulties (i.e. difficulties that have lasted, or are expected to last, six months or more) in one or more of the following areas:

- *vision* – is blind, or has trouble with his/her eyesight, which is not corrected by glasses or contact lenses
- *hearing* – is deaf or has trouble hearing, which is not currently corrected (not including children with grommets who have no trouble hearing, but including children with grommets who have trouble hearing, or those with hearing aids)
- *speech* – has difficulty speaking and being understood as a result of a health condition
- uses any of the following *special, technical or medical equipment* as a result of a health condition:
    - special buggy or trolley
    - standing frame
    - braces (excluding those for teeth)
    - wheelchair
    - crutches, walking sticks, walking frame or any other walking aid
    - artificial leg, arm, hand or foot
    - any other equipment (excluding asthma inhalers, braces for teeth, grommets)
- *mental health* – has a long-term emotional, behavioural, psychological, nervous or mental health condition that limits the kind/amount of activity that he/she can do at home, at school or at play (excluding children too young to diagnose or those who are unsure if this condition exists)
- specific health conditions:
    - asthma – has been told by the doctor that this is ‘severe’
    - diabetes
    - cancer
    - epilepsy
    - cerebral palsy
    - muscular dystrophy
    - spina bifida
    - any chronic gastro-intestinal condition (e.g. chronic diarrhoea)
    - any lung condition or disease that limits his/her activities
    - any kidney condition or disease that limits his/her activities
    - any heart condition or disease that limits his/her activities (excluding heart murmurs unless they limit activity)
    - growth failure/failure to thrive
    - autism/Asperger syndrome
    - intellectual disability/general developmental delay

  - learning difficulties, including dyslexia, attention deficit disorder, attention deficit hyperactivity disorder (i.e. mental capacity to learn, excluding children with physical barriers to learning or physical limitations on attending a place of learning)

- any other condition or health problem not already mentioned that limits what the child can do at school, at play or in any other activity that children of the same age can usually do (excluding conditions that are not long term; that is, that affect the child for less than six months)
- schooling:
  - attends a special school, unit or class or requires special education services as a result of a health condition
  - has an Individual Education Programme or Individual Development Programme as a result of learning difficulties.

The parents and caregivers of children selected in this way were then asked to participate further in the 2001 Statistics New Zealand Child Disability Survey by answering the Child Content Questionnaire. This contained questions about transport, education, health and other services accessed by or available to these children with identified disabilities.

What did the Child Content Questionnaire ask?

The Child Content Questionnaire focused on five main areas:

- services and assistance
- education
- transport
- accommodation
- economic characteristics.

Services and assistance

The section on services and assistance focused on the use of health services and help in managing day-to-day activities. Questions covered the type of service accessed, frequency of service access, and availability of service when needed. The following service providers were specifically listed and asked about: general practitioner, nurse, chemist, dentist, dental nurse, physiotherapist, occupational therapist, speech-language therapist, medical specialist, counsellor, psychologist, social worker, optician, optometrist, podiatrist, chiropodist, alternative therapist (homoeopath, naturopath, iridologist), traditional healer, Māori/Pasifika Islands health worker, any other health professional, therapist or healer.

A series of similar questions were asked regarding:

- medication
- dietary needs
- disposable items
- household help/personal care
- respite care/carer support
- special equipment (e.g. special chair or glucose meter).

The questions focused mainly on the availability of each of the above items and services, and on specific reasons for being unable to access them. For example, two standard questions used for each of the above areas were:

- In the last 12 months, has [name of child] needed anything special in regards to his/her [specific disability] that you were not able to get?
- Why couldn't you get it?
  - It was too costly or you could not afford it?
  - You applied for financial help and were not eligible?
  - You did not know you could apply for financial help or where to apply?
  - Or was there another reason? Specify.

Other questions focused on whether financial assistance such as the Disability Allowance, Special Needs Grant, funding from government agencies (including Ministry of Health services, Work and Income of the Ministry of Social Development, and the ACC) or medical insurance were already being accessed and, if so, whether this financial assistance covered all costs.

The final questions in this section focused on needs assessment: whether this assessment had been undertaken and, if so, when; whether the child was booked in to have one; and/or why one had not been undertaken recently. A needs assessment was described as follows: 'where someone from a needs assessment agency asks you questions about the support [child's name] needs for everyday living, such as home help, personal care or respite care, which is not funded by ACC'.

Education

The section on education divided the children into those of early childhood age (under 5 years) and those of school age (5–14 years). Questions about school enrolment related to the week ending Sunday, 4 March 2001. This was the only context in which a specific date was mentioned.

Parents and caregivers of young children were asked three simple questions. First, they were asked whether the child was enrolled in or was already getting an early childhood education and, if so, what type. The second and third questions determined whether a professional assessment of developmental and educational needs had ever been done and, if so, by whom.

Parents and caregivers of school-age children were asked a series of questions as to what type of school the child was attending: a primary or intermediate school, an area or composite school, a secondary school, a special school, kura kaupapa Māori, home schooling, Correspondence School, or 'another type of education'. They were then asked what type of schooling had been received in the previous week: only regular classes, only a special unit, or a mixture of both. Transport to and from school was asked about, as well as whether the child's health problem limited the child in any way in taking part in sports, games, playing, outings or making friends. The ability to enrol the child in the school of first choice was asked about, as was any special equipment, needs or teacher aide required to help the child's education.

As with the previous section, the final questions in this section focused on professional assessment. Specifically, had an assessment been undertaken to determine developmental or professional needs and, if so, by whom?

Transport

The transport section was addressed only for those children aged two years or older. The first part focused on transport in a private motor vehicle (not counting taxis), specifically:

- whether there was a vehicle available within the household
- in cases where a vehicle needed to be purchased, whether it was purchased and whether funding assistance was available
- what difficulties, if any, there were in travelling as a passenger
- what modifications, if any, had been made to the vehicle, when, and how they were funded
- what modifications, if any, had not been possible to make, and why
- what parking requirements applied.

Other questions included the following.

- Are long-distance trips (longer than one hour) possible? By what method – car/plane/bus/train/ferry/van?
- For short-distance trips, can they get around by themselves? Do they need assistance? Do they require special transport (e.g. modified taxis)? Do they use public transport? How often? What difficulties have they encountered in the last 12 months? What can be done to make bus services more accessible?
- Use of taxis in the last 12 months: have they heard of the Total Mobility Scheme?
- Have they had any financial assistance regarding transport?

Accommodation

The accommodation questions were about where the child lived. They covered:

- special features required to leave/enter the house (e.g. ramps, lift devices, widened doorways, hand rails) and whether these were available at present
- special features within the house – including only those attached to the house, not portable equipment such as shower stools, and when these were introduced, whether funding was available, the availability of these features, and reasons for not having such alterations.

Economic characteristics

The section on economic characteristics related to the government financial help that was available and whether it was being accessed. In particular, questions covered:

- the Child Disability Allowance (formerly called the Handicapped Child’s Allowance), which is a set amount that does not depend on income or costs and is aimed at helping with the costs of caring for a child or young person with a disability at home
- the Disability Allowance, which is income-related, paid with main income support and aimed at people who have disabilities and need ongoing medical care and help with everyday tasks
- the Pharmaceutical Subsidy Card
- the High Use Health Card
- the Community Services Card.

Levels of disability as defined by Statistics New Zealand

Statistics New Zealand uses a severity of disability scale that it describes as coming from the Ministry of Health.

- Level 1 is mild. Someone with a Level 1 disability has a chronic illness or disabling condition, without the need for personal help or aids.
- Level 2 is moderate. Someone with a Level 2 disability needs a combination of aids or features, or personal help.
- Level 3 is severe. Someone with a Level 3 disability needs personal help on more than one level, such as respite care and personal care.

The levels for children are defined by Statistics New Zealand as follows.

- Level 1: Positive response to any screening question (activity limitations, presence of chronic conditions).
- Level 2: Reported met or unmet need for any of the following:
  - special equipment/aids
  - respite care (without other needs)
  - special transport arrangements
  - accommodation adaptations
  - special assistance in school situation
  - reported unmet need for ‘personal care’ or ‘household tasks’
- Level 3: Reported unmet need for:
  - assistance with personal care (undefined in the questionnaire for children but assumed to consist of medication, washing and dressing) or household tasks (e.g. housework, shopping)
  - respite care plus one other form of support identified in Level 2.

Defining children with physical disabilities for this research project

This database project aimed to identify a subgroup of children with physical disabilities within the estimated 90,000 children aged up to 14 years who had already been identified by Statistics New Zealand from the HDS 2001. By looking specifically at information collected in both questionnaires from the parents and caregivers of these children, the database project hoped to describe:

- services received and services needed
- important aspects of the lives of New Zealand children with physical disabilities
- some key characteristics of the group, such as estimated breakdown by gender, ethnicity and age, as well as estimated age of onset of disabling condition, and severity of disability.

Physical disability could be defined using the responses to any of the questions in the Child Content or Screening Questionnaires. It was also important to ensure that the subgroup of children was large enough to reflect children with physical disability as envisaged by the reference group commissioning this research.[4] Further, ideally the subgroup

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[4] The database project, and the case studies which comprise Part 2 of this report, were commissioned by the Ministry of Education-convened Advisory Reference Group for Students with Physical Disabilities.

would be large enough to enable meaningful analysis of the combined responses to specific questions in the questionnaires. If the subgroup were too small, the number with positive responses to questions of interest might be low, with large relative sampling errors. Thus the larger the subgroup selected, the more reliable the estimates would be.

Some data sets relating to physical disability in children had already been created by Statistics New Zealand. As will be seen, however, they included only small numbers of children. For example, using the responses to the HDS 2001, Statistics New Zealand estimated that 4,600 children had a limitation requiring the use of technical equipment.[5] This concept of a limitation requiring the use of technical equipment is used in *Disability Counts 2001* (Statistics New Zealand, 2001) as denoting physical disability. However, it would include children using glucose meters because of diabetes mellitus.

Using the same data, an estimated 3,700 children had a physical disability requiring the use of technical equipment. This estimate excludes children using technical equipment that is not related to a physical activity limitation (Child Screening Questionnaire Q13). This particular disability type is not in *Disability Counts 2001* (Statistics New Zealand, 2001). It was derived specifically for the web-based 2001 New Zealand Disability Survey Snapshot 7 (Physical Disabilities) (Statistics New Zealand, 2002).

These 3,700 children formed the core of the definition of physical disability used by the database research team. Other questions where a positive response was judged to be likely to indicate physical disability were then included, as described below. This provided an estimated 10,800 children, giving an estimated total of 14,500 children and young people with physical disabilities.

Definition of the population with physical disability used for this research project

In the analysis of HDS 2001 data for this research, children with physical disabilities were defined as children using technical equipment related to physical disability as defined already by Statistics New Zealand (n = 3,700) and/or:

- all children who on Child Screening Questionnaire had:
  - cerebral palsy (Q27a), and/or
  - muscular dystrophy (Q27d), and/or
  - spina bifida (Q27e), and/or
- all children who on the Child Content Questionnaire:
  - were receiving physiotherapy (Section B Q2e), and/or
  - were receiving occupational therapy (Section B Q2 f), and/or
  - wanted physiotherapy (Section B, Q5_5), and/or
  - wanted occupational therapy (Section B Q5_6), and/or
  - needed ramps etc. to get in and out of house (Section E Q1 [yes] plus Section E Q3 [yes]).

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[5] Child Screening Questionnaire: Q6a special buggy; Q7a standing frame; Q8a braces other than braces for teeth; Q9 wheelchair use if over two years of age; Q11a crutches, walking sticks, a walking frame or any other kind of walking aid if over two years of age; Q12 artificial leg, arm, hand or foot if over two years of age; Q13 use of any other kind of equipment for a condition expected to last for six months or more for all ages.

The estimated number of children identified in this way, and information about their needs and experiences, are described in the results below.

Conventions for the presentation of results

Numbers presented in the results subsection are estimated by Statistics New Zealand, using the responses of the 2,055 children with disabilities and their parents and caregivers in the HDS 2001, and information about the New Zealand population as a whole obtained in the 2001 Census of Population and Dwellings. The smaller the estimated number of subjects answering a particular question in a particular way, the less certain one can be that the true answer is similar to the estimated number reported.

As a general guide, estimates for children that are smaller than 1,140 have relative sampling errors of 50% or more. In other words, the true number of children in New Zealand with that particular experience could be plus or minus 50% of the number given. Estimates smaller than 540 have been suppressed for reliability reasons, as they have relative sampling errors of 70% or more.

Results

Characteristics of children with physical disabilities

This discussion draws on HDS 2001 data to describe some of the characteristics of the estimated 14,500 children aged up to 14 years with physical disabilities.

Number of children with physical disabilities, and how questions selected for the definition contributed to this estimate

At the time of the HDS 2001 there were an estimated 14,500 children aged up to 14 years with physical disabilities, as defined for this research project, who were living at home.

Table 1.2 below shows the estimated percentage of children with physical disabilities identified by responses to specified questions or groups of questions in the Child Screening Questionnaire. As can be seen, the core of this group of children corresponded to the definition of children with physical disabilities already used by Statistics New Zealand for its web-based media release; namely, children using equipment suggesting physical disability.

Table 1.2.: Percentage of the estimated 14,500 children aged up to 14 years with physical disabilities captured by responses to specific questions in the Child Screening Questionnaire, 2001

Group	Questions used	Percentage of total children		
		Non-Māori	Māori	Total
1 Use equipment suggesting physical disability	Standard Statistics New Zealand variable	25	30	26
2 Answers suggesting a medical condition that could cause a physical disability	Q27a *or* Q27d *or* Q27e = yes	18	18	18
1 and 2		**33**	**39**	**34**
3 Receive physiotherapy	Section B Q2e = yes	61	58	60
4 Receive occupational therapy	Section B Q2f = yes	51	32	46
5 Want physiotherapy *or* want occupational therapy	Section B Q5_5 *or* Q5_6	Numbers too small to be used		
1 to 5 combined		**98**	**91**	**96**
6a Use ramps	Section E Q1 = yes	7	12	9
6b Want ramps	Section E Q3 = yes	8	12	9
6 Use or want ramps	Section E Q1 *or* Q3 = yes	14	21	16

As all data in Table 1.2 are estimates, the responses are given as a percentage of the total group. Using raw numbers would imply a level of accuracy not possible with these estimated data.

The percentages identified in each way appear to differ in some respects between Māori and non-Māori. It was not considered appropriate to look for statistically significant differences between these groups. It was not possible to be sure that parents and caregivers from different self-identified ethnic groups had even understood the terms used in these questions similarly. In particular, no definitions or explanations of the terms *physiotherapy* and *occupational therapy* were given when the questionnaire was administered.

Gender and ethnic group of children with physical disabilities as defined for this research project

Among the children identified as having physical disabilities, an estimated 9,600 were New Zealand European, 3,800 Māori and 600 Samoan. The estimated numbers for Cook Island Māori, Tongan and other ethnic groups were too small to be reliable.

The age group and gender breakdowns for Māori and for non-Māori children are shown in Table 1.3. It can be seen that there were more boys than girls with physical disabilities.

Table 1.3.: Age group and gender for Māori and non-Māori children with physical disabilities, 2001

Age group (years)	Gender	Māori	Non-Māori	Total
Under 5	Male	400	1,000	1,400
	Female	..s	600	900
	Total both sexes	700	1,600	2,300
5–14	Male	1,800	5,100	6,900
	Female	1,300	4,000	5,300
	Total both sexes	3,100	9,100	12,200
All ages	**Total**	**3,800**	**10,700**	**14,500**

Note: s = suppressed as estimate not reliable

Table 1.4 shows the area of residence broken down by age group for Māori and non-Māori children.

Table 1.4.: Age and area of residence of Māori and non-Māori children with physical disabilities, 2001

		Region				
Ethnicity	Age group (years)	North Health	Midland	Central	Southern	Total NZ
Non-Māori	0–4	..s	..s	600	..s	1,600
	5–14	2,400	1,200	2,300	3,200	9,100
	All ages	2,900	1,300	2,900	3,600	10,700
Māori	0–4	..s	..s	..s	..s	700
	5–14	1,200	800	600	500	3,100
	All ages	1,400	1,100	800	500	3,800
Total	0–4	700	..s	800	..s	2,300
	5–14	3,600	2,000	2,900	3,700	12,200
	All ages	**4,300**	**2,400**	**3,700**	**4,100**	**14,500**

Note: s = suppressed as estimate not reliable

Rate per 1,000 children

The four geographical areas used by Statistics New Zealand for these data, and the number of children with physical disabilities per 1,000 children living in each area, are given below. This form of analysis allows for areas with higher or lower population densities, and gives the estimated proportion of children with physical disabilities in each area rather than just the total number.

Overall, an estimated 17 per 1,000 children had physical disabilities (14,500 out of 844,300 children living in private households). The rates per 1,000 children in each geographical area are:

- Northern: 13.6 per 1,000 (4,300 out of 316,500 children)
- Midland: 13.5 per 1,000 (2,400 out of 177,000 children)
- Central: 19.5 per 1,000 (3,800 out of 194,400 children)
- Southern: 26.2 per 1,000 (4,100 out of 156,500 children).

This analysis, then, shows that while the estimates of the actual number of children with physical disabilities were similar in the Central and Southern regions, the number per 1,000 population was higher in the Southern region. What these data cannot show, of course, is the cause of the difference in rates.

Single versus multiple disability, type of disability, and level of severity of disability

Among the children in the group analysed, more had a multiple than a single disability. This finding was true for both Māori and non-Māori (Table 1.5). Number of disabilities is a standard Statistics New Zealand variable derived by examining how many different 'conditions or health problems' were identified during the Child Screening Questionnaire.

Table 1.5.: Estimated numbers of Māori and non-Māori children with physical disabilities who have a single or a multiple disability, 2001

Number of disabilities	Non-Māori	Māori	Total
Single	3,600	1,400	5,000
Multiple	7,100	2,400	9,500
Total	**10,700**	**3,800**	**14,500**

The kinds of disabilities experienced by the children identified as having physical disabilities are shown in Table 1.6.

Table 1.6.: Type of disabilities in Māori and non-Māori children with physical disabilities, 2001

Type of disability	Non-Māori	Māori	Total
Hearing	1,300	800	2,100
Seeing	1,500	800	2,200
Use of technical equipment	2,900	1,200	4,100
Chronic health problem	5,400	1,700	7,200
Intellectual	3,300	1,000	4,400
Psychiatric/psychological	3,600	1,400	5,000
Special education	5,900	1,600	7,500
Other	4,900	1,900	6,800

Note: Definitions of types of disability come from Statistics New Zealand (2001), pp. 130–133.

Because almost two-thirds of children had more than one disability (Table 1.5 above), the estimated number totalled across types of disability is greater than the estimated number with physical disabilities (14,500) described in this section.

The number of children at each level of severity of disability, using Statistics New Zealand's criteria as described in the method subsection above (see 'Levels of disability as defined by Statistics New Zealand'), is shown in Table 1.7. Around a third of children defined for this research project as having physical disabilities had a severe disability, meaning that they needed personal help on more than one level (e.g. needing both respite care and personal care). The proportions with a severe disability were similar in Māori and non-Māori.

Table 1.7.: Severity of disability, Māori and non-Māori, 2001

Severity	Non-Māori	Māori	Total
Mild	1,600	900	2,400
Moderate	5,600	1,600	7,200
Severe	3,500	1,300	4,800
All levels	**10,700**	**3,800**	**14,500**

Cause of disabling condition

Parents and caregivers in the survey were asked what was the cause of each condition or health problem of their child. In all, the estimated 14,500 children with physical disabilities had an estimated 20,200 disabling conditions or health problems (Table 1.8). This finding is consistent with data from Table 1.5 which show that the majority were estimated to have more than one disabling condition or health problem.

Table 1.8.: Cause of disabling condition or health problem, 2001

Cause	Non-Māori	Māori	Total
Disease	3,800	1,300	5,100
Birth	6,100	2,100	8,200
Accident or injury	700	400	1,100
Other	1,600	700	2,300
Not specified	2,700	800	3,500

Note: More than one cause is possible for a single child.

Experiences of children with physical disabilities and their families

The following subsection uses the responses to the Child Content Questionnaire to describe aspects of the experiences of the estimated 14,500 children with physical disabilities, and their families. The results are presented in the order that the topics appear in the Child Content Questionnaire (Appendix B).

Services and assistance

Therapies

Based on the Household Disability Survey sample, it was estimated that in the 12 months previous to the administration of the Child Content Questionnaire:

- 8,700 children had had a consultation with a physiotherapist
- 6,600 had seen an occupational therapist
- 4,000 had seen a speech-language therapist
- 3,900 had seen a counsellor, social worker or psychologist
- 800 had seen a podiatrist or chiropodist
- 1,700 had seen an alternative therapist, homoeopath, naturopath or iridologist.

The numbers consulting traditional healers were too small for estimates to be valid. No reliable estimate of the number of children needing to see specific types of therapist other than those given above was available, due to small numbers.

Of the estimated 90,000 children identified as having a disability of any kind in the HDS 2001, all of those who had received physiotherapy or occupational therapy within the past year were included in the estimated 14,500 with physical disabilities as defined for this research project. So too were the few who had disabilities and wanted but were not getting such therapy. New Zealand children who were not identified as having disabilities but who were getting physiotherapy or occupational therapy were not included in the estimated 90,000 children with disabilities as described by Statistics New Zealand (2001). They were therefore also not included in the estimated subgroup of 14,500 with physical disabilities described in this section.

Personal care and housework

Based on the reports of parents and caregivers, it was estimated that in the 12 months prior to the administration of the Child Content Questionnaire:

- 4,400 families needed help with their child's personal care or with household work because of their child's condition
- 1,600 needed help with personal care but were unable to get this help
- 1,200 needed but were unable to get help with household tasks such as housework or shopping
- 1,500 needed but were unable to obtain help with repair or maintenance of property.

These data suggest a high level of perceived unmet need.

Respite care

In the 12 months prior to the administration of the Child Content Questionnaire, based on the reports of parents and caregivers, an estimated 5,500 children needed respite care or carer support. Of this total, it is estimated that:

- 2,400 received free respite care
- 3,000 received government, hospital or Ministry of Health funding for care
- 1,100 had to pay for care themselves.

Equipment needs

In the 12 months prior to the administration of the Child Content Questionnaire, based on the reports of parents and caregivers, an estimated 3,600 children needed special equipment (including some items that were not related to physical disability; e.g. blood glucose meters). An estimated 800 needed equipment but were unable to get it.

The number who received a special needs grant for disability-related equipment for their child was too small to be estimated reliably. An estimated 700 received other financial help to get equipment, and an estimated 1,300 had to pay for the equipment themselves. An estimated 3,500 families had to pay for other things (not specified) because of the child's health condition.

Therapy needs

The parents and caregivers of an estimated 800 children (5.5%) had paid for physiotherapy, speech-language therapy or other therapy for their child with a disability within the last year. The number paying for input from a psychologist or for counselling was too small to be estimated reliably.

Needs assessment

An estimated 5,600 children had had a needs assessment at some point in their life. An estimated 8,700 had not. Parents and caregivers of the remaining children with physical disabilities were unsure or did not answer. A description of a needs assessment was read out prior to the administration of this question.

Education

The children in the Child Content Questionnaire were enrolled at the following types of schools 'in the week ending Sunday 4th March 2001'. (It should be remembered that the children considered here are aged up to 14 years.) From the responses it is estimated that:

- 8,700 were at primary or intermediate school
- 1,900 were at secondary school
- 800 were at a special school.

The numbers at other types of schools were all too small for reliable estimates.

By using the responses to different questions in the Child Screening and Content Questionnaires, it was possible to derive two estimates of how many children had attended a special school at some time in their life. Based on data from the Child Screening Questionnaire,[6] an estimated 1,100 children were attending a special school. Based on responses to questions 6 and 7 of the Education section of the Child Content Questionnaire, an estimated 2,000 children either attended a 'special school' in the week ending Sunday, 4 March 2001 or had done so at some stage. An estimated 9,500 had never attended a special school. The parents and caregivers of an estimated 600 children either did not respond or did not know.

A large proportion of children – about 90% (10,800 out of the 12,200 aged 5 to 14 years) – were able to be enrolled in the school of their choice. This is similar to the estimated proportion of all children with disabilities. Respondents to the Statistics New Zealand Household Disability Survey (2001) were asked to give reasons for not being able to enrol their child at the school of their choice. Common reasons given for this larger group included 'the school was unwelcoming' and 'special services or equipment were not available'. Because only a few parents and caregivers of children with physical disabilities gave the reasons for their children not being able to enrol, there are no valid estimates for this subgroup.

Transport to and from school

An estimated 3,300 children needed special transport or help getting to and from school. An estimated 8,800 did not. A small proportion of parents and caregivers were reported by Statistics New Zealand as not knowing the answer to this question.

The main way of getting to school was by private car for an estimated 5,900, by school bus for an estimated 1,400, by subsidised special transport/taxi for an estimated 1,500, and on foot for an estimated 2,500. The numbers using other modes of transport such as bicycles or public buses were too small to yield reliable estimates.

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[6] Q35a and b: 'Does … [child's name] attend a special school, or a special unit or class at a regular school, or a regular class where special education services are provided?', and if so, 'is this because of a long-term condition or health problem?'

Participation at school

Based on the responses to the survey, approximately half of the estimated 12,200 school-age children in this group, were prevented from taking part in sports and games at school because of their condition or health problem. However, in the survey, because a parent or caregiver would have answered for younger children in particular, the estimates based on the survey responses reflect the views of a parent or caregiver as to how participation at school was affected.

An estimated 5,700 children were prevented from playing because of their health condition. An estimated 6,300 were not. Some respondents did not know.

An estimated 4,200 were prevented from making friends because of their health condition. An estimated 7,700 were not. Again, some parents and caregivers were unsure.

An estimated 3,400 were prevented from going on school outings or camp because of their health condition. An estimated 8,600 were not. Some parents and caregivers were unsure.

An estimated 2,900 children were limited in participation in another way (not specified) by their health condition. An estimated 9,000 were not. Again, some parents and caregivers were unsure whether their child's condition or health problem affected their participation at school in some other way not already covered by the earlier questions.

Professional assessment of the child

A professional assessment had been conducted for an estimated 6,800 children aged 5–14 years at some time in the past. An estimated 5,200 had never had one. Some parents and caregivers were unsure.

Of those who had had a professional assessment, it is estimated that:

- 3,400 had the assessment conducted by a special education advisor or educational psychologist
- 2,200 had it conducted by a clinical psychologist or paediatrician
- 2,100 had it conducted by a special education teacher or early intervention teacher
- 1,800 had it conducted by a teacher
- 3,700 had it conducted by a physiotherapist or occupational therapist
- 2,000 had it conducted by a speech-language therapist
- 1,200 had it conducted by someone other than any of those listed above.

Information on professional assessment in children under five years old was not requested from Statistics New Zealand, and is therefore not included in this report.

Transport

Travel in private cars

An estimated 13,300 children travelled as a passenger in a private car. Others did not, and some parents and caregivers were unsure. Where they reported that their child did not travel in a private car, parents and caregivers were asked whether there was a private motor vehicle in the household that the child would travel in, were it modified. Too few people answered this question to allow reliable estimates.

For an estimated 700 children, a private motor vehicle had been modified so they could travel in it. There had been no such modifications for an estimated 12,600 children. An estimated 600 children had needed modifications to a private motor vehicle but it had not been possible to make these modifications. The parents and caregivers of an estimated 4,500 children needed to park close to where they were going, while the parents and caregivers of an estimated 8,800 did not. Of those who needed to park close, an estimated 3,100 had experienced problems finding car parks in the last six months. An estimated 1,400 had experienced no such problems.

Accommodation

Home and building modifications

Based on responses of parents and caregivers, an estimated 1,200 children required special features to enter/leave their home while an estimated 12,500 did not. Some parents and caregivers were unsure.

The only specific type of equipment or modification mentioned by a significant number of parents and caregivers was an easy-to-get-at driveway, ramp or street-level entrance, necessary for an estimated 700 children. (It should be remembered that all children with disabilities who reported the need for a special feature to enter or leave the house would be included by definition in the group with physical disabilities described here.) Numbers needing an easy drop-off or pick-up area, a lift/elevator, a widened door, an automatic door, a handrail, lever door handles or other types of equipment were too small to yield reliable estimates.

Economic characteristics

In regard to allowances, from the reports of parents and caregivers it is estimated that:

- 5,500 children were receiving the Child Disability Allowance
- 1,300 were receiving the Disability Allowance
- 8,100 were not receiving either the Child Disability Allowance or the Disability Allowance.

In regard to cards that assist with access to health services, from the reports of parents and caregivers it is estimated that:

- 1,000 children had a Pharmaceutical Subsidy Card
- 700 had a High User Health Card
- 10,700 had a Community Services Card
- 3,000 did not have any of the above cards.

Discussion

This database project defined a group of children with physical disabilities based on the questions in the HDS 2001. Although data about older students would have expanded the information base still further, young people aged over 14 years are treated as adults by Statistics New Zealand and therefore take part in the Adult Screening and Adult Content Questionnaires.

Out of an estimated 90,000 New Zealand children aged up to 14 years with a disability or chronic illness, an estimated 14,500 have physical disabilities as defined for this research. Of this subgroup, an estimated 12,200 are between the ages of 5 and 14 years, inclusive. There were slightly more boys than girls. In the HDS 2001, too, a higher proportion of boys than girls had disabilities (Statistics New Zealand, 2001, Table 5.02a).

Two questions arise when reviewing the estimated number of New Zealand children aged up to 14 years with physical disabilities:

1. Given that the database research project used as its starting point all 90,000 children estimated by Statistics New Zealand as having disabilities, is the estimated rate of total disability in New Zealand similar to the rate in other possibly comparable countries, such as Australia?
2. How does the estimated rate of childhood physical disability compare with the rates in other countries?

Based on the above data, the overall rate of disability in New Zealand children aged up to 14 years is 11%. As such it is similar to that in Australian children (one in seven) (Australian Bureau of Statistics, 2002). However, the rate is higher than that reported in the United Kingdom where, for those aged 10 to 15 years, only 4% of boys and 3% of girls had a moderate or serious disability (Department of Health [London], 2001; information for younger children was not presented). New Zealand's rate is also higher than that in Canada, where 3.3% of children aged up to 14 years were estimated to have disabilities, or 4% of boys and 2.5% of girls (Statistics Canada, 2002). The Canadian figures exclude three areas with a high proportion of indigenous people, where disability rates are higher. For example, in the Yukon 17% disability rates were observed in school-age children, one-quarter of whom had physical disabilities (Yukon Association of Children with Learning Disabilities, 1978, reviewed by National Aboriginal Network on Disability, 1990).

Based on the original research definition, an estimated 14,500 or 1.7% of New Zealand children aged up to 14 years had physical disabilities. This percentage is higher than the 1% of 10- to 15-year-olds in the United Kingdom reported to have a locomotor disability. It is also higher than the 0.5% of Canadian children aged 5 to 14 years with mobility problems. If the analysis includes only those New Zealand children identified for the research purposes as having a moderate or severe physical disability, the New Zealand rate drops to an estimated 1.4%.

The data on New Zealand children with physical disabilities may have captured some children who are described in the data sets of other countries as having a self-care disability or a dexterity disability. This difference in categorisation could explain why the figure of 1.7% is higher than rates estimated in the United Kingdom and Canada. An estimated 1% of boys aged 10 to 15 years in the United Kingdom were reported to have a moderate self-care disability, and an estimated 0.8% of Canadian children aged 5 to 14 years had a dexterity disability. Such children might have been receiving occupational therapy. In the current research project, all children with disabilities (as defined by Statistics New Zealand) who were receiving occupational therapy or who were felt to be in need of such therapy were identified as having physical disabilities.

In summary, disability rates in New Zealand appear higher than those in some other countries. The rate of physical disability estimated for the database research project is higher than estimated rates for other countries, but some of this difference is likely to be due to methodological differences whereby children described elsewhere as having a dexterity problem or a self-care disability are included in the New Zealand data set of children with physical disabilities. The definition used for this database project is in line with the original aim of identifying children with physical disabilities that could impact on their learning and access to the curriculum.

In the majority of children, their disabling condition or disability started before the age of seven years. This finding is important from a planning point of view as it suggests that it is possible to identify most children with physical disabilities before they start school. There was an apparent increase in the number of children per 1,000 population who had physical disabilities in the Southern region relative to the regions further north. This difference is unexplained. A similar pattern was present when all children with disabilities were considered (based on data shown in Statistics New Zealand, 2001, Table 3.02a), and in all children estimated to have disabilities in the HDS 1996 conducted by Statistics New Zealand and reported in *Our Children's Health* (Ministry of Health, 1998).

In many instances it was possible to obtain data for both Māori and non-Māori. This breakdown by ethnicity could provide useful background information when planning services for Māori children with physical disabilities. Of course, caveats apply about the interpretation of such information. Although Statistics New Zealand uses self-assigned ethnicity, it is possible that ethnicity assigned by a parent or caregiver will not be the ethnicity that the child identifies with most strongly when he or she grows up. Statistics New Zealand does, however, over-sample Māori in order to make its estimates more robust.

Physical disabilities that affect learning and access to the curriculum are of particular relevance when examining integrated effective service provision as described in this report. It was not possible to distinguish between physical disabilities that affected learning and access to the curriculum and those that did not. However, some questions clearly relate to integration into school life. Around half of children with physical disabilities could not participate in school games and sports. A slightly smaller proportion were prevented from playing with their peers. These forms of exclusion are of concern as sport and playing with other children are important parts of school life for most children. These data also suggest that some 4,200 children (35%) were prevented from making friends as a result of their disability.

The responses of parents and caregivers to a number of questions on access to supports and services also raise concerns. Clearly at least some families perceived unmet needs in each area covered in the Child Content Questionnaire. Thus an estimated 1,600 families needed help with the personal care of their child but did not get it, an estimated 1,200 needed help with household care but did not get it, and an estimated 1,100 had had to pay for respite care for their child, presumably because some other form of funding was not available or was insufficient. Furthermore, an estimated 600 children needed but had not received modifications to the family car, and an estimated 1,300 needed special features to enter or leave their home but had not received them.[7]

Of the 14,500 children estimated to have physical disabilities based on the definition used for this research project, an estimated 8,700 had seen a physiotherapist and an estimated 6,600 had seen an occupational therapist in the last year. An estimated 800 children had seen a therapist (occupational therapist, physiotherapist or speech-language therapist) paid for privately. The use of private therapy could suggest unmet need, or a difference in view between family and public services as to what the therapy needs of certain children are and where these needs fall relative to those of other children for a service with a finite budget. The questions of when and why families pay for private therapy for children with physical disabilities could not be explored further with these data, but are certainly important.

It is of concern that, at least according to parents and caregivers, such a large proportion of children (at least 60%) had never had a needs assessment (though this is neither a requirement nor entitlement). A needs assessment[8] is one of way of accessing a large number of Health-funded services. These include Health-funded occupational therapy and physiotherapy; which is the funding stream for such therapy for children before they start school and for children and young people who need therapy but do not qualify for Education-funded therapy.

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[7] See also *Living with Disability* (2004), a descriptive analysis of results from the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities.

[8] Needs assessments are conducted by Needs Assessment and Service Co-ordination organisations (NASC), contracted to the Ministry of Health's Disability Services Directorate (from 1 July 2007 known as the Health and Disability National Services Directorate) and that work with disabled people to help identify their needs and to outline what disability support services are available. They allocate Disability Services-funded support services and assist people to get other support that is available.

Of course some parents and caregivers could have forgotten an assessment or may not have been aware that a meeting they had was in fact a needs assessment. Thus the figure of 60% may be an overestimate of those who have never had a needs assessment. Assuming that parents and caregivers are correct in their reporting, however, two interpretations of the data are possible. First, it could be that over half of the children described here as having physical disabilities do not have a disability as defined by Health (see ‘How disability is defined in this report’ in Section 1.1). An alternative explanation is that a number of children with physical disabilities are missing out on an important service (needs assessment), and so are perhaps lacking access to services and supports for which they would be eligible, including home help, help with personal care and respite care.

Fewer than half of the children with physical disabilities were reported to be receiving the Child Disability Allowance, a non-means-tested benefit for children and young people with a long-term disabling condition that meets certain criteria (see Section 1.3). Fewer still were reported to be receiving the Disability Allowance, which is means-tested. A large proportion, however, had a Community Services Card, perhaps indicating that some belong to low-income families, and that all children and young people for whom a Child Disability Allowance is granted are eligible for this card.

Taken together, these findings provide a useful picture of the characteristics and certain aspects of the lives of New Zealand children with physical disabilities, and of the lives of their family and whānau.

Section 1.3: Child Disability Allowance

This section describes children and young people receiving the non-means-tested Child Disability Allowance. It looks at the gender and age of recipients, and the geographical location of the Work and Income offices dealing with the allowance. It also examines uptake rates across New Zealand.

Background

The Child Disability Allowance (CDA) is a benefit that is not means-tested, and is paid to the caregiver of eligible dependent children and young people aged up to 17 (i.e. up to the end of the year in which the young person turns 17).[9] It was introduced in 1978, and was originally known as the Handicapped Child Allowance. The CDA is worth $35.75 a week (as of July 2003). The applicant and child or young person must ordinarily be lawfully and permanently resident in New Zealand.

The application form is filled in by the caregiver, and a doctor who has examined the child or young person on whose behalf the application is being made (see Appendix C for a copy of the Child Disability Allowance Application Form).When filling in the form, the doctor indicates if and when the eligibility for the allowance should be reviewed. To qualify, a child or young person must meet all the requirements of Section 39A(1), plus at least one of the Section 39A(2) criteria. Thus the child or young person must:

- have a physical or mental disability, and
- because of that disability, need constant care and attention, and
- be likely to need such care and attention permanently, or for more than 12 months.

In addition, the child or young person must require:

- from another person, frequent attention in connection with his or her bodily functions, or
- attention and supervision substantially in excess of that normally required by a child or young person of the same age and gender, or
- regular supervision from another person in order to avoid substantial danger to himself or herself or to others.

The Ministry of Social Development, Work and Income, administers this allowance, and it made available the information on current uptake used for this research project. The database provided included age, gender, self-identified ethnicity of the main caregiver and the location of the office dealing with the application. Information on the area of residence of the main caregiver, which would have been much harder to abstract, was not provided.

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[9] Exceptions may be made so that the CDA can continue to be paid until the end of the year in which the young person turns 18.

Methods

Processing of applications

A decision is made, at the time of processing the application form at the Work and Income office, as to whether the child or young person has a predominantly physical disability, a predominantly mental disability, or a mixture of both. Guidelines are available to the data-entry staff, though these were not made available to the research team. Physical disability includes chronic illness.

Limitations of the data

Data relate to location of Work and Income office, not recipient's place of residence

Work and Income records the office administering the CDA for each child or young person. The address of the child or young person is recorded in a free field, making data retrieval from this field difficult and time consuming. For this reason, the data supplied by the Ministry of Social Development included the name of the administering office but did not include area of residence.

Information on the uptake of the CDA per 1,000 children and young people by geographical area (here territorial local authority, or TLA) is depicted in tables and bar charts in the results subsection below. This information is based on the TLA in which the office dealing with each child or young person is situated. This approach is likely to produce different results from a calculation using the TLA in which the child or young person resides. For example, there are 11 TLAs with no Work and Income offices. Children and young people from these TLAs would clearly have their benefit administered by an office in a different TLA.

Any calculation of numbers of children and young people receiving the CDA per 1,000 in the population, therefore, needed to allow for those who live in TLAs with no Work and Income offices. This factor was accounted for by combining each TLA without an office with the neighbouring TLA, or a TLA that families would be likely to have used. It also became clear that some offices administered the CDA for most children and young people from a wide surrounding area, even those from surrounding TLAs with offices. After discussion with staff from the Ministry of Social Development, these TLAs were combined to give the most accurate picture possible of the number of CDA recipients in any geographical area.

Lack of ethnicity data for children and young people

Of note also is that the CDA application form requests the ethnicity of the main caregiver but not that of the child or young person on whose behalf the application is being made. For this reason, no analysis involving the ethnicity of children and young people with disabilities could be carried out.

Preparation of the data

Before the analysis of the proportion of children and young people receiving the CDA was produced, the following TLAs were combined to allow for those TLAs with no Work and Income offices:

- No. 18 Otorohanga with No. 19 Waipa
- No. 49 Carterton and No. 50 South Wairarapa with No. 48 Masterton
- No. 54 Kaikoura with No. 53 Marlborough
- No. 58 Hurunui District with No. 59 Waimakariri

- No. 61 Banks Peninsula and No. 62 Selwyn with No. 60 Christchurch
- No. 57 Westland with No. 56 Grey District
- No. 65 Mackenzie and No. 66 Waimate with No. 64 Timaru
- No. 73 Southland with No. 75 Invercargill.

Data relating to a few CDA recipients administered under ‘North’ and ‘Other’ were not included. This approach reduced the total of 74 TLAs (73 excluding the Chathams) by 11. It allowed for children and young people from TLAs with no Work and Income offices, while still leaving geographical units in numbers sufficient to be able to describe any geographical variation in uptake rates.

The location of each TLA in New Zealand is shown in Figure 1.3.

Figure 1.3.: Territorial local authorities

When correlating median income and CDA uptake rates, the following additional amalgamations were made: Manukau (No. 8) with Franklin (No. 10) and Papakura (No. 9); Nelson (No. 52) with Tasman (No. 51); Kaipara (No. 3) with Whangarei (No. 2); and Kawerau (No. 26) with Whakatane (No. 25). The reason for making these further amalgamations was that, after discussion with the Ministry of Social Development, the researchers believed that people from the combined areas were predominantly being looked after by one office.

Results

Number of children and young people receiving the CDA

On 6 September 2002 a total of 24,423 children and young people were receiving the CDA. Of this total, 13,907 were boys and 7,800 were girls; the gender of 2,753 children and young people (11%) was not recorded.

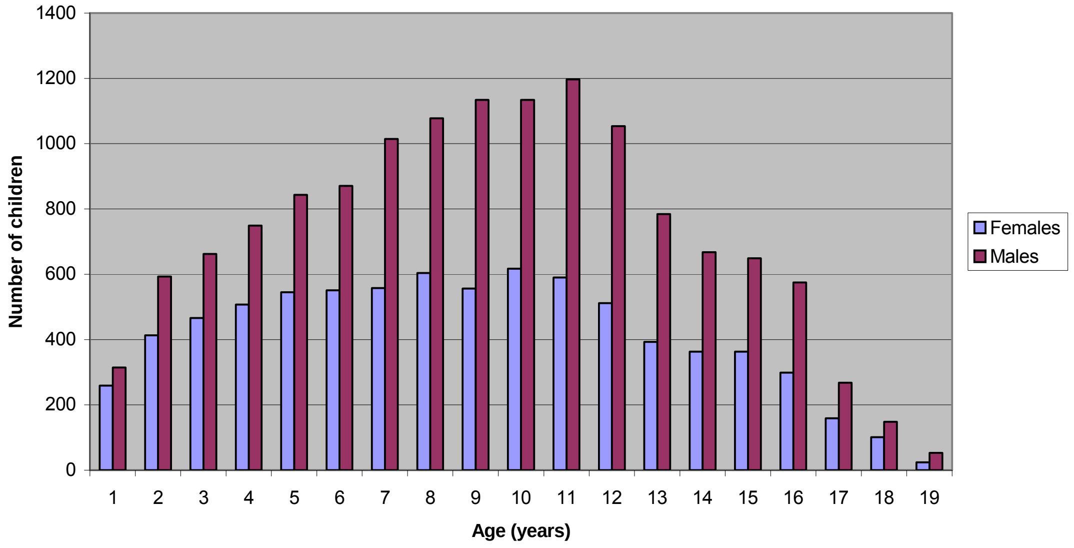
Age of recipients

The number of children and young people on the CDA increased in each age bracket until the age of 11 years, after which the number of children and young people in each age bracket decreased (Figure 1.4).

The drop was particularly steep after the age of 15, for which there are likely to be several reasons. Some young people would have become eligible for the Invalid's Benefit[10] on reaching 16 years of age, and would have transferred to this. Others may no longer have been dependent on the adult carer to whom the allowance was being paid. Still others may no longer have had a disability. There may also have been a reduced awareness of the CDA and its applicability among some professionals and perhaps parents of older children and young people.

Because there were no data available to look at the number of 16- and 17-year-olds on the Invalid's Benefit, this issue could not be examined further. The medical criteria for the Invalid's Benefit are stricter than for the CDA so the two would not be directly comparable anyway. Some 18- and 19-year-olds appeared to be receiving the CDA. These young adults have been omitted from calculations of uptake per 1,000 children and young people in the community as they were not eligible for the allowance.

Figure 1.4.: Number of boys versus girls receiving the CDA, by age, where gender is known, 2002



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[10] People with a permanent sickness, injury or disability that stops them from working may be able to get an Invalid's Benefit to help meet their living costs. To qualify, the person needs to be 16 years of age or over and meet other criteria.

Gender of recipients

The numbers of boys and girls receiving the CDA, by age, are compared in Figure 1.4 above. At all ages boys had higher rates than girls, where gender was recorded.

Indications of medical diagnoses of CDA recipients

To provide a better understanding of the range of conditions experienced by children and young people receiving the CDA, the text in the free fields of the application form was parsed and the most common words made available to this research team. Examining the number of times that words suggesting physical disability rather than chronic illness occur is a second way of analysing these data, and is more likely to give an indication of the number of children and young people with physical disabilities as opposed to chronic illness.

Table 1.9.: The 19 words appearing most frequently on CDA recipient application forms (September 2002)

Word	Number of forms containing the word
Disorder	2,779
Delay	2,196
Developmental	1,962
Attention	1,931
Syndrome	1,903
ADHD	1,716
Deficit	1,640
Severe	1,170
Asthma	1,083
Palsy	846
Diabetes	835
Disease	831
Hyperactivity	795
Epilepsy	774
Congenital	762
Intellectual	740
Disability	680
Downs	668
Learning	665

Of the 10 words used most frequently (see Table 1.9), two related to mental health or behavioural difficulties (attention and ADHD), one was a medical disability (asthma) and one related to a physical disability (palsy). There was a notable drop in frequency from asthma at number nine, mentioned 1,083 times, and palsy at number 10, which represents the most commonly mentioned physical disability yet was mentioned only 846 times in over 24,000 CDA application forms.

If only the application forms in which a medical term suggested physical disability are considered, the number of children and young people affected appears to be somewhere between 1,000 and 2,600. A more precise estimate within this range depends on a best guess of whether some children and young people had several of the terms on one form or not. (For further detail on words related to physical disability that appeared in this analysis, see Appendix C.)

How do estimated uptake rates vary across New Zealand?

Examining uptake of the CDA per 1,000 possible recipients by geographical area allows us to take into account whether areas are densely or sparsely populated. Total numbers of CDA recipients in densely populated areas are likely to be higher than total numbers in sparsely populated areas.

While a description of high uptake or low uptake per 1,000 population does not explain the variation, it does raise an issue that could warrant further investigation. Variation in uptake rates may be relevant to this research project, which included among its aims to look for evidence of unmet need. One interpretation of low uptake in an area could be that some children and young people who are eligible for the allowance or service are not getting it.

The actual uptake rates for each area for those aged under 18 years and for those aged under five years are shown in Table 1.10.

Table 1.10.: CDA uptake per 1,000 population, by area, for those aged under 18 years and for those aged under 5 years, 2002

TLA	Recipients on CDA per 1,000 population	
	Total under 5 years	Total under 18 years
Ashburton District	1.57	8.46
Auckland City	3.87	15.14
Buller District	5.10	24.34
Central Hawke's Bay District	3.46	14.89
Central Otago District	4.93	26.38
Christchurch–Banks–Selwyn	9.98	41.13
Clutha District	3.58	24.02
Dunedin City	6.75	38.94
Far North District	3.86	13.97
Franklin District	0.13	0.45
Gisborne District	5.54	23.30
Gore District	9.10	39.91
Grey–Westland	7.50	28.66
Hamilton City	6.64	34.17
Hastings District	4.59	19.61
Hauraki District	9.80	41.79
Horowhenua District	8.78	34.36
Lower Hutt City	4.01	23.26
Invercargill–Southland	14.69	40.14
Kaipara District	1.75	10.31
Kapiti Coast District	4.59	27.95
Kawerau District	5.61	20.43
Manawatu District	2.86	19.26
Manukau City	1.15	5.53
Marlborough–Kaikoura	4.17	21.32
Wairarapa	6.73	24.63
Matamata–Piako District	3.30	26.76
Napier City	8.36	27.60
Nelson City	6.55	35.43
New Plymouth District	3.93	21.36
North Shore City	4.49	17.90
Opotiki District	4.59	17.39
Palmerston North City	6.03	25.50
Papakura District	36.90	125.71
Porirua City	6.56	29.28
Queenstown–Lakes District	4.40	18.72
Rangitikei District	5.95	24.45
Rodney District	4.32	21.91
Rotorua District	4.72	20.87
Ruapehu District	3.33	17.10
South Taranaki District	2.04	10.22
South Waikato District	3.71	20.73
Stratford District	5.01	20.42
Tararua District	2.03	14.78
Tasman District	5.16	24.30
Taupo District	4.54	18.92
Tauranga District	8.25	37.11
Thames–Coromandel District	7.50	39.27
Timaru–MacKenzie–Waimate	9.78	42.52
Upper Hutt City	6.12	24.40
Waikato District	4.10	16.81
Waimakariri–Hurunui	0.37	3.19
Waipa–Otorohanga	3.92	22.05
Wairoa District	2.73	17.06
Waitakere City	5.11	22.55
Waitaki District	6.51	33.96
Waitomo District	4.41	25.09
Wanganui District	4.40	25.82
Wellington City	4.21	18.87
Western Bay of Plenty District	2.84	11.80
Whakatane District	2.49	11.01
Whangarei District	4.30	23.13
Grand total	**5.43**	**24.00**

Note: Figures have been rounded to two decimal places.

An explanation for the high rates in Dunedin City, Invercargill City, Christchurch, and Papakura was found in discussion with the Ministry of Social Development: each of these areas administers the CDA for surrounding offices. Once this arrangement was allowed for by combining each of these high-uptake areas with its surrounding low-uptake areas, the range of uptake rates was smaller but remained statistically significant.

The uptake rates for those aged under 16 years were also examined, as those aged 16 and over could have been on the Invalid's Benefit. This analysis indicated that areas with high uptake for those under 18 also had high uptake for those under 16 (results not shown). The rate was higher if only younger children are considered because the uptake for older children and young people was low, as discussed above. Uptake for those under five years of age may be of interest to those planning services for school-age children (see Table 1.10).

Discussion

As expected, for example from the 2001 Household Disability Survey data (Section 1.2), more boys than girls appear to have disabilities in that more boys than girls were receiving the CDA. A number of conditions for which the CDA may be applicable are more commonly diagnosed in boys than girls. One of these is Attention Deficit Hyperactivity Disorder (ADHD), a diagnosis that was mentioned on a significant proportion of CDA application forms.

Possible interpretation of varying rates of uptake

There are a number of possible explanations for the apparent variation in uptake.

Some variation is likely to be due to the lack of data on where CDA recipients live, as well as to the arrangements under which Work and Income offices administer the CDA. These limitations were overcome by combining the data for certain TLAs. Importantly, some of the geographical variation related to the way certain offices administer the benefit for families looked after by surrounding offices. Thus, for example, the Papakura office tends to also administer the CDA for children and young people from the south Auckland area. Christchurch administers CDA applications from the whole of the Canterbury area, and Dunedin tends to cover a large part of the lower part of the South Island. Even after allowing for these distorting factors as best as was possible, however, there was still significant variation in uptake rates.

One reason for true variation in uptake rates could be that parents move with their families to certain magnet areas. Thus parents may move to be near hospital facilities, or to be near schools that they feel are particularly good at providing a quality education for children and young people with disabilities.

Additionally, true variation in uptake could result if parents are more likely to be made aware of the CDA in some areas than in others. There was no information on how parents tend to find out about the CDA. One possibility is that people are better informed in areas where parent support groups and parent networks are more developed; the author is aware of many families who have heard of the allowance from other parents. In some areas, too, therapists or teachers may have taken on an important role in raising parental awareness of this allowance.

As doctors are the gatekeepers for this allowance, varying awareness among doctors, and perhaps differences in ability or willingness to recognise certain conditions, may also be contributing to the variation in uptake. All general practitioners were sent information about the CDA in 2000, when family doctors and paediatricians took over the role of filling out the CDA application forms from designated doctors. There should therefore be equal knowledge of the CDA among general practitioners. It seems likely, however, that awareness is higher in some areas than others. The availability of services or individuals who investigate children and young people for certain types of conditions and make the relevant diagnoses varies geographically, yet a diagnosis is needed when filling out the CDA application form. This varied availability may be another reason why rates of CDA uptake were higher in some areas than others.

Furthermore, it is conceivable that socioeconomic conditions could account for some of the variation in uptake. There is some reason to believe that recurrent and perhaps also chronic illness is more common in families with lower income. For example, children's physical health is worse in single-parent and stepfamilies, which O'Connor et al. (2000) account for in terms of the increased exposure to psychosocial risks of these types of families. In keeping with this argument, children in the United Kingdom from single-parent households were reported to consult family doctors for a number of conditions, including infections and accidents, more frequently than those from families with more than one adult (Fleming & Charlton, 1998).

In New Zealand, single-parent families are generally poorer than two-parent families. There is, moreover, a large number of single-parent families: figures from Statistics New Zealand showed that there were 339,156 dependent children in two-parent families and 141,036 children in one-parent families (Melville, 2003). Other data in the same publication showed that the proportion of single-parent families with an annual income of less than $20,000 (61%) was larger than the proportion of couples with children in this income bracket (6%). In the north of the North Island researchers reported that children and young people in rural Waikato and south Auckland lived in the areas of greatest deprivation and suffered the poorest health of the groups studied (Graham et al., 2001). This database research project, however, found no relationship between the median income of a geographical area or areas and uptake rate of the CDA administered by the office in that area.

In summary, therefore, while some of the variation in uptake occurs because certain offices administer the CDA for people living in other geographical locations, there also appears to be a genuine geographical variation in uptake rates. It may be that the true variation relates to the organisation and availability of services, including services that make specific medical diagnoses. The variation in uptake suggests that some areas are under-using the CDA, while in others there is a high level of awareness of the CDA and a willingness to apply for it. It is estimated that, if the relatively high but believable rate of 40.99 per 1,000 population in the combined Timaru–McKenzie–Waimate districts were extrapolated across the whole of New Zealand, there would be an estimated 43,474 children and young people receiving the CDA rather than the observed 24,433. It therefore appears likely that some children and young people who would be eligible are not receiving this allowance.

There are alternatives to the CDA from Work and Income New Zealand. In total, 892 children and young people aged under 18 years who were disabled due to an accident received an allowance from ACC, and others received ACC-funded services. These children and young people are described in the following two sections.

Section 1.4: ACC Claimants: Lump Sums or the Independence Allowance

This section and the next look at two groups of children and young people funded by ACC. The first group, on which this section focuses, received an Independence Allowance or a lump sum payment, somewhat analogous to the Child Disability Allowance. Section 1.5 covers the second group, who receive ACC services for presumed physical disability based on a definition developed for this research.

Background

Children and young people who are disabled as the result of an accident are not eligible for the Child Disability Allowance (CDA) (refer to Section 1.3). Instead they may qualify for an Independence Allowance (IA) or may have qualified for a lump sum, both of which are ACC benefits. In other ways they may be similar to many children and young people receiving the CDA.

For the purposes of this research project, ACC kindly agreed to provide anonymised data on children and young people who were receiving the IA and who had received lump sums.

Definitions

Lump sum

An amount of money was paid to a claimant for either 'loss of enjoyment of life' and/or a level of impairment. The level of impairment (see below) was assessed by a doctor. The entitlement to lump sums ceased in 1992 and was replaced by the IA, but it has recently been reinstated under the Injury Prevention Rehabilitation Corporation Act 2001 (see below).

Independence Allowance (IA)

For injuries after April 1992, a quarterly allowance is paid based on the assessed level of impairment. Initially the IA was based on assessed disability. It is now based on assessed impairment (*Guides to the Evaluation of Permanent Impairment*, 4th edition, American Medical Association, 1993, and the *ACC User Handbook to the AMA Guides to the Evaluation of Permanent Impairment, 4th edition).* Only impairments or combinations of impairments over 10% have an entitlement, and the amount paid then increases with the level of impairment (Table 1.11). The IA is reassessed if the level of impairment changes, if the claimant requests it, or at a maximum of five-yearly intervals.

Lump sums paid previously are deducted from the IA. If, for example, the impairment is 60% and the lump sum was paid for 20% impairment, the IA is paid at 40%.

Table 1.11.: Amount paid quarterly through the Independence Allowance for each level of impairment

Impairment level	Quarterly amount (13 weeks)
10%	$143.13
20%	$245.44
30%	$347.49
40%	$449.80
50%	$552.11
60%	$654.29
70%	$756.60
80–100%	$858.78

Injury Prevention Rehabilitation Corporation Act 2001

Under this Act, entitlement to lump sums has been reinstated for injuries sustained after 1 April 2002 (assessed when rehabilitation is complete or 12 months after the injury date, whichever is the sooner). Claimants already receiving the IA will continue to receive it. They are entitled to a lump sum for a new injury only.

Methods

Eligibility criteria for inclusion in data analysis

The data analysis included all children and young people aged under 18 years who had received lump sums or who were receiving the IA at the time of data abstraction (September 2002) and whose claims were still open.

Among this group, those who had acquired a piece of equipment costing at least $60 at some time in the history of the claim were also identified and classified as having physical disabilities, as $60 is the cost of a pair of crutches.

Defining areas of residence

Information was available on the town or area of residence for many – but not all – of the children and young people in this data analysis. Information on region was close to complete, so uptake was grouped according to the following 16 regions: Auckland, Bay of Plenty, Canterbury, Gisborne, Hawke’s Bay, Manawatu–Wanganui, Marlborough, Nelson, Northland, Otago, Southland, Taranaki, Tasman, Waikato, Wellington and West Coast.

Results

Number of children and young people receiving a lump sum or the IA

In all, 892 children and young people (aged under 18 years) had received lump sums or were receiving the IA at the time of data abstraction. All these claims were currently open. Of these 892 children and young people, 320 were classified as physically disabled based on the definition developed for this research project – that is, they had acquired equipment costing over $60.

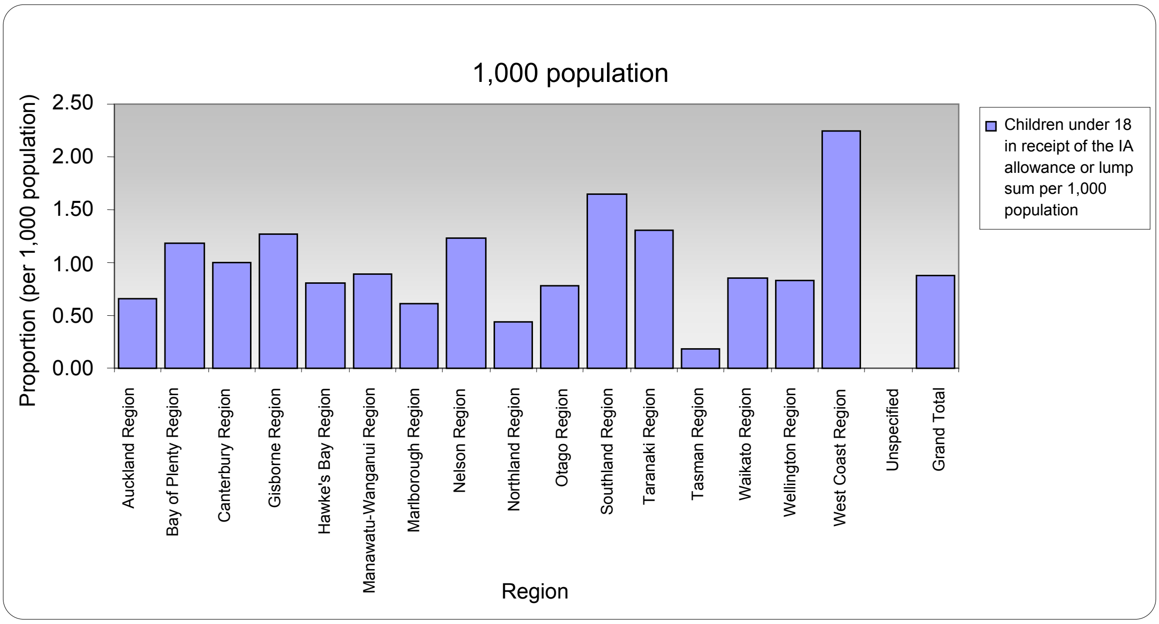
Amounts received

For the 892 children and young people with and without physical disability, amounts received up to September 2002 as lump sums or the IA ranged from $45 to $33,354 per claimant. For the 320 children and young people with physical disabilities, amounts received up to September 2002 as lump sums or the IA ranged from $801 to $26,999 per claimant.

Where do these children and young people live?

Across the country, the distribution of children and young people receiving the IA or a lump sum (all recipients, not just the subgroup of those with physical disabilities) was 0.88 per 1,000 population. Figure 1.5 breaks down this distribution by region. The variation in rates for individual regions is statistically significant. The highest uptake was along the West Coast of the South Island (in the combined Westland–Grey–Buller districts), followed by the Southland region (combined Invercargill–Gore area). High uptake was also seen in the Taranaki region (combined New Plymouth–Stratford–South Taranaki area) and Gisborne region. The Northland region (far north of the North Island) had both low absolute numbers and a low proportion of children and young people receiving the IA or lump sum. This pattern of distribution remained similar across all age groups (results available from author).

Figure 1.5: Children and young people aged under 18 years on the Independence Allowance or lump sum per 1,000 population, by region, 2002



Uptake by Māori and Pasifika children and young people

The proportion of Māori children and young people aged under 18 years who received the IA or a lump sum was 0.9 per 1,000 population, similar to the overall rate of 0.88 per 1,000. The uptake rate for Pasifika children and young people in this sample was low at 0.46 per 1,000 population.

Discussion

The figures reported in the results subsection are open to a range of different interpretations. It may be that accidents that lead to disability are occurring at a higher rate in some geographical areas than in others, or that access to ACC funding is easier in some parts of New Zealand than in others, or even that both these explanations apply. Some less densely populated areas had relatively high uptake rates.

ACC is aware that the uptake of its allowances and services by Pasifika peoples is low (Wendy Browne, personal communication, 2002).

Various authors have found that preventable injury is more likely to occur in more disadvantaged populations (Kemp & Sibert, 1997; Kendrick, 1993; O'Connor et al., 2000), in which case uptake might be expected to be higher in regions with a low median income. Alternatively, better-off families might feel more comfortable about accessing ACC services and more able to advocate for their child's needs, in which case uptake might be expected to be higher in regions with a higher median income.

Median income is, of course, a blunt measure of disposable income. It is an even blunter measure of important aspects of socioeconomic status. Indeed, its use in an analysis to explore the possible impact of socioeconomic status produced no statistically significant relationship between median income in a region and uptake of the CDA and lump sums in this population of children and young people.

Taken together, these data suggest that while income could still be an important variable, local factors not measured by median income are also likely to be important in affecting who is injured and/or who gets ACC funding in the form of a lump sum or the IA.

This information suggests that, along with the approximately 24,400 children and young people receiving the CDA (see Section 1.3), a further 892 received a similar allowance funded through ACC. Within this group, there were up to 2,920 children and young people aged under 18 years with a presumed physical disability who were receiving an allowance or lump sum (2,600 via Work and Income, and 320 via ACC).

Section 1.5: ACC Claimants: ACC-funded Services

This section describes children and young people receiving funding from ACC who were deemed to have physical disabilities based on a definition developed for this research project. It describes the types of services they received, and provides information about how much ACC spent on providing services of various kinds.

Background

As it did with the data examined in Section 1.4, ACC kindly agreed to provide information on children and young people with physical disabilities, based on a definition developed for this research project, who were receiving ACC funding. The anonymised data were abstracted from the main ACC claimant database, Pathway. The research team members were all aware of individual children and young people with physical disabilities who were receiving services provided by ACC. No one, however, knew how many such children and young people there were.

Methods

How were children and young people with physical disabilities defined?

This section describes children and young people who, at the time that data were abstracted in July 2002, fell into the following categories.

- They were ACC claimants who were under 18 years of age.
- The accident happened more than six months prior to data collection (i.e. before 1 February 2002).
- The claim was still open (July 2002).
- The claimant had a payment made for equipment of at least $60. This criterion assumes that they had a physical disability at some time in the life of the claim.

It was decided to use a claim for equipment to identify these children and young people. The cut-off cost was $60 as this represents the cost of a pair of crutches. The reasons for not using Read Codes are given below.

Why not use Read Codes?

Read Codes are a standard set of clinical terms that are an important part of the process of developing national clinical data standards and clinical data management tools. The National Health Service Information Authority in the United Kingdom produces and maintains the data that are the clinical terms (the Read Codes). These are supplied for incorporation into the user's or developer's electronic record software. When implemented in a software system, the files can be used for storage, retrieval, cross-mapping and analysis of patient information.[11]

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[11] For clinical terms (the Read Codes), see: http://www.nhsia.nhs.uk/terms/pages/clin_terms.asp

The information for ACC clients is collected when medical help is sought following an accident. The accuracy of the code then entered depends on the relevant person (often the practice receptionist) appreciating the exact nature and extent of the injury, and choosing the most appropriate code. Codes are not necessarily updated on the ACC database when the nature of the injury is revealed to be more extensive than first thought, or perhaps fundamentally different in nature. Thus, for example, laceration to the scalp might be recorded for someone who has actually sustained a significant head injury.

Results

Number and age of children and young people

In total, 557 children and young people (349 boys and 208 girls) were funded by ACC. Table 1.12 shows the ages of the children and young people in this group when the accident occurred and their ages as of July 2002. For 381 children and young people (68%), their accident occurred between 0 and 5 years of age.

Table 1.12.: Age at accident and at July 2002

Age at accident (years)	Age now (years)			
	0–5	**6–10**	**11–17**	**Total**
0–5	60	153	168	**381**
6–10		25	85	**110**
11–17			66	**66**
Total	**60**	**178**	**253**	**557**

Year when accident occurred

Table 1.13 shows the calendar year in which the accident occurred for children and young people still funded through ACC. It is evident that, as the time since injury increases, the number of children and young people still funded gets smaller. Not many of those who sustained their injury 10 years before or more were still receiving funding in August 2002.

This trend could suggest that many of these children and young people had injuries that improved over time, and would be consistent with ACC’s aim of restoring its clients to normal functioning. Another, not mutually exclusive, interpretation is that some children and young people injured in the past were now over 18 years of age and therefore did not appear in these data, even though they may still have been receiving funding.

Table 1.13.: Year of accident and number of children and young people under 18 years still funded in August 2002

Year of accident	Number of claims open (August 2002)
1984	9
1985	13
1986	18
1987	23
1989	25
1990	25
1991	31
1992	26
1993	43
1994	44
1995	35
1996	47
1997	44
1998	38
1999	46
2000	40
2001	45

Ethnicity

ACC records the ethnicity of each ACC-funded child or young person, and believes that this information is generally self-identified. Table 1.14 shows the ethnicity of the 557 children and young people with physical disabilities as defined above. Over half were New Zealand European/Pakeha, with the next most commonly represented group being Māori. Māori children and young people are considered separately later in this section.

Table 1.14.: Ethnicity of ACC-funded children and young people with physical disabilities, 2002

Ethnicity	Number
NZ European/Pakeha	313
NZ Māori	141
Other	27
Declined to answer	23
Samoan	17
European not further defined	9
Other European	7
Tongan	5
Cook Island Māori	4
Not stated	3
Fijian	2
Indian	2
Chinese	1
Middle Eastern	1
Other Asian	1
Other Pacific Island	1
Total	**557**

Pasifika children and young people were under-represented in these data, as is the case generally for Pasifika peoples receiving ACC services. This issue is addressed in the discussion below.

Types of ACC funds

Children and young people receiving ACC funding can be paid through one of a number of different ACC funds, based on the cause of their injury. The number of children and young people with physical disabilities being supported through each type of fund is shown in Table 1.15.

Table 1.15.: Children and young people with physical disabilities supported through each ACC fund, 2002

Fund	Number of children and young people
Non-earners	317
Motor vehicle	129
Medical misadventure	105
Earners	5
Residual	1
Total	**557**

Cause of accident or injury

In most cases the accident or injury for this group of children and young people was certainly of a kind that might result in a physical disability, such as ‘collision with/knocked over by a car’ or ‘other loss of control of vehicle’. For 100 children and young people (almost a fifth of the total), the type of accident or injury was ‘other or unclear cause’ and no further information was available.

Further details on the causes of the accidents among this group of children and young people are given in Appendix D.

Serious Injury Portfolio

Of the 557 claims analysed for this research project, 368 or 66%, were in the Serious Injury Portfolio. Claims in the Serious Injury Portfolio are for spinal injuries, moderate-to-severe brain injuries, or a similar level of disability, such as blindness, multiple amputation and/or burns over 50% of the body. The high proportion of cases in this portfolio suggests that it has been possible to identify children and young people with significant disability using the cost of equipment as the key defining factor.

Rehabilitation costs

ACC aims wherever possible to rehabilitate. Its pledge, as described on its website, is ‘to prevent injury, to provide the best treatment and care if injury occurs, and to quickly rehabilitate people back to work or independence at a price that offers high value to premium payers and all New Zealanders’. Costs of specific components of rehabilitation for the 557 children and young people in this analysis are shown in Table 1.16.

Table 1.16.: Rehabilitation costs for children and young people with physical disabilities over the length of the claim, as at July 2002

Component of rehabilitation	Number of claimants receiving this entitlement	Average cost	Minimum cost	Maximum cost
PT, OT, SLT[1]	170	$784	$7	$5,918
Equipment	557	$13,615	$65	$118,728
Consumables	243	$7,107	$2,816	$66,287
Education support	412	$37,700	$20	$128,374
Attendant care	399	$114,741	$48	$646,720
TIL[2]	369	$16,679	$45	$147,699
Housing modifications	204	$26,234	$3,070	$181,687
Vehicle modifications	134	$22,462	$5,188	$58,781
School transport	130	$5,387	$5	$58,869
Residential support	93	$5,168	$63	$77,962
Inpatient rehabilitation (post acute)[3]	14	$58,900	$3,937	$162,181
Other[4]	557	$86,557	$33.75	$844,441
Total cost to date (per claimant)	**557**	**$234,922**[5]	**$211**	**$1,457,797**

Note:

[1] PT = physiotherapy; OT = occupational therapy; SLT = speech-language therapy

[2] TIL = training for independent living

[3] Only funded since 1999; came under bulk funding before 1999.

[4] 'Other' may include: assessments, doctor and specialist fees, X-rays and imaging, visual aids, dental, audiology, surgery, emergency transport, transport to treatment, pharmaceuticals, weekly compensation, loss of potential earnings, Independence Allowance, lump sums (pre-1992), backdated attendant care.

[5] Average total cost to date for all claimants in this group.

This research project is focused on describing the range of sources and the quantum of resourcing of children and young people with physical disabilities. The costs for physiotherapy, occupational therapy and speech-language therapy given in Table 1.16 appear low because most of these services will be given as part of programmes working on training for independent living (TIL). Further physiotherapy, occupational therapy and speech-language therapy will be provided in the school setting as ACC-funded children and young people are entitled to the usual Education-funded services, as discussed in Section 1.1. ACC may, however, decide to top up therapy provision in some cases, and it is these cases that are reflected in the above data.

The geographical location of this group of children and young people, and hence the uptake per 1,000 population in different areas, could not be examined as there were data for only the location of the ACC office administering the funding, rather than for the area of residence of individual children and young people.

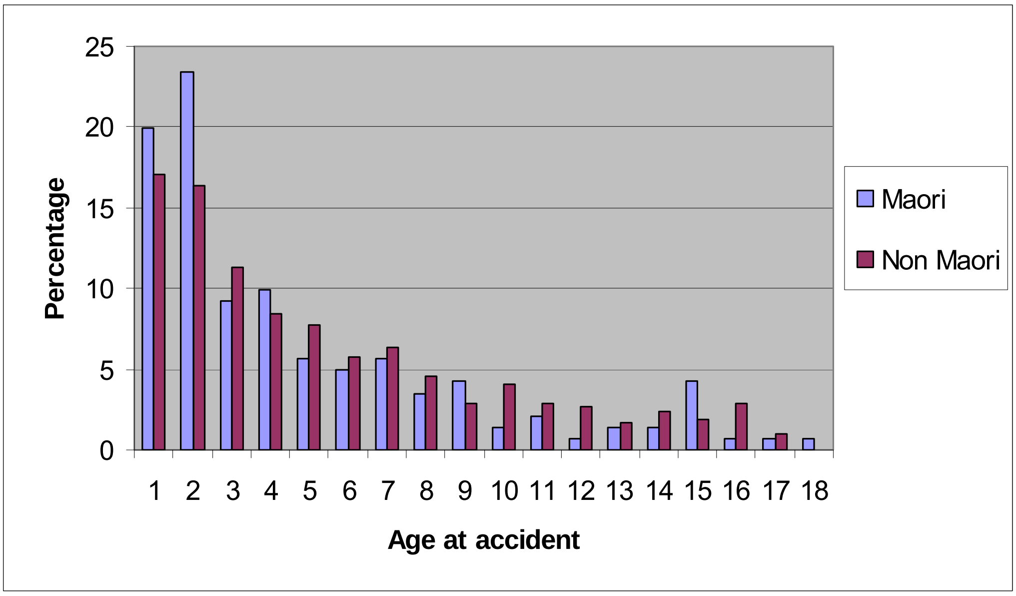
Māori children with physical disabilities under ACC

A variety of sources suggest that Māori children and young people are over-represented among those with disability. Therefore, data for Māori children and young people have been analysed separately.

Age of children and young people at time of accident

Figure 1.6 shows the age of Māori and non-Māori children and young people at the time of accident as a percentage of the total of accidents in each ethnic group. The distribution of age at accident varied between the two groups. It can be seen that Māori were slightly more likely to have their accidents in the first two years of age than non-Māori.

Figure 1.6.: Age of Māori and non-Māori children and young people at time of accident as a percentage of the total number of accidents in each group



Cause of accident

The cause of accident for Māori and non-Māori children and young people with physical disabilities appears to differ in some ways. Table 1.17 shows the proportion of children and young people who suffered each type of accident who were Māori. Māori, as 14% of the total population of New Zealand children and young people, would be expected to make up 14% of each category unless they were over- or under-represented. It is evident from the table that they were generally over-represented, with only accidents related to medical treatment occurring at the expected rate.

Table 1.17.: Percentage of children and young people injured through each cause of accident who are Māori

Accident cause	Total number	Number of Māori	% of total who are Māori
Loss of balance	78	17	22
Loss of hold	15	3	20
Tripping/stumbling	15	6	40
Slipping	14	3	21
Total	**122**	**29**	**24**
Collision with / knocked over by vehicle	51	16	31
Other loss control vehicle	40	13	33
Driving into hole/object	3	3	100
Lurching in vehicle	1	1	100
Total	**95**	**33**	**35**
Struck by hand-held implement	2	1	50
Struck by person/animal	29	15	52
Shooting	1	1	100
Criminal act	3	3	100
Total	**35**	**20**	**57**
Fire	14	5	36
Explosion	2	2	100
Total	**16**	**7**	**44**
Medical treatment	121	16	13

Discussion

Has the research truly identified children and young people with physical disabilities?

Within the group identified for this research project, there will be some children and young people who did not have a physical disability. For example, a child who had a cognitive impairment as a result of an accident might receive a computer and hence be included because they fit the criterion of making an equipment claim of at least $60. However, case histories of children and young people within this group show that they tended to be representative of those of interest for this research project (data not included).

Are there any gaps in provision?

Māori children and young people were over-represented in the figures for ACC-funded services. Assuming that ethnicity was correctly assigned, this finding suggests that more Māori than non-Māori are suffering from preventable injuries. This subject is an area of active research, for example by the Injury Prevention Research Unit at the University of Auckland.[12] It also suggests that services are accessible to Māori, unless of course the true need and eligibility are

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[12] For further information, see: http://www.health.auckland.ac.nz/ipc/

even greater than appreciated; for example, because some Māori families and whānau prefer not to access what they perceive to be a Pakeha service.

Pasifika children and young people, on the other hand, were under-represented. ACC realised that the reach of its services was limited in this way, and was looking at initiatives to increase the accessibility and raise the profile of ACC services to the Pasifika communities within New Zealand (Wendy Browne, personal communication, 2003).

ACC uses information from the Notification of Accident form completed by a health professional to identify those claims that should be managed intensively. Some claims are referred for intensive management at a later date as a result of additional information received. There are several points at which contact between the family and ACC might lapse and not be taken up again by families, even though their child might well be eligible for more help. ACC provides claimants with information about both the processes for accessing entitlements and the entitlements themselves. Families might still decide not to lodge a claim, even though apparently eligible.

In a similar way, if a child or young person appears rehabilitated, ACC may close the case. The child or young person, or family, whānau or others with family consent could re-approach ACC if new needs arise as a result of the preventable injury. They may, however, be unaware that this is possible, or be unwilling to do so. Differences in access to entitlements may be due to incorrect initial advice by treatment providers, differences in assessment outcomes, differences in case management decision-making, socioeconomic reasons, cultural factors and parental choice.

Quantum of funding

Service is needs-driven and not site-specific. Clearly, some cases have involved a lot of ACC funding. A significant proportion of this funding will have gone towards therapy provision; for some with multiple disabilities, personal care will have been a large component of expenditure.

Do these data indicate whether the operational protocol between the Ministry of Education and ACC is being implemented?

Two important points raised in the operational protocol (as described in Section 1.1 and provided in Appendix A) are that the school should have a key person identified, and that assessments should be co-ordinated between the different services involved. The main ACC claimant database, Pathway, was the source of the data for all information on children and young people with ACC funding presented in this report. There was no specific field for recording the key school contact person. The ACC case manager could enter such details in a free text field, and it would be likely to be available on the paper copy of the Individual Education Programme. Information in free text fields, however, was not easily abstracted.

Whether assessments were linked in with those done by Education-funded professionals is not known.

A satisfaction survey was recently carried out of those children and young people who are under the Serious Injury Portfolio. One area that it covered was, where appropriate, Education-based rehabilitation. Best possible outcomes for the student are a key goal of the protocol governing the interaction between the Ministry of Education and ACC. The survey summary provided by ACC (see Appendix D) suggests a fair degree of satisfaction among the parents of a group of children and young people whose disabilities are significant, as indicated by their presence on the Serious Injury Portfolio.

Section 1.6: Ongoing and Reviewable Resourcing Schemes

This section describes children and young people receiving assistance through the Ongoing and Reviewable Resourcing Schemes (ORRS). Initially, all children and young people with this resourcing are considered. Then there is discussion of what is known or can be extrapolated about those ORRS-resourced students with significant physical needs. Finally, some information about how specialist service providers administer their budgets is presented.

Background

ORRS resourcing was introduced to provide students who have very high or high ongoing special educational needs with additional help to take part in education. Around 7,500 students, or 1% of the school-age population, can receive help under the schemes. Money is available for therapies and for teacher aide support. Additionally, 0.1 or 0.2 full-time equivalent (FTTE) resourcing for extra teacher time is provided.

The schemes began in 1997. As would be expected, the number of applications and the number of students accepted into the schemes were initially high, as the initial wave of applications included children and young people across the whole school-age range. Once the majority of the school-age children and young people who were eligible were verified, the numbers entering each year fell. Now new verifications are confined mainly to new entrants, and to older students with special needs who have recently entered New Zealand or who have newly acquired needs or recently worsening needs due to illness or injury.

The applications are submitted by teachers, either in the early education or school-age services. Applications are filled in using information provided by those working with the student, including parents. Therapists have a vital role in providing information, especially for students with physical disabilities that contribute to their special educational needs. The application form is 13 pages long, although not all sections are required to be completed for each individual applicant.

The information reported in this section was obtained from the Ministry of Education, Special Education's Te Pataka database, which keeps a record of applications for assistance through ORRS, and of the outcome of such applications. The database is also used to keep track of those receiving ORRS resourcing. All information obtained had had all identifying features removed. Several data sets were provided, each relating to a different period.

Levels and criteria of ORRS resourcing

Children and young people with significant physical disability, learning problems, communication disorders and vision or hearing impairments may be eligible to receive extra resourcing and assistance from the following strands of the ORRS. The number of different parts to the scheme has changed over the years. At the time of writing, they were as follows.

- *Very high needs:* Students receiving this resourcing are expected to have ongoing needs throughout their school years. Those who receive it because of a predominantly physical disability will be granted it in recognition of their very high therapy and personal care needs. Others may receive assistance because they need the content of the curriculum to be totally adapted, sign-language interpreters, teaching in Braille, or very high levels of specialist input for disordered use of language and social communication.
- *Very high needs reviewable* (available from 2001): Students with physical disabilities may receive this resourcing. It is provided for the year that the application is received and the following three years. After that the need for such resourcing is reviewed. Again, the resourcing acknowledges a student’s very high therapy and personal care needs.
- *High needs:* Students who receive this resourcing are expected to have ongoing needs throughout the school years. Those with a predominantly physical disability are likely to be granted this assistance in recognition of their high therapy and personal care needs. Other students in this group might need significant adaptation of almost all the curriculum content, specialist teacher contact time of at least half a day per week to assist with concept development missed because of hearing or vision loss, or significant specialist input for severe communication and social disorders such as autism.
- *High needs reviewable* (available from 2001): Students with physical disabilities may receive this resourcing. It is provided for the year that the application is received and the following three years. After that the need for such resourcing is reviewed. Again, the assistance acknowledges a student’s high therapy and personal care needs.
- *Combined moderate needs* (available from 2001): Through this strand of funding, students with a moderate need for curriculum adaptation plus two other needs at the moderate level may also be funded at the high needs level. This funding may be reviewable – that is, for the year in which it is granted and the following three years – or ongoing.

Results: Overview

The first set of results presents data for all students receiving ORRS funding. This is followed by results that cover data specific to students with physical disabilities, and by information from specialist service providers. Finally, the section reports briefly on the process of abstracting local data from the Ministry of Education, Special Education Te Pataka database.

Results: ORRS students overall

Application and verification rates

Table 1.18 shows the number of applications received, along with the numbers that were verified, from 1997 to 2001; that is, from the start of the scheme to the last year for which complete data were available (Special Education Newsletter, 8 April 2002). The number of verifications was highest in the first year, as explained above.

Table 1.18.: Number of ORRS applications and verifications, 1997–2001

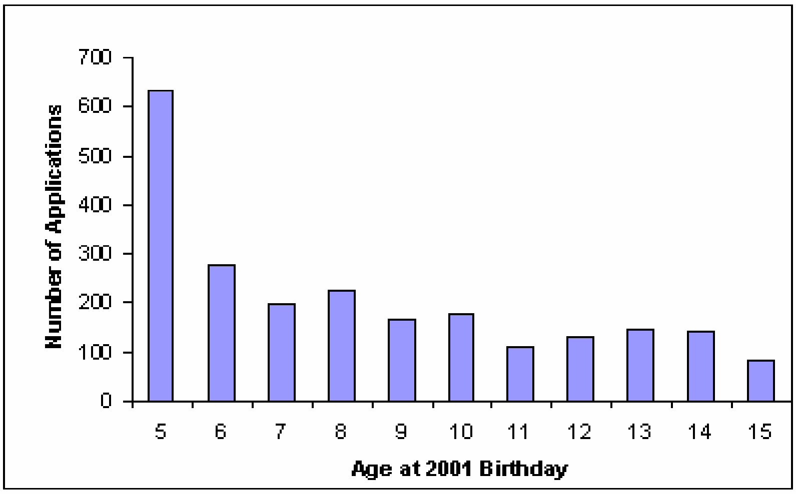
Year	Total applications	Verified	Not verified
1997	13,653	5,602	8,051
1998	5,508	2,873	2,635
1999	2,839	1,183	1,656
2000	2,330	977	1,353
2001	2,329	1,081	1,248

While most applications were made for very young children, as shown in Figure 1.7 below, applications continued to be received for students up to the age of 15 in 2001.

Age and gender of applicants

The number of applications for each age level is shown in Figure 1.7 for applications received in 2001.

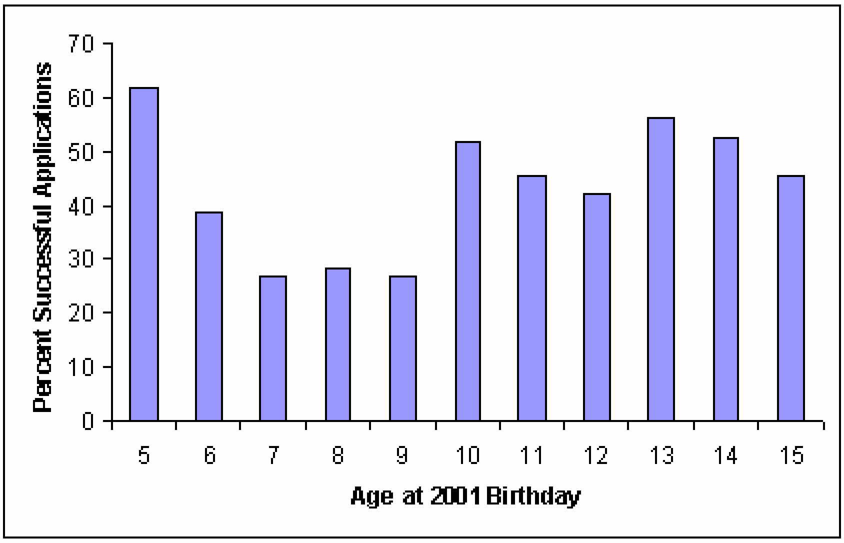
Figure 1.7.: Number of ORRS applications for each age level, 2001



Source: Special Education Newsletter, 8 April 2002

Figure 1.8 shows the percentage of applications in 2001 that did not receive verification for each age level. The highest success rates were for those turning five years old in 2001, but applications for 10- to 15-year-olds, though fewer in number, also had a high rate of verification.

Figure 1.8.: Percentage of ORRS applications that were verified for each age level, 2001



More applications were received for boys than for girls in 2001 (Table 1.19). At the same time, the percentage of verified applications for males was lower than for females. One interpretation of this gender difference is that the threshold for applying assistance through ORRS may be higher for girls, thereby increasing their rate of verification. Importantly, any ORRS applications submitted on the grounds of severe behaviour alone are declined as this resourcing stream is not the correct route for gaining extra help for such students. It is likely that some of the applications for boys that were not verified would have been on behavioural grounds.

Table 1.19.: Number of ORRS applications and verification rates, by gender, 2001

	Males	Females
Applications received	1,549	780
Number verified	677	404
Percentage verified	43.71	51.79

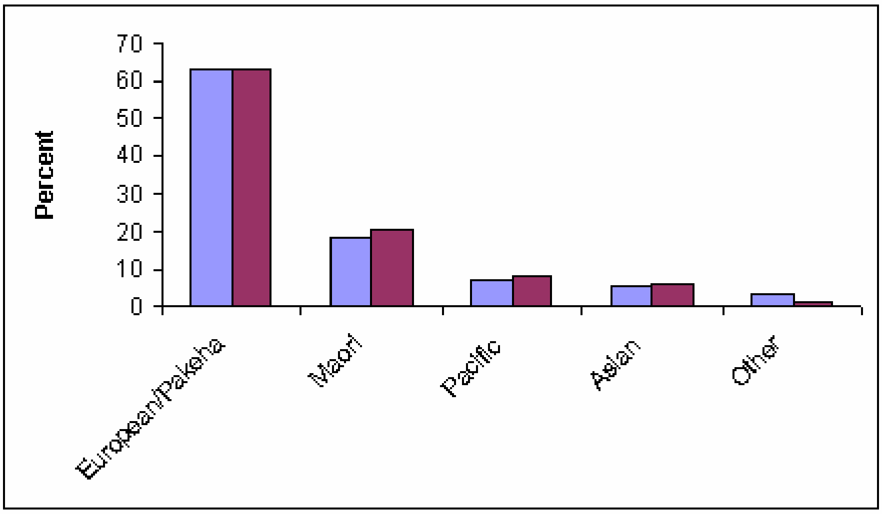
How many children and young people get ORRS resourcing?

In total 7,592 school students were receiving ORRS resourcing at some time in 2002, of whom 2,988 were girls and 4,598 were boys. This total represents a little more than 1% of the school-age population. (This information is available in tabulated form from the author.) Over the year, some students joined the schemes and some left, such that the totals varied from day to day.

Ethnicity and gender of applicants

Fewer Māori and Pasifika students were being assisted through ORRS in mid-2001 than would be expected from their numbers in the New Zealand population as a whole. Figure 1.9 depicts this under-representation, as well as showing that the proportion of students from ‘other’ ethnic groups who were getting ORRS was more than expected.

Figure 1.9.: Ethnic group representation of all ORRS students compared with ethnic group representation in the total student population, 1 July 2001



Source: Special Education Newsletter, 8 April 2002

Note: The left-hand bar shows the ORRS-verified students; the right-hand bar shows the percentage of the ethnic group in the school-age population.

Māori students at 18%, Samoan students at 4.2%, and all Pasifika students at 6.4% of ORRS students in 2001 were all represented in lower proportions than their respective percentages in the school-age population.

Uptake rates for ORRS resourcing in each territorial local authority (TLA) were generally higher for boys than girls but the extent of the gender difference varied widely from one TLA to another.

Urban and rural schools compared

Ministry of Education data current for July 2000 show that the percentage of ORRS-resourced students varied between rural and urban schools. When grouped together across TLAs, main urban schools had 1% of their students verified, secondary urban 0.94%, minor urban 0.78% and rural 0.64%. Of the 3,971 students in correspondence schooling, 158 were receiving ORRS resourcing. There was no way of knowing where they lived, but it was noted that even if all correspondence students were rural, it would still not bring the percentage of ORRS-resourced students in rural areas anywhere near 1%.

Applications and verification rates by decile

The Ministry of Education can examine ORRS applications and ORRS-resourced students by the decile of the school they attend. Table 1.20 shows the student population in each school decile, along with the numbers and percentages of ORRS applications and of ORRS students for each decile.

Table 1.20.: ORRS applications and uptake, by school decile, 2000

Decile	Number of students (March 2001)	% of standard population	Number of ORRS applications (2000)	% of ORRS applications (2000)	Number of ORR students	% of ORRS students	ORRS students as % of standard population
1	59,514	8.5	149	10.0	534	8.0	.89
2	60,151	9.0	171	11.0	830	12.0	1.38
3	66,528	9.0	172	11.0	993	15.0	1.49
4	78,671	11.0	226	15.0	1,240	19.0	1.57
5	71,379	10.0	151	10.0	704	11.0	.98
6	68,967	10.0	155	10.0	644	10.0	.93
7	66,482	9.0	138	9.0	398	6.0	.59
8	73,533	10.0	136	9.0	587	9.0	.79
9	59,448	8.5	97	6.0	358	5.0	.6
10	103,972	15.0	146	9.0	380	6.0	.36
Total	**708,645[1]**	**100.0**	**1,541**	**100.0**	**6,668[2]**	**100**	

Note:

[1] The total student population is 716,608. Not all students are allocated to a decile as the decile system does not include those enrolled at a private school or The Correspondence School.

[2] Only ORRS students who are identified in a school with a decile ranking are included. The students not included here are those who are yet to begin school and those who are enrolled at The Correspondence School.

From Table 1.20, it can be seen that decile 10 schools, deemed to be the most affluent, had the highest proportion of the school population (15%), submitted only 9% of ORRS applications, and had a very low proportion of their students in ORRS. In contrast, schools in deciles 2 and 3 submitted around the expected percentage of applications but had more than 1% of their students verified (remembering that, in theory, approximately1% of the school-age population are expected to qualify for ORRS). Decile 4 schools, with only 11% of the school-age population, submitted many applications and had the highest percentage of verified students of any decile.

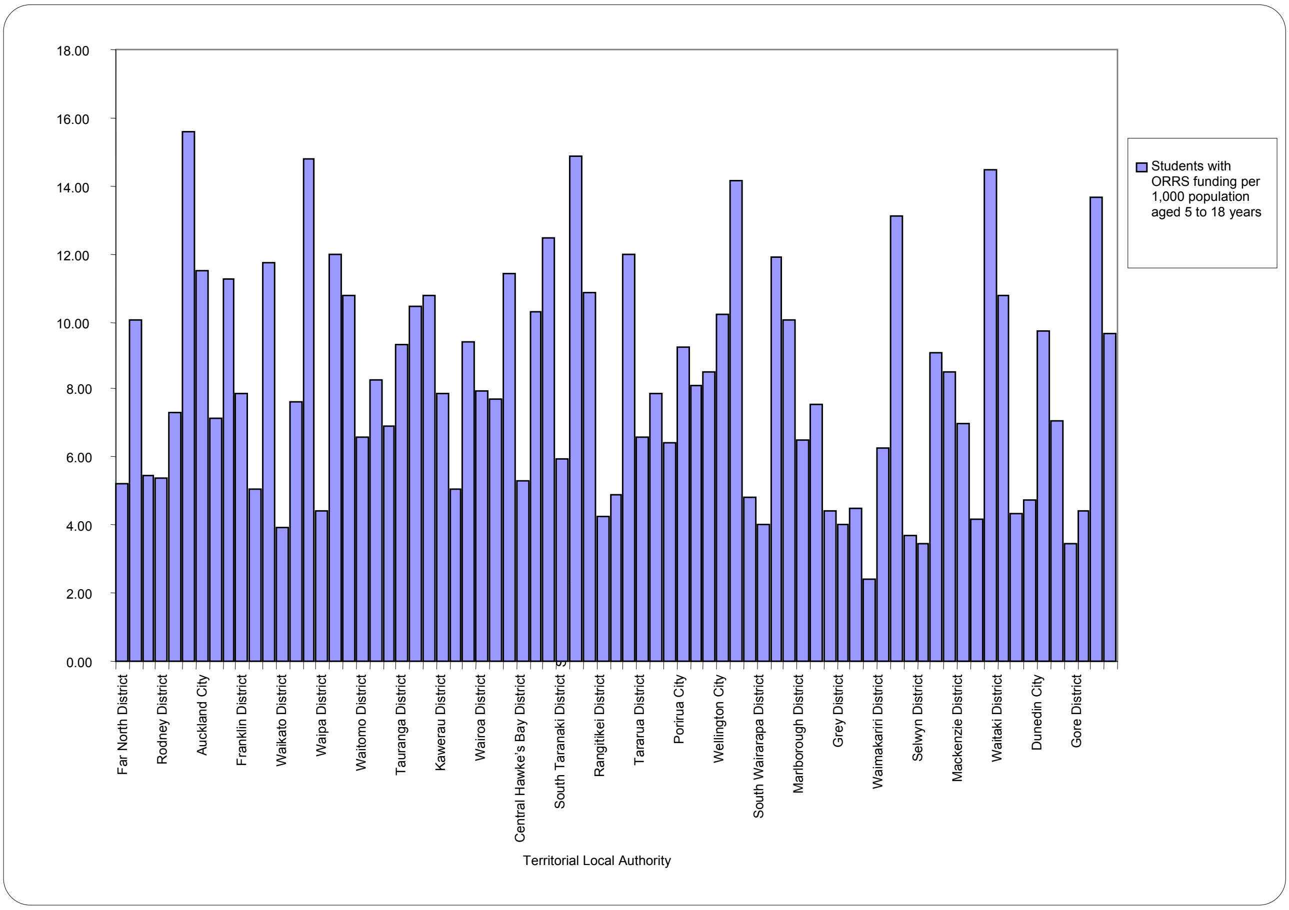
The majority of special schools are in deciles 2 to 4 which would affect the proportions.

Geographical variation in ORRS uptake

ORRS-resourced students, as expected, were spread across New Zealand. It is already appreciated that the location of students is more scattered in some areas than in others. For therapists visiting students in regular schools, the relative clustering or scattering of students is important as it clearly affects time spent on travel. More time will also need to be spent on liaison if many different school teams are involved with students on a therapist's workload.

Data current in March 2000 show that the percentage of students receiving ORRS resourcing in each TLA varied from 0.32% to just over 3%, though most TLAs had close to the 1% predicted by the resourcing arrangements. Figure 1.10 uses a bar chart to represent the uptake per 1,000 students aged 5 to 18 years in each TLA (for more detailed regional data, see Appendix E).

Figure 1.10.: ORRS uptake for 5- to 18-year-olds in each TLA (bar chart), 2000



Results: ORRS students with physical disabilities

The data for ORRS students with physical disabilities, like the data for all ORRS-resourced students, were obtained from the Ministry of Education database that tracks and records ORRS applications and all recipients of ORRS resourcing. The database was not set up with the aim of collecting data on the number of children and young people with physical disabilities who were receiving assistance through this resourcing stream. Nevertheless, it includes data that relate to physical disability or disabilities, and these can be used, although caution is needed when interpreting the findings.

A general descriptor indicates area of need

Each application is sent to three verifiers, who assess its merits against the agreed criteria for ORRS funding. Each application is currently assigned to one of four groups depending on the type of condition that appears to be a significant cause or the predominant cause of the educational difficulties experienced: general learning, vision, hearing or physical. Each verifier has particular expertise in at least one of these areas, and the team assigned to each student will contain at least one specialist verifier. This descriptor is solely for the purpose of balancing workloads among the verifier team. Therefore it is possible, for example, that a student assigned a physical descriptor could have a lesser degree of need in the physical area and a greater need for general learning.

Reason for granting ORRS can indicate physical disability

The grounds for receiving ORRS are also recorded on this Ministry of Education database. Students applying or having ORRS resourcing granted because of 'very high therapy and personal care needs' or 'high therapy and personal care needs' are those with significant physical disabilities.[13]

A complicating issue is that it was only at the beginning of 2001 that this method of recording began to differentiate students needing therapy and personal care because of their physical disability from those needing therapy and personal care because of disordered language use and social communication. For students verified before 2001, one way of indicatively identifying those with a predominantly physical disability has been to refer to the use of a physical descriptor for their application, with one of their verifiers having particular expertise in physical disability.

Thus there are two ways of looking at the data in order to gain more precise knowledge of the number of ORRS-resourced students with physical disabilities:

1. For those verified for ORRS resourcing before the database began to discriminate between the two different sets of therapy and personal care needs, it is possible to examine those verified by someone with expertise in the field of physical disability, and who have been coded with a physical descriptor.
2. It is possible to describe those students recorded on the database as having high or very high therapy and personal care needs from the beginning of 2001.

Table 1.21 shows the number of students accepted for ORRS resourcing whose special educational needs were described as having been caused by a predominantly physical disability. Students assessed by a verifier with expertise in the field of physical disability are included here. As for the overall number of students who were accepted for ORRS resourcing, the year when the most students with physical disabilities were accepted was 1997, at the start of the scheme. The number being granted ORRS resourcing because of physical disability has since settled to about 300 new students a year. By way of context, it will be remembered that around 1,000 applications for ORRS resourcing are verified each year (see Table 1.18 above).

Table 1.21.: Number of students with physical disabilities (coded as 'physical') that received verification for ORRS funding, 1997–2001

Year	Very high needs	Very high needs reviewable	High needs	High needs reviewable	*High needs reviewable*[1]
1997	495	n/a	999	n/a	n/a
1998	149	n/a	402	n/a	91
1999	72	n/a	176	n/a	60
2000	71	n/a	174	n/a	67
2001	62	14	111	91	n/a

Note: [1] Formerly known as Transitional

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[13] The other reasons for the granting of ORRS that are recorded on the database are the need for 'total adaptation of the curriculum content', 'assistance with all communication', 'very high need for specialist intervention in response to a severe disorder of language use and appropriate social communication', 'significant need for specialist intervention, severe disorder of language use', and 'significant need for specialist teachers of hearing or vision'.

Rates of verification for applications for students with physical disabilities

In 2001, 470 students who applied for ORRS resourcing were described as ‘physical’. Of these, 62 were given very high needs, 14 very high needs reviewable, 111 high needs, and 91 high needs reviewable resourcing; another 192 applications did not receive verification. Thus of those applying for ORRS who were deemed to be ‘physical’, 59% were verified.

The verification rates for students described as having general learning problems (40%) or hearing problems (53%) were lower, whereas the verification rate for those with vision problems (65%) was higher. These variations may reflect the relatively clear-cut nature of some vision problems compared with the high prevalence of some types of hearing problems such as glue ear and mild hearing loss. The chance of an ORRS application for a student with a clear physical disability being verified appears quite high when compared with that for a student with a predominantly general learning problem.

What were the grounds on which students with physical disabilities were granted ORRS resourcing?

This analysis examines the overlap between those described as having a predominantly physical disability and those who were granted ORRS resourcing because of high or very high personal care or therapy needs.

Students described as need type physical

The grounds for granting ORRS resourcing in 2001 for the 278 students described as having predominantly physical needs are listed in Table 1.22 for each ORRS strand. The need for total adaptation of the curriculum was the main reason for granting the ORRS resourcing, followed by very high or high therapy and personal care needs.

Table 1.22.: Grounds for granting ORRS resourcing to students with physical disabilities, 2001

ORRS strand	Grounds for resourcing	Number of students
Very high needs	Total adaptation of the curriculum	35
	Very high therapy and personal care needs	19
	Very high need for specialist intervention in response to severe disorder of language use and appropriate social communication	6
	Assistance with all communication	2
Total		**62**
Very high needs reviewable	Very high therapy and personal care needs	9
	Very high need for specialist intervention in response to severe disorder of language use and appropriate social communication	3
	Assistance with all communication	2
Total		**14**
High needs	Significant adaptation of almost all the curriculum content	52
	High therapy and personal care needs	44
	Significant need for special teacher of hearing or vision	6
	Significant need for specialist intervention (severe disorder of language use)	3
	Hearing	6
Total		**111**
High needs reviewable	Significant adaptation of almost all curriculum content	44
	High therapy and personal care	35
	Significant need for specialist teacher of hearing and vision	7
	Significant need for specialist intervention	5
Total		**91**

The findings reported in Table 1.22 suggest that many of the students in the physical category have multiple disabilities, including learning disabilities. In addition, the totals derived may be an underestimate of the prevalence of physical disability in this population because the database would not have recorded any physical disability at the high needs level for students who met any of the very high needs criteria.

Students granted ORRS resourcing because of therapy and personal care needs

In 2001 there were 156 students granted ORRS resourcing because of high or very high therapy and personal care needs. Of these, 107 were described as ‘physical’. Another seven were categorised under vision, two under hearing, and 40 under general learning.

The high proportion under general learning suggests that this category is used for administrative purposes for some students with high therapy and personal care needs. This approach needs to be taken into account when estimating the number of students with physical disabilities who are receiving ORRS resourcing.

What percentage of students with general learning problems also had physical disabilities?

In 2001, out of 522 (7.7%) students described as having general learning problems who were granted ORRS resourcing, 40 were likely to have also had significant physical disability. These 40 students are identified because the grounds for granting them ORRS resourcing were that they had high therapy and personal care needs.

In 2002, 12 of the first 296 students (4%) with general learning problems who were granted ORRS funding received it due to their therapy and personal care needs. This indication of physical needs again suggests that just looking at the number of students described as having the need type 'physical' will underestimate the total number of students with physical disabilities.

Total number of ORRS-resourced students with physical disabilities in 2002

On 15 December 2002 there were 1,078 students described with a need type physical who were receiving ORRS resourcing at very high, high, or combined moderate needs level. At the same time 608 students with need type general learning had physical needs verified at the very high, high or combined moderate needs level. A total of 65 students with need type vision (n = 48) or hearing (n = 17) (included under need type general) also had physical needs in that ORRS resourcing was granted because of high or very high personal care or therapy needs.

Thus on 15 December 2002 a total of 1,751 students receiving ORRS resourcing were known to have physical disabilities.

Results: Information from specialist service providers

Specialist service providers for ORRS students are required to report to the Ministry of Education. The schools are also visited by Ministry of Education verifiers, who observe what is happening at grassroots level (e.g. by reviewing Individual Education Programmes). Reports for Milestone One, 2002 were reviewed and collated by the Ministry. A summary report and spreadsheet of the data were made available for the purposes of this research project.

There were 76 specialist service providers. Some schools held the resourcing for a cluster of schools; others had enough students with ORRS resourcing to hold funds just for their own school. The level of completeness and clarity of information received from each school was highly variable, making interpretation of the data difficult. What was clear, however, was that there was a wide variation in how specialist service providers appeared to be allocating or apportioning their resourcing.

Money spent on therapists

On average, 17% of the ORRS budget was spent on traditional therapies (occupational therapy, physiotherapy and speech-language therapy combined). The percentage of schools spending their ORRS budget in this way ranged from less than 2% to over 40% for a handful of schools.

Money spent on teacher aides

The average teacher aide allocation was 65% of ORRS resourcing across all schools. Almost half of the schools were spending over 70% of their budget in this way. Secondary schools spent an average of 73% on teacher aides. The exact picture for secondary schools was complicated, however, by the arrangement of approximately 20 secondary schools within clusters that included primary schools. Only 19 secondary schools were specialist service providers holding funds for themselves. In practice this means that secondary schools would have been spending less that 73% of ORRS funding on teacher aides.

Some schools, particularly those receiving additional central funding for therapy positions, were spending over 75% of their ORRS budget on teacher aide time. It was noted that lower therapy spending might have also reflected difficulties with recruiting or retaining therapists. These findings highlighted a need for verifiers to look at the level and effectiveness of service provision when visiting schools. It was appreciated that some schools might have been providing a very good therapy service in spite of the low percentage of spending on therapists.

Other spending

On average 5.6% of ORRS funding was spent on administration and 3% on consumables.[14]

Intensity of provision

The intensity of provision could in theory be analysed through the examples of Individual Education Programmes (IEPs) that schools send in as part of the reporting process. IEPs are not provided for all students. Thus, in making their report, schools are asked to indicate how many of their ORRS-resourced students have IEPs, how many do not, and the expected timeframe for updating any that are outstanding. IEPs are the only aspect of the reporting process that looks at outcomes rather than inputs. Their content would give an indication of planned intensity of therapy provision. IEPs from reporting schools were not made available to the research team for reasons of confidentiality.

Alongside the information on IEPs, schools are asked to specify how many of their students have a service level agreement signed by the parents. For those agreements that are still outstanding, schools are asked to indicate when they expect to have them completed. Service level agreements are meant to specify the amount of special education resources that will be provided for up to one year.

The above information on money spent on therapy services gives some insight into the quantum or amount of therapy provision for ORRS-resourced students in specialist service provider schools. Other students in the facility or school who were not ORRS-resourced might also benefit from such spending. The above data also show that the percentage of the ORRS budget spent on therapy varies, and tends to be lower in schools spending more on teacher aide time.

This spending-based information does not directly address intensity of provision. It seems likely, however, that the intensity of provision would be lower in schools spending a smaller proportion of their ORRS budget on therapy. This relationship might not apply, however, if the school had an alternative or additional source of therapy funding, in particular the three-year transitional package of centrally funded therapy provision. It also seems likely that co-ordination of services, and not just total amount spent, will have a major impact on therapy provision. Co-ordination of services could not be assessed using these data.

Results: Ministry of Education, Special Education (GSE) database abstraction

It was possible, but time consuming, to abstract local data from the GSE Te Pataka database that is used to record hours of service to clients. It was possible to examine the workload of any individual therapist, describe the students who that therapist saw by ethnic group, gender and age, and present the hours of direct contact time over any school term or any combination of terms. It was also possible to present information on how the therapist in question had recorded spending his or her time. Time in direct contact with students (including writing up reports or programmes) was clearly separated from time spent on general administrative tasks, travel and continuing education/professional development.

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[14] Consumables cover such items as audio tapes, disposable gloves, and play materials.

These data were examined for one therapist only. The data are not presented here because there was no way of knowing whether they were representative of the GSE service to ORRS students.

Discussion

The analysis has shown that at least 1,751 students with physical disabilities were receiving ORRS resourcing on 15 December 2002. This figure is likely to be an underestimate as it misses some students who have physical disabilities but who also have other needs verified at a higher level.

The analysis has demonstrated variation in the rate of ORRS resourcing per 1,000 school-age children and young people across different territorial local authorities. Such variation cannot, of course, be explained conclusively. Some may be the result of genuine differences in the number of eligible children and young people in different areas. For example, low uptake in rural areas could reflect a tendency for families of children and young people with significant physical disabilities to move to urban areas. Margaret Parkin, Chief Verifier at the Ministry of Education, hypothesised that parents of students with high or very high needs move to be nearer services, and that schools with lower numbers of students were less likely to apply for ORRS resourcing or were less successful at applying for ORRS resourcing.

Areas with special residential schools do tend to have higher ORRS rates; for example:

- Christchurch, where 1.2% of students receive ORRS resourcing, contains two residential special schools, Halswell (formerly Hogben) and Van Asch Deaf Education Centre
- Tasman District, where 1.3% of students receive ORRS resourcing, contains Salisbury special residential school, where 24 boarders have ORRS resourcing
- Waitakere City, where 1.7% of students receive ORRS resourcing, contains Kelston Deaf Education Centre with 130 residential students.

By contrast, in Manukau City only 407, or 0.7%, of the 56,822 school-age children and young people receive ORRS resourcing, even though 44 students with ORRS resourcing were resident at Homai National School for the Blind and Visually Impaired[15] in this TLA. This relatively low rate could well reflect the low uptake of ORRS resourcing among Pasifika students, who comprise a high proportion of the Manukau City population relative to many other TLAs.

Of the ORRS applications for students described as having a predominantly physical disability, 41% did not receive verification in 2001. In other words, approximately 192 students were believed by those around them to potentially qualify for the extra help and input provided by ORRS resourcing but were turned down. As each application is looked at against the criteria established by the Ministry of Education, these data also suggest that many students being put forward for ORRS resourcing do not meet these criteria. The chance of gaining verification with an application for a student with a physical disability, however, has been shown to be higher than that for a student with a problem that predominantly relates to general learning.

The 2001 Household Disability Survey showed a higher-than-expected rate of disability and chronic illness in Māori children, and a lower-than-expected rate in Pasifika children (Section 1.1). The Ministry of Education appreciates that lower-than-expected proportions of Māori and Pasifika students are receiving ORRS resourcing. Taken together, these data suggest that a disproportionate number of Māori or Pasifika students with physical disabilities may be missing out

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[15] Renamed as Blind and Low Vision Education Network NZ (BLENNZ) in 2005.

on applying for ORRS resourcing. Whether this under-representation suggests unmet need is hard to know. These students may be receiving optimal educational and life experience without the need for ORRS, perhaps as a result of the attitudes of their wider family or whānau and in their school environment.

It follows from the above discussion that the reasons for the under-representation of Māori and Pasifika students as recipients of ORRS resourcing are not yet known. The Ministry of Education believes that the ORRS application process itself may be a stumbling block for certain groups and is looking at ways of making the process easier for kura kaupapa Māori (Margaret Parkin, Chief Verifier, personal communication, 2002).[16]

The high proportion of students from ‘other’ ethnicities who are receiving ORRS funding relates to New Zealand’s refugee policy, which specifically allows refugees with disabled children to come to New Zealand.[17] Anecdotally, families also move to New Zealand specifically to get better educational opportunities for their child or children with special educational needs. As data in this section have made clear, they make up only a small part of the ORRS-resourced population.

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[16] The application form is now available in Māori.

[17] At the time the research was conducted, immigrants with children with disabilities could enter New Zealand. In April 2006 the policy changed to bar the entry of children who would meet ORRS criteria.

Section 1.7: Students with Moderate Physical Disabilities

This section describes the services for students with moderate physical disabilities, and how many students were receiving therapy through the contract for provision of therapy services for students with moderate physical disabilities (the moderate contract).

Background

Students with moderate physical needs may be eligible for physiotherapy and/or occupational therapy through the moderate contract. There are nine school-based contract holders, who together receive $740,000 for provision of the services. Additionally, $1.1 million goes to Ministry of Education, Special Education (GSE) districts to provide services for eligible students not covered by the school-based providers.

The moderate contract is for students who have a moderate to high sensory/motor, perceptual motor and/or physical motor disability that is a barrier to learning in the educational context of school and/or home.

To qualify for the service, students must present with three or more of the following and must have ‘significant’ difficulties in one of the three categories:

- mobility difficulties
- fine/gross motor co-ordination difficulties
- problems in relation to personal self-management and physical safety
- need for specialised equipment and/or modifications to their learning environments
- physical deterioration or at risk of loss of function (e.g. those with progressive conditions). This category covers a recent increase in barriers to a student’s participation at school due to deterioration in physical condition and/or growth, change of educational environment, or change in learning demand.

Those that do not meet these criteria may still meet the criteria for Health-funded occupational therapy and/or physiotherapy.

In a survey prior to the implementation of the moderate contract, the Ministry of Education asked all schools to provide information on the number of students who might qualify under the categories listed above. Following the survey, the scheme was set up and an application form designed.

A copy of the Students with Moderate Physical Disabilities Application Form is found in Appendix F. The questions on the form give a good indication of the type of student who might expect to receive funding through this stream. The category of physical safety, for example, includes questions on whether the student falls frequently in the playground and/or within the classroom, whether they are in danger because of a lack of sensation or a poor perception of distance, or are unsafe using equipment. It asks whether the student frequently bumps into objects and/or people. The questions that follow cover current support adaptations: What strategies have been tried already and what were the results?

Applicants are then asked to circle one statement that best describes the overall current level of adaptation assistance required in the area of physical safety (nil, minimal, significant or extensive), with each level being defined.

Methods

Information was obtained from two sources. First, the Ministry of Education (Joanna Curzon, personal communication, 2003) provided information on the number of students receiving GSE-funded occupational therapy and physiotherapy services in Term 2, 2002, through the moderate contract. Although in theory moderate contract holders should have been reporting to the Ministry, in practice the amount of information provided to the Ministry has been highly variable. Certain issues raised by school-based contract holders were described to the research team.

Second, school-based contract holders were also contacted individually to check the number of students waiting to be assessed during the period under analysis, the number deemed eligible for services but on a waiting list, and the number seen by occupational therapists and by physiotherapists. However, they were not asked directly about the total workload, or those students deemed to need therapy but who had not received it during Term 2, 2002.

Results

How many students are receiving therapy via the moderate contract?

The Ministry of Education estimates that around 1,000 students were receiving therapy through the moderate contract at any one time in 2002. This estimate includes students receiving moderate contract services through GSE, and is more than the target of 356 shown in Table 1.23 below, which is for school-based providers only.

School-based therapy providers

School-based therapy providers provided information on how many students were receiving occupational therapy and how many were receiving physiotherapy. The resulting data are shown in Table 1.23.

Table 1.23.: Moderate contract holders, centrally funded therapy positions, and the expected and actual number of students for each school-based contract holder, Term 2, 2002

Contract holder	Funded positions	Target number of students per year	Reported number of students seen during term
Hillcrest High	1.2	23	10 seen (6 OT and 6 PT)1 0 waiting
Kimi Ora Special	1.4	25	37 seen (20 OT and 17 PT) 3 assessed and waiting
Kings High	1.1	20	18 seen (13 OT and 5 PT) 6 waiting to be assessed
Mairehau High	3.6	66	80 seen (70 OT and 20 PT) 20 on waiting list
Mt Roskill Intermediate	3.6	67	91 students on their books: 27 PT and 30 OT seen weekly 58 ‘monitored’ for PT and 59 ‘monitored’ for OT 18 on the waiting list
Papatoetoe South Primary	Funding in place of staffing	74	110 seen (79 OT and 82 PT) 35 waiting to be assessed
Waihopai Primary	1.0	18	60 on contract: 18 seen for joint OT and PT No figures available for waiting list
Waitakere College	1.6	30	11 seen (10 OT and 11 PT) 3 waiting, of whom 1 assessed
Wilson Home	Funding in place of staffing	33	54 seen 35 waiting
Total		356	

Note: [1] PT = physiotherapy; OT = occupational therapy

The moderate contract for North Shore City is held by Waitemata District Health Board through Child Development Services North Shore and Rodney. For the Waitemata area, in December 2002, the contract was for 33 students, 54 were being seen, and there were 35 on the waiting list. The service leader kindly provided the following information on how the service works:

> *Referrals are made by the principal of the school who agrees to support the programme for the particular student. The therapists use a consultative model of service delivery with some hands-on as required. The occupational therapist and physiotherapist work closely with the school staff particularly with the class teacher and teacher aide as well as the families. Classroom programmes are developed and supported by the moderate contract therapists. Some home programmes are also developed.*

Ministry of Education, Special Education, as therapy provider

There were 181 students receiving physiotherapy (a total of 265.5 hours of contact time) and/or occupational therapy (a total of 511.9 hours of contact time) during Term 2, 2002. Students were counted as having received zero hours of the therapy in question if they had received therapy in the preceding term or in the following term. In this situation it was assumed that the students had been on the workload even though they had not been seen during Term 2.

The figures below show the amount of contact time that students had with their occupational therapist (Figure 1.11) and with their physiotherapist (Figure 1.12) over this term. One to two hours of direct therapist contact time was the most common for occupational therapy, whereas for physiotherapy slightly more students had two to three hours than one to two hours of contact time. Contact time includes time spent writing up reports or programmes for individual students, and talking to other staff about that student. The students themselves are expected to have received more therapy than that provided by GSE; for example, through therapy programmes administered by staff at the school, or perhaps at times by family and whānau.

Figure 1.11.: Hours of direct contact with an occupational therapist for students who had the Ministry of Education, Special Education, as therapy provider (moderate contract), Term 2, 2002

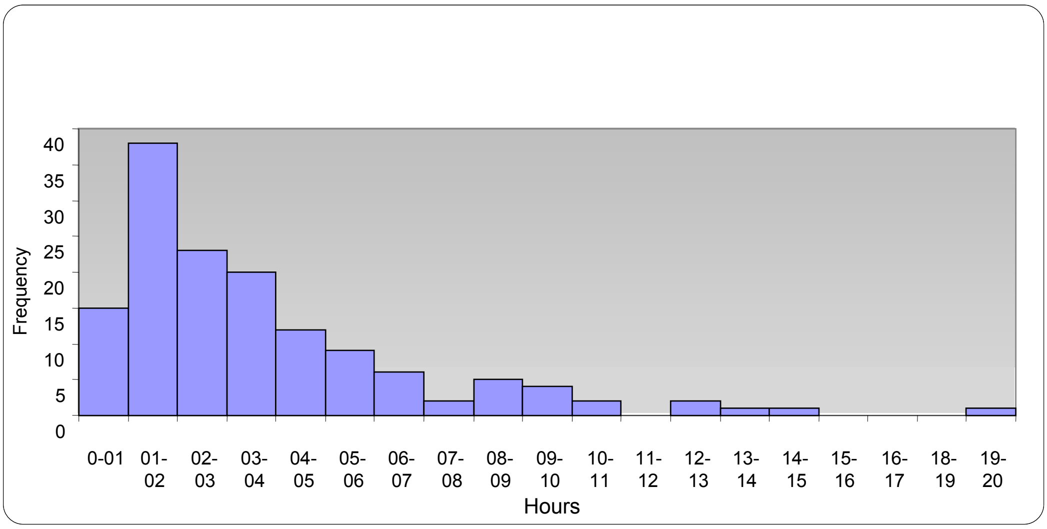
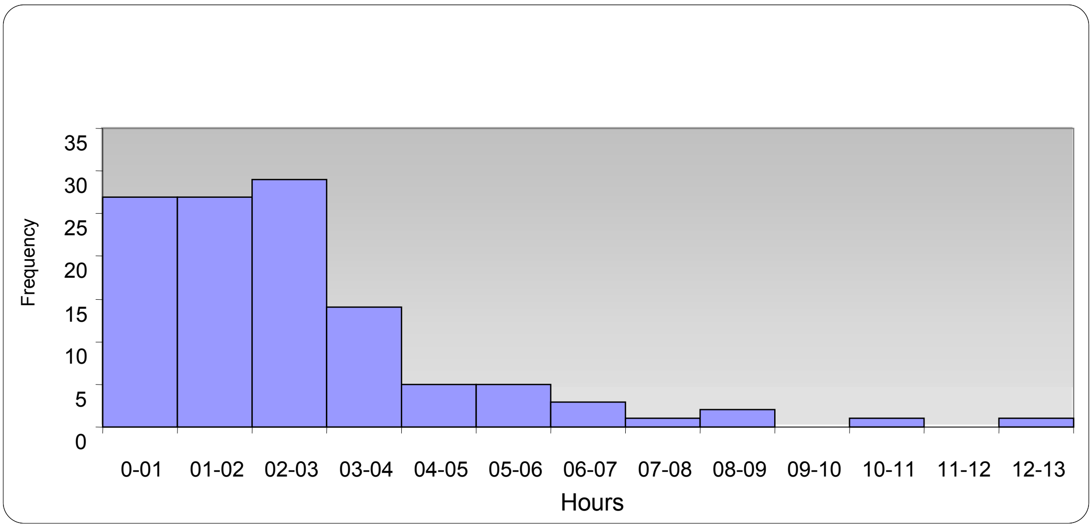


Figure 1.12.: Hours of direct contact with a physiotherapist for students who had the Ministry of Education, Special Education, as therapy provider (moderate contract), Term 2, 2002



Discussion

The data in this section show that more students than initially expected were getting physiotherapy and/or occupational therapy through the contract for provision of therapy services for students with moderate physical needs. Specifically, an estimated 1,000 students received therapy funded through the moderate contract, though it appears unlikely that this many students received therapy in any one term.

Anecdotally, if some students who had been on the moderate contract for some time were to apply for funding now, they might be more appropriately provided with Health-funded occupational therapy and physiotherapy services. Their inclusion may have an important effect on numbers on the contract. There is currently no way of knowing.

What is known, however, is that many services have students waiting who have recently been screened and found to be eligible for the services provided through the moderate contract rather than through Health. Service records differ in the way they deal with students in this situation. Some providers operate a ‘revolving door’ approach, listing students as receiving their services only while there is active therapist involvement, then discharging and later re-enrolling if necessary. Others keep all the students ever referred to them on their books. For this reason it is not possible to calculate exactly the number of students on the moderate contract at any one time, or indeed the number with needs such that they would qualify for therapy funded through this stream. The above information does, however, give a snapshot of the number of students receiving therapy through the moderate contract over one term.

Section 1.8: Health-funded Occupational Therapy and Physiotherapy to School Students

This section gives an example of the way Health-funded Child Development Services (CDS) teams work with children and young people aged five years of age and over. It looks at what information could have been abstracted to describe the students, and the workload and pattern of work of the therapists. It then explains why there are no nationally available data on Health-funded occupational therapy and physiotherapy provision to students.

Background

The research covered in this section was undertaken with the aim of describing the kind of data stored by local CDS teams, and to look at the feasibility of abstracting such data for future research or policy development.

Methods

The way that data were stored and recorded was discussed with two managers of Health-funded CDS teams, with one manager describing two services. The quantum and intensity of therapy provision was also discussed with the Chief Advisor, Disability Services Directorate, Ministry of Health.

Results

The information in Table 1.24 was kindly provided by the Child Development Services consulted. It shows how the Health-funded services in the north and west of Auckland were operating in 2002 for children and young people aged five years and over. Not everyone in this client group would have been at school.[18]

Table 1.24.: Health-funded Child Development Services, north and west Auckland, 2002

	North Auckland	West Auckland
Number of current clients	253	170
Number on current waiting list	61	29
Number of FTE positions	OT[1] 1.6	OT 1.2
	PT[1] 0.82	PT 1.0

Note: [1] PT = physiotherapy; OT = occupational therapy

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[18] This could be for a number of reasons such as a child not starting school until age 6, being in hospital, being home-schooled, or being enrolled at the Correspondence School.

The CDS teams, North Shore and Rodney, provided the following description of its procedures:

> *The clients transferring from the under 5 team are managed depending on need and type of support required.*
>
> *If they have a neurological difficulty they are placed on a review list with a time frame for the next contact to be made. When the client is seen the therapists intervene as appropriate both in the centre and at the school. Once this episode of care is completed the therapist advises the next review date if six months or more. If less than six months it is considered to be part of the existing episode of care.*
>
> *If it is felt involvement in a group would be beneficial they are included in an appropriate group.*
>
> *New referrals are placed on a waitlist, which is currently around nine months. When they are assessed this is by a team comprising an occupational therapist, physiotherapist, and social worker. The assessment and family interview takes up to 1.5 hours and is followed by a second appointment for discussion with the family and planning of goals. Intervention as appropriate then follows the plan. This could be a group, a visit to the school, a school or home programme or a combination of all or any of these.*
>
> *The Child Development Service 5+ team is also responsible for housing alterations and home equipment for school-age students even when they have no other involvement with the child and family. This means that there can be four therapists involved – two from Education and two from Health. These referrals are prioritised as they come in and actioned as soon as possible.*
>
> *We also have referrals for children post surgery who are not necessarily clients of Child Development Service (i.e. ORRS or moderate contract) and we then provide therapy as appropriate until they can be handed back to their own therapy teams.*
>
> *Over the past year new work has been added with the increased use of Botox for children with a range of physical difficulties. This treatment is intensive and often repeated in six months.*

Another Health-funded CDS team, in this case from central Auckland, stated that it had 82 clients over five years of age on its active list. Clients that no longer needed its services were not kept on the books. Should they need therapy input again, they were seen in the next available time slot. There were a further 29 clients waiting for service (July 2003). These clients were the responsibility of approximately one full-time equivalent (FTE) occupational therapist and one FTE physiotherapist. Data on workloads of therapists, dieticians and social workers are generally not broken down by client age. The service records data on ethnicity, age group and gender broken down by the diagnostic categories of physical, intellectual, autism, multiple and sensory.

Lester Mundell, Chief Advisor, Disability Services Directorate, Ministry of Health, informed us that information on the number of students receiving occupational therapy or physiotherapy, and on the intensity of provision, is not held nationally. He doubted that it would be available at a local level either. There were no national specifications for Child Development Services contracts with district health boards and the reporting requirements also varied.

Discussion

A better understanding of the quantum and intensity of service provision of Health-funded therapy is needed in order to fully answer the research question of how much therapy students are getting, how often they are getting it, and through which funding streams.

Section 1.9: Survey of Schools

This section examines the quantum and intensity of occupational therapy, physiotherapy and speech-language therapy provision in a subgroup of New Zealand schools. The good response rate to the survey means that the following data broadly describe the situation in this defined subgroup.

Background

A survey was undertaken to better understand the quantum and intensity of provision of occupational therapy, physiotherapy and speech–language therapy in special schools, schools that held the moderate contract, schools that were in the three-year package of additional central funding for therapy provision, or some combination of these. It was also relevant to examine some key indicators of integrated effective practice as identified in the scoping project report (McDonald et al., 2001, pp. 93–94). While not providing a picture of therapy provision in *all* schools nationwide, the survey data does describe the situation for most of this particular group of schools.

Methods

A questionnaire was developed (see Appendix G) that covered:

- the provision of occupational therapy, physiotherapy and speech-language therapy
- some key aspects of integrated effective practice, such as where therapy was provided
- what kind of supervision and professional development was provided for therapists working in the schools surveyed.

At the start of the development process, the questionnaire was discussed with a group of special school principals and, where possible, their ideas and feedback were incorporated.

The questionnaire was mailed with a reply-paid envelope. Non-responders were contacted by a member of the research team, or by a school principal who had offered to help in this way. Where information needed clarification, and permission to contact the respondent was recorded on the returned questionnaire, a researcher telephoned and discussed the relevant responses. The Ministry of Education provided the information on the number of students on each school roll as of June 2002.

All questions, unless otherwise stated, relate to Term 3, 2002. For the various data reported, the number of responses is denoted as n = …. The number of respondents who did not fill in an answer to a particular question was recorded in the category of ‘no response’. There was usually no indication as to why the question had not been filled in.

Definitions

In the questionnaire the following terms, among others, were used. They were not defined in the questionnaire; instead respondents were left to interpret them in their own way. The understanding of the authors of the questionnaire was that the roles were approximately as follows:

- *teacher aide:* a paraprofessional employed to work with the class teacher in implementing the curriculum
- *therapy assistant:* a term used in some special schools to denote a paraprofessional employed to implement therapy programmes, or to help the therapist in much the same way that a teacher aide helps the teacher
- *communication support worker:* a term used in some educational settings to denote someone employed to help implement a speech-language therapy programme
- *special education assistant:* a term used in some schools to denote a paraprofessional employed in a similar capacity to a teacher aide.

It became clear that, apart from the generally understood term of 'teacher aide', the above terms were used differently by different schools.

Results

Schools included in the survey

Fifty-seven schools were eligible to take part in the survey on the grounds that they were a special school, or a school that held the moderate contract, or received the three-year package of additional central funding for therapy provision, or received some combination of these, shown in Table 1.25 below.

Table 1.25.: Schools eligible for survey

Type of school	Number
Special school only	30
Special school + three-year package + moderate contract	2
Special school + three-year package	1
School in three-year package only	16
School in three-year package + moderate contract	7
Information not available	1
Total	**57**

One of the eligible schools was a school for the deaf and another was a school for the blind and visually impaired. At least three schools offered conductive education rather than the traditional model of occupational therapy and physiotherapy.

Survey response rate

Forty-six schools responded in time to be included in the analysis, and their responses are reported in this section. Two further questionnaires were returned after analysis had been completed. The response rates for special schools, for those in the three-year package and for those schools that also held the contract for students with moderate physical disabilities are shown in Table 1.26. Of the 46 schools responding, 22 were special schools only and 15 were in the three-year package only. One was a special school that was also in the three-year package and a moderate contract holder, two were special schools and moderate contract holders, and six were in the three-year package and were moderate contract holders as well.

Table 1.26.: Survey response rate

Type of school[1]	Percentage of responses	Number of responses out of possible total responses
Special school	76	25 out of 33
School in three-year package	92	24 out of 26
Moderate contract holder	89	8 out of 9
Overall response rate	**81**	**46 out of 57**
Non-response	19	11 out of 57

Note: [1] Responding school can appear in more than one category

Percentage of school roll that spent some time in a regular school setting

The percentage of students spending time in a regular class or school setting is shown in Table 1.27. In almost half of the schools, fewer than 10% of the total school roll spent some time in a regular setting during Term 3, 2002.

Table 1.27.: Percentage of students on school roll spending time in a regular setting, Term 3, 2002

Percentage of school roll spending time in mainstream setting (n = 38, no response = 8)	Number of schools	Percentage of schools
≤ 10	18	47.4
> 10 ≤ 50	10	26.3
> 50 ≤ 90	6	15.8
> 90	4	10.5

Those eligible for and those receiving therapy

The percentage of students on the school roll who were described as eligible for occupational therapy, physiotherapy and/or speech-language therapy, and the percentage of those eligible who were receiving such therapy are shown in Table 1.28. Question numbers refer to the questionnaire (Appendix G). The subsections that follow consider each type of therapy separately.

Table 1.28.: Percentage of students eligible for therapy, and percentage of those eligible who were receiving therapy, Term 3, 2002

Q5. How many students were eligible?			
Percentage of school roll	**OT[1] (n = 44) Number (%) of schools**	**PT[1] (n = 44) Number (%) of schools**	**SLT[1] (n = 43) Number (%) of schools**
≤ 10	21 (47.8)	20 (45.5)	18 (41.9)
> 10 ≤ 20	3 (6.8)	3 (6.8)	4 (9.3)
> 20 ≤ 30	1 (2.3)	5 (11.4)	2 (4.6)
> 30 ≤ 40	2 (4.5)	4 (9.1)	2 (4.6)
> 40 ≤ 50	–	2 (4.6)	–
> 50 ≤ 60	2 (4.5)	–	2 (4.6)
> 60 ≤ 70	2 (4.5)	–	1 (2.3)
> 70 ≤ 80	2 (4.5)	1 (2.3)	2 (4.6)
> 80 ≤ 90	–	–	–
>90 ≤ 100	10 (22.7)	8 (18.2)	10 (23.3)
> 100[2]	1 (2.3)	1 (2.3)	2 (4.6)
Q6. How many of these students received therapy?			
Percentage of school roll			
≤ 50	3 (6.8)	8 (18.2)	6 (14.0)
> 50 ≤ 75	6 (13.6)	3 (6.8)	4 (9.3)
> 75 ≤ 100	9 (20.5)	3 (6.8)	13 (30.2)
100	25 (46.8)	28 (63.6)	20 (46.5)
> 100[2]	1 (2.3)	2 (4.6)	–

Note:

[1] OT = occupational therapy; PT = physiotherapy; SLT = speech-language therapy

[2] Reflects a likely discrepancy between school roll data of the Ministry of Education and number of students used by schools in responding to the survey. See main text below for detail.

Most schools reported that either fewer than 10% or over 90% of eligible students were receiving therapy. In only nine schools did fewer than three-quarters of those eligible receive therapy. Examination of the returned questionnaires, and discussion with some respondents who had indicated their willingness to be contacted to clarify responses, revealed that many respondents considered that the term ‘eligible for therapy’ was not synonymous with ‘needing therapy’. Rather, they saw the term as describing those students who would have been able to have therapy had they needed it. Many schools described all ORRS-funded students as eligible. This may be one reason why in some schools a low proportion of students received the therapy for which they were deemed eligible.

Also of note is that the school roll provided by the Ministry of Education was in some instances lower than the number of students eligible for or receiving therapy. While the data on school rolls from the Ministry of Education relate to June 2002, the numbers used by the surveyed schools may reflect any point in the term. Given that school rolls fluctuate, this will be the reason that the number of eligible students receiving occupational therapy in one school and the number receiving physiotherapy in two schools was over 100%. In these schools the intention was clearly to indicate that 100% of the students on the school roll were receiving occupational therapy or physiotherapy during the term specified.

Occupational therapy provision

This subsection reports on occupational therapy provision as described by the respondents to the questionnaire.

Table 1.29.: Quantum, nature and funding of occupational therapy provision, Term 3, 2002

Occupational therapy provision		Number (%) of schools	p value
Q7. How often were individual students receiving OT[1]? (n = 44, no response = 2)	Once during the term	0	< 0.0001
	Twice during the term	3 (6.8)	
	Every 3–4 weeks	3 (6.8)	
	Fortnightly	5 (11.4)	
	Weekly	27 (61.4)	
	Daily	6 (13.6)	
Q8. Were any students receiving OT seen in groups? (n = 44, no response = 2)	Yes	38 (86.4)	< 0.0001
	No	6 (13.6)	
Q8a. How often were students receiving group OT? (n = 38)	Once during the term	0	< 0.0001
	Twice during the term	1 (2.2)	
	Every 3–4 weeks	1 (2.2)	
	Fortnightly	3 (6.5)	
	Weekly	27 (58.7)	
	Daily	6 (13.0)	
Q9. Was Term 3, 2002 a typical term for OT provision?	Yes	36 (78.3)	0.0001
	No	10 (21.7)	
Q13. Where does the OT programme mainly occur? (n = 44, no response = 2)	Within regular class activities	28 (63.6)	< 0.0001
	Outside regular class activities	14 (21.8)	
	Outside any school site	0	
	Other	2 (4.6)	
Q14. Funding for OT			
ORRS[2]	Yes	45 (97.8)	< 0.0001
Moderate contract	No	1 (2.2)	0.008
SEG[3]	Yes	14 (30.4)	0.003
ACC[4]	No	32 (69.6)	0.77
Health-funded services	Yes	13 (28.3)	< 0.0001
Other	No	33 (71.7)	< 0.0001
	Yes	22 (47.8)	
	No	24 (52.2)	
	Yes	3 (6.5)	
	No	43 (93.5)	
	Yes	6 (13.0)	
	No	40 (87.0)	

Note:

[1] OT = occupational therapy

[2] ORRS = Ongoing and Reviewable Resourcing Schemes

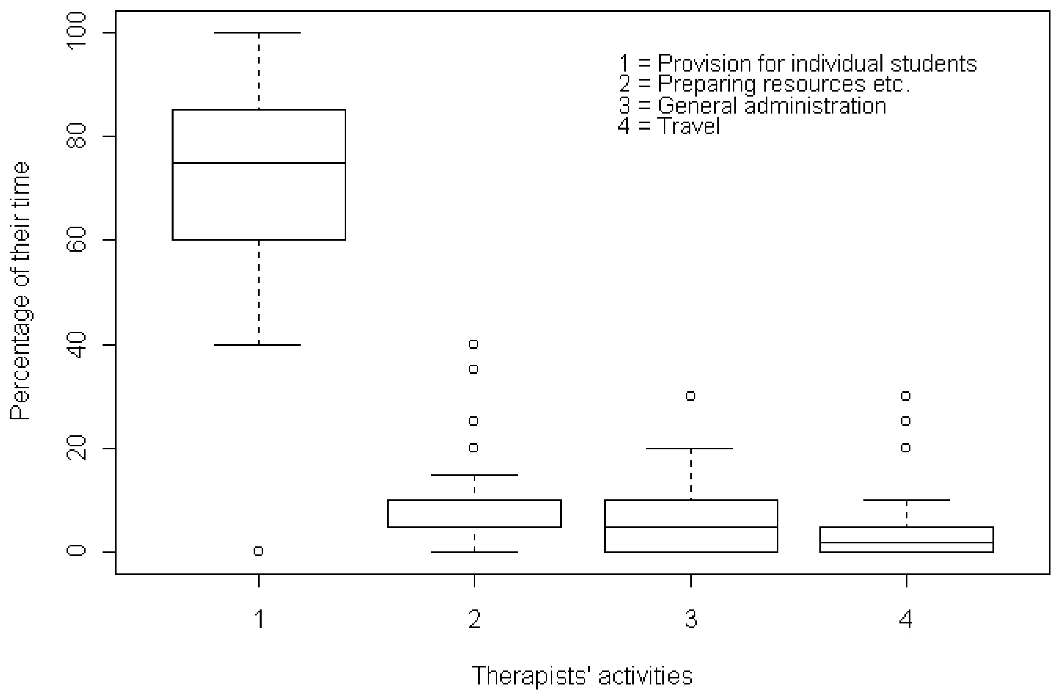
[3] SEG = Special Education Grant

[4] ACC = Accident Compensation Corporation

In Table 1.29, the right-hand column indicates whether the differences within each question were statistically significant (significant differences being indicated by $p < 0.05$ or lower). Thus there was significant variation in the frequency with which students were seen for therapy, with weekly being the most common answer. In a few instances respondents indicated that ‘weekly’ actually signified twice, three times or even four times weekly. Significantly more schools provided occupational therapy in groups than did not. Significantly more schools had occupational therapy occurring mainly within regular class activities than did not. ORRS, the moderate contract and the Special Education Grant (SEG) were funding occupational therapy services for students in more schools than not, but the split between those schools with and without students receiving therapy funded by ACC was fairly even. Very few schools mentioned that students were receiving occupational therapy services funded through Health or ‘other’ means.

Figure 1.13 shows respondent estimates of the proportion of time that occupational therapists spent on various tasks, using categories described in the questionnaire.

Figure 1.13.: How did occupational therapists spend their time, Term 3, 2002?

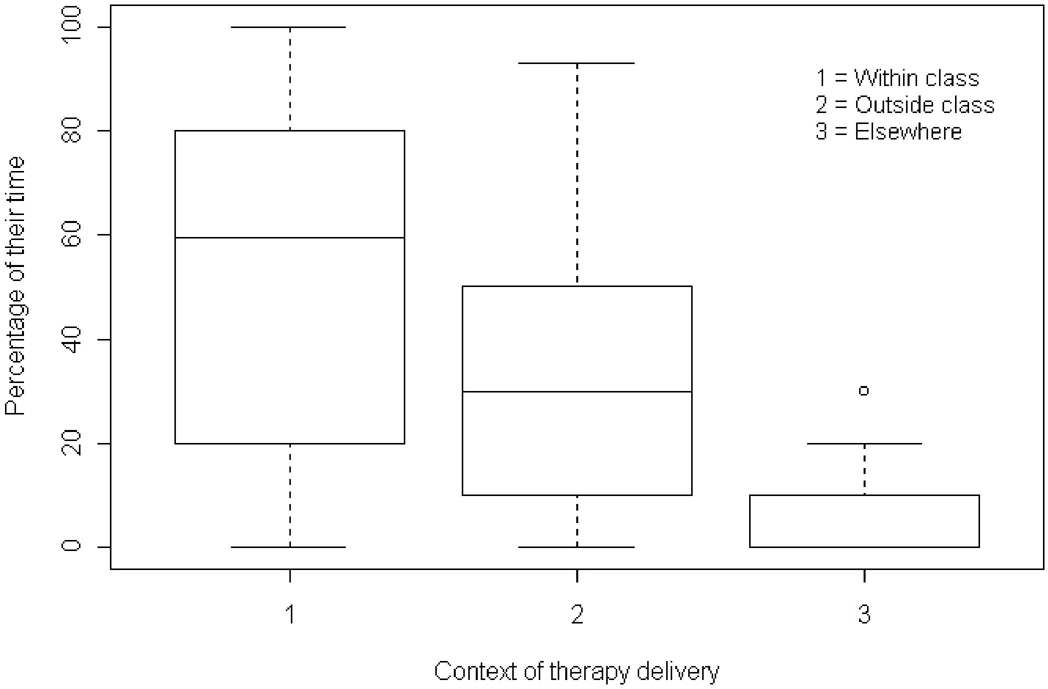


The box plot in Figure 1.13 shows the calculated range (top and bottom bars), the values within which 25% to 75% of responses fell (box) and the median value (horizontal line in the box) for each task. Responses that fell a long way above or below the rest of the data are shown as individual circles. Thus, apart from in one school where the occupational therapist(s) were not spending any time on occupational therapy provision for individual students, occupational therapists in the schools surveyed spent between 40% and 100% of their time in this way; half the schools indicated that their occupational therapist(s) spent 60% to 85% of their time in this way. It is expected that the percentages that schools provided are estimates rather than information that was recorded on time sheets during that term.

Time spent on occupational therapy activities not directly related to students (e.g. preparing resources, educating/training staff) was generally lower, as was time spent on general administration. In most cases, the percentage of time spent on travel was low, apart from three schools where therapists spent about 20% to 30% of their time on travel. One of these schools was a moderate contract holder covering several sites.

Figure 1.14 shows the proportion of time that occupational therapists spent in various settings (within regular class activities, outside regular class activities but still on the school site, and elsewhere – meaning outside any school site, e.g. at home, or 'other') when providing therapy.

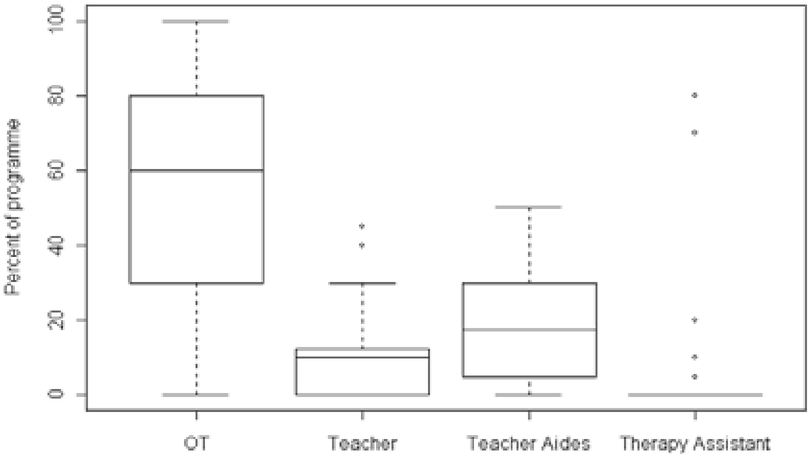
Figure 1.14.: Where did occupational therapists provide therapy, Term 3, 2002?



Occupational therapists provided therapy to students within regular class activities for between 0% and 100% of their time spent on therapy. Half the schools indicated that the therapist worked within regular class activities for approximately 20% to 80% of the time spent on therapy. Percentage of time spent providing therapy within school but outside regular class activities was correspondingly lower. Respondents indicated that therapists did not provide much therapy in settings outside the school site.

Figure 1.15 shows how much of the occupational therapy programme is provided by people in four different roles: occupational therapists, teacher aides, therapy assistants and teachers. The box plot shows the range of responses for each role. The middle half of responses is represented within the box. The median is indicated by the horizontal line through the box, meaning that half the responses had values above that line, half below. Three-quarters of responses had values equal to or less than the top of the box.

Figure 1.15.: Percentage of occupational therapy programme provided by occupational therapists, teachers, teacher aides and therapy assistants, Term 3, 2002



Note: OT = occupational therapist

Figure 1.15 summarises the answers of the 43 schools that responded to the question of who provides the occupational therapy programme. The data include answers where schools indicated that no one in one (or more) of the roles identified contributed to the programme. Further analysis, based on the data from these 43 responding schools, revealed the following.

- In 38 schools, occupational therapists provided some of the occupational therapy programme. The percentage of the programme they provided ranged from 10% to 100% (median 65%). In four schools, 100% of the programme was provided by the occupational therapist.
- Teachers were involved in the programme in 30 schools, and were estimated to be providing between 2% and 45% of the programme (median 10%).
- In 35 schools, teacher aides contributed between 5% and 50% of the programme (median 20%).
- Therapy assistants in 10 schools provided between 5% and 80% of the programme (median 15%).
- Therapists other than occupational therapists were involved in 14 schools, providing between 5% and 45% of the programme.
- Special education assistants in five schools were estimated to provide between 5% and 50% of the programme (median 10%).
- Parents were estimated by 15 schools to be providing between 2% and 30% of the programme (median 5%).
- A communication support worker was estimated to be providing 10% of the programme in one school.
- In three schools, conductors[19] were estimated to be providing between 40% and 100% of the programme (median 50%).
- Two schools estimated volunteer workers provided either 1% or 2% of the programme.
- Three schools estimated that some other person not mentioned above provided from 1% to 10% of the programme (median 5%). The ‘other’ was an ‘OT student’ in two schools, one of whom was ‘overseen by an OT’.

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[19] Conductors are specialists trained in conductive education, a specialised system of education, developed in Hungary, for habilitation/rehabilitation for motor disorders.

Was the term typical for occupational therapy provision?

As shown in Table 1.29 above, 10 schools said that Term 3, 2002 – the term on which this survey focused – was not typical.

In one school, this term had involved more occupational therapy than in the following terms. In one case, a child had been assessed but usually no occupational therapy involvement was needed. One respondent made the point that no term is typical. In other schools there had been less occupational therapy input than usual; for example, because a therapist had been on leave for a variety of reasons, including one attending a further education course. One school had been working with only one conductor instead of two.

Physiotherapy provision

This subsection reports on physiotherapy provision as described by the respondents to the questionnaire.

The results mirror those for occupational therapy. There was significant variation in the frequency with which students were seen for physiotherapy, with weekly being the most common answer. In a few instances respondents indicated that ‘weekly’ actually signified twice or three times weekly. Significantly more schools provided physiotherapy in groups than did not. Significantly more schools had physiotherapy occurring mainly within regular class activities than did not. ORRS funding, moderate contract funding, and the SEG were funding physiotherapy services for students in more schools than not, but the split between those schools with and without students receiving ACC-funded therapy was fairly even. Very few schools mentioned that any students were receiving physiotherapy services funded through Health or ‘other’ means.

Table 1.30.: Quantum, nature and funding of physiotherapy provision, Term 3, 2002

Physiotherapy provision		Number (%) of schools	p value
Q19. How often were individual students receiving PT[1]? (n = 43, no response = 3)	Once during the term	0	< 0.0001
	Twice during the term	1 (2.3)	
	Every 3–4 weeks	3 (7.0)	
	Fortnightly	4 (9.34)	
	Weekly	28 (65.1)	
	Daily	7 (16.3)	
Q20. Were any students receiving PT seen in groups? (n = 44, no response = 2)	Yes	33 (75.0)	0.0009
	No	11 (25.0)	
Q20a. How often were students receiving group PT? (n = 33)	Once during the term	0	< 0.0001
	Twice during the term	1 (2.2)	
	Every 3–4 weeks	0	
	Fortnightly	3 (6.5)	
	Weekly	24 (52.2)	
	Daily	5 (10.9)	
Q21. Was Term 3, 2002 a typical term for PT provision? (n = 45, no response = 1)	Yes	36 (80.0)	< 0.0001
	No	9 (20.0)	
Q25. Where does the PT programme mainly occur? (n = 44, no response = 2)	Within regular class activities	24 (54.6)	0.001
	Outside regular class activities	16 (36.4)	
	Outside any school site	4 (9.1)	
	Other	0	
Q26. Funding for PT (n = 45, no response = 1)			
ORRS[2] Moderate contract SEG[3] ACC[4] Health-funded services Other	Yes No Yes No Yes No Yes No Yes No Yes No	44 (97.8) 1 (2.2) 13 (28.9) 32 (71.1) 14 (31.1) 31 (68.9) 19 (42.2) 26 (57.8) 3 (6.7) 42 (93.3) 7 (15.6) 38 (84.4)	< 0.0001 0.005 0.01 0.30 < 0.0001 < 0.0001

Note:

[1] PT = physiotherapy

[2] ORRS = Ongoing and Reviewable Resourcing Schemes

[3] SEG = Special Education Grant

[4] ACC = Accident Compensation Corporation

Figure 1.16 shows respondent estimates of the proportion of time that physiotherapists spent on various tasks.

Figure 1.16.: How did physiotherapists spend their time, Term 3, 2002?

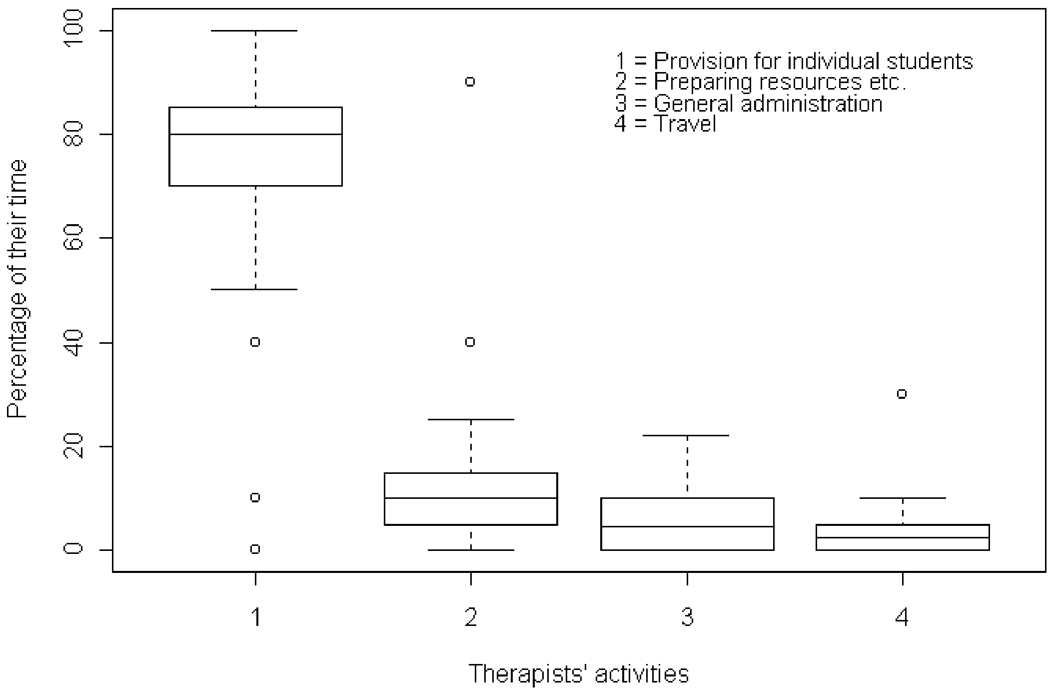
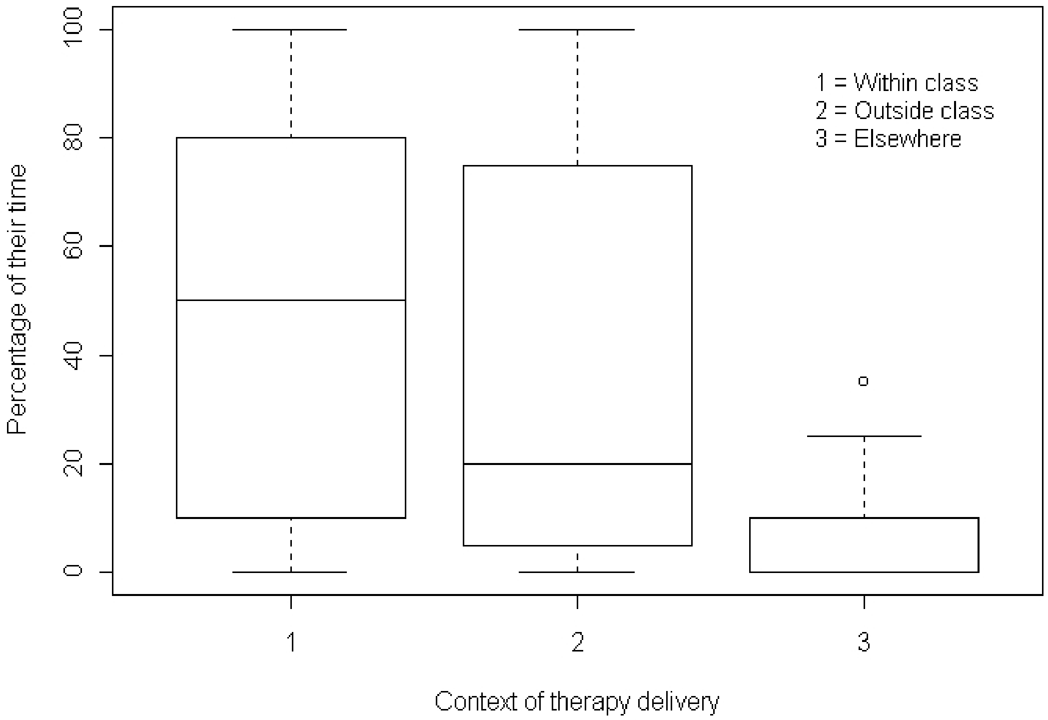


Figure 1.16 clearly shows that physiotherapists were reported to be spending most of their time on physiotherapy provision for individual students. This category was defined in the questionnaire (Q23) as:

> *e.g. preparing programmes, providing therapy and related activities, contact with teachers, parents, teachers' aides, environmental and assistive equipment needs, case discussion meetings, student related communication, liaison, writing up notes/reports/documentation.*

Figure 1.17 shows the proportion of time that physiotherapists spent in various settings (within regular class activities, outside regular class activities but still on the school site, and elsewhere – meaning outside any school site, e.g. at home, or 'other') when providing therapy.

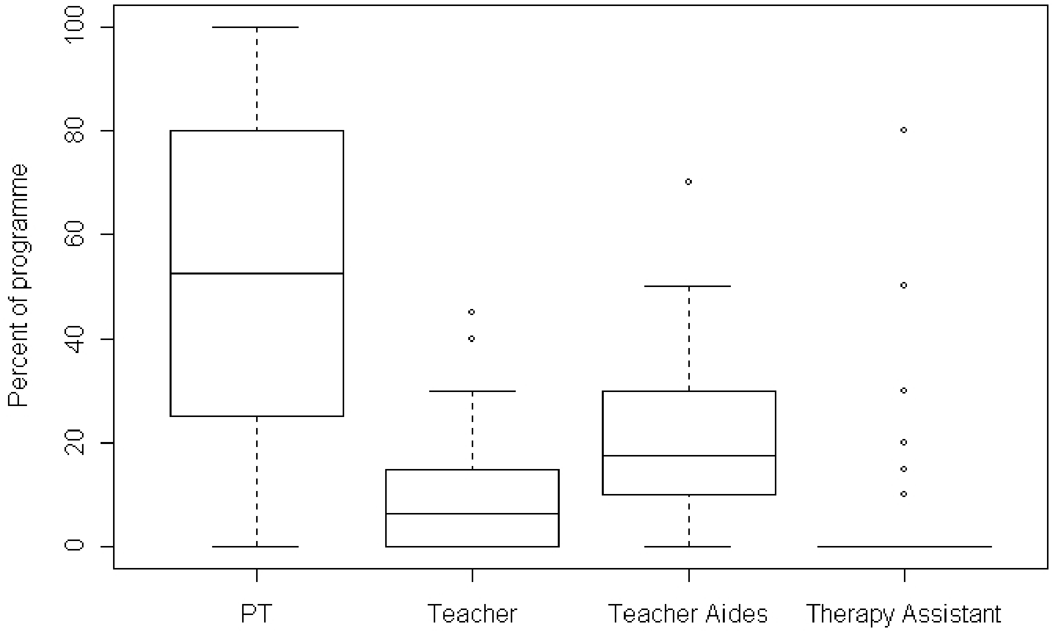
Figure 1.17.: Where did physiotherapists provide therapy, Term 3, 2002?



Schools indicated that the proportion of time that physiotherapists spent within regular class activities and outside regular class activities varied widely. A higher median proportion of time was spent within class activities than outside regular class activities. Respondents felt that therapists were not providing much therapy in settings outside the school site.

Figure 1.18 shows how much of the physiotherapy programme is provided by people in four different roles – physiotherapists, teachers, teacher aides and therapy assistants.

Figure 1.18.: Percentage of the physiotherapy programme provided by occupational therapists, teachers, teacher aides and therapy assistants, Term 3, 2002



Note: PT = physiotherapist

The extent to which people in four different roles contributed to the physiotherapy programme is shown in Figure 1.18. The data are from all 43 schools who responded to this question, and include answers where schools indicated that no-one in one (or more) of the roles identified contributed to the programme. Further analysis of how much of the programme was provided through each role, based on data from the 43 schools above (except where otherwise stated), revealed the following.

- Physiotherapists provided some of the physiotherapy programme in 40 schools. The percentage of the programme they provided ranged from 10% to 100% (median 55%). In four schools, 100% of the programme was provided by the physiotherapist.
- Thirty-nine schools indicated that teacher aides contributed between 1% and 70% of the physiotherapy programme. Half the schools estimated that teacher aides contributed 23% or less of the programme.
- Therapy assistants were used in seven schools for between 10% and 80% of the programme (median 20%).
- Teachers in 28 schools were estimated to be providing between 1% and 45% of the programme (median 10%), which is essentially the same as their input to the occupational therapy programme.
- In 13 schools, therapists other than physiotherapists were providing between 2% and 10% of the programme, which is less than the reported input of therapists other than occupational therapists to occupational therapy programmes.
- Special education assistants in six schools were estimated to provide between 1% and 35% of the programme (median 13%).
- Parents were estimated by 13 schools to be providing between 1% and 10% of the programme (median 6%).
- A communication support worker was mentioned by three of 45 schools as providing between 40% and 80% of the programme (median 50%).
- In three schools, conductors were estimated to be providing between 1% and 5% of the programme (median 5%).

- Four schools estimated volunteer workers provided between 1% and 10% of the programme (median 5%).
- No schools mentioned anyone else as being involved in providing the physiotherapy programme, though there was a space on the questionnaire for ‘other’.

Was this a typical term for physiotherapy provision?

As shown in Table 1.30 above, nine respondents said that Term 3, 2002 – as the term on which this analysis focused – was unusual. Most of these schools reported that in this term there was less therapy available than in other terms for one of the following reasons.

- There were staff shortages; for example: ‘We had two physios working 0.4 and 0.6 but were understaffed by 0.9. Therefore children were having less than usual individual time’.
- Therapists were busy with extra tasks; for example: ‘Three students had spinal surgery and required significant input for rehab/home visits/new programmes’, and ‘During this period the PT also led the playground development working party – investigating and helping design best option for our school.’

Speech-language therapy provision

This subsection reports on speech-language therapy provision as described by the respondents to the questionnaire.

Table 1.31.: Quantum, nature and funding of speech-language therapy provision, Term 3, 2002

Speech-language therapy provision		Number (%) of schools	p value
Q31. How often were individual students receiving SLT[1]? (n = 39, no response = 7)	Once during the term	1 (2.6)	< 0.0001
	Twice during the term	2 (5.1)	
	Every 3–4 weeks	0	
	Fortnightly	9 (23.1)	
	Weekly	25 (64.1)	
	Daily	1 (2.6)	
	No therapy given, though needed	1 (2.6)	
Q32. Were any students receiving SLT seen in groups? (n = 43, no response = 3)	Yes	30 (69.8)	0.01
	No	13 (30.2)	
Q32a. How often were students receiving group SLT?	Once during the term	0	0.0004
	Twice during the term	0	
	Every 3–4 weeks	0	
	Fortnightly	4 (8.7)	
	Weekly	26 (56.5)	
	Daily	0	
Q33. Was Term 3, 2002 a typical term for SLT provision? (n = 44, no response = 2)	Yes	39 (88.6)	< 0.0001
	No	5 (11.4)	
Q37. Where does the SLT programme mainly occur? (n = 41, no response = 5)	Within regular class activities	22 (53.7)	0.0004
	Outside regular class activities	17 (41.5)	
	Outside any school site	2 (4.9)	
	Other	0	
Q38. Funding for SLT (n = 44, no response = 2)			
ORRS[2]	Yes	42 (95.5)	< 0.0001
Moderate contract	No	2 (4.6)	< 0.0001
SEG[3]	Yes	4 (9.1)	0.003
ACC[4]	No	40 (90.9)	0.76
Health-funded services	Yes	12 (27.3)	< 0.0001
Other	No	32 (72.7)	< 0.0001
	Yes	21 (47.7)	
	No	23 (52.3)	
	Yes	3 (6.8)	
	No	41 (93.2)	
	Yes	4 (9.16)	
	No	40 (90.9)	

Note:

[1] SLT = speech-language therapy

[2] ORRS = Ongoing and Reviewable Resourcing Schemes

[3] SEG = Special Education Grant

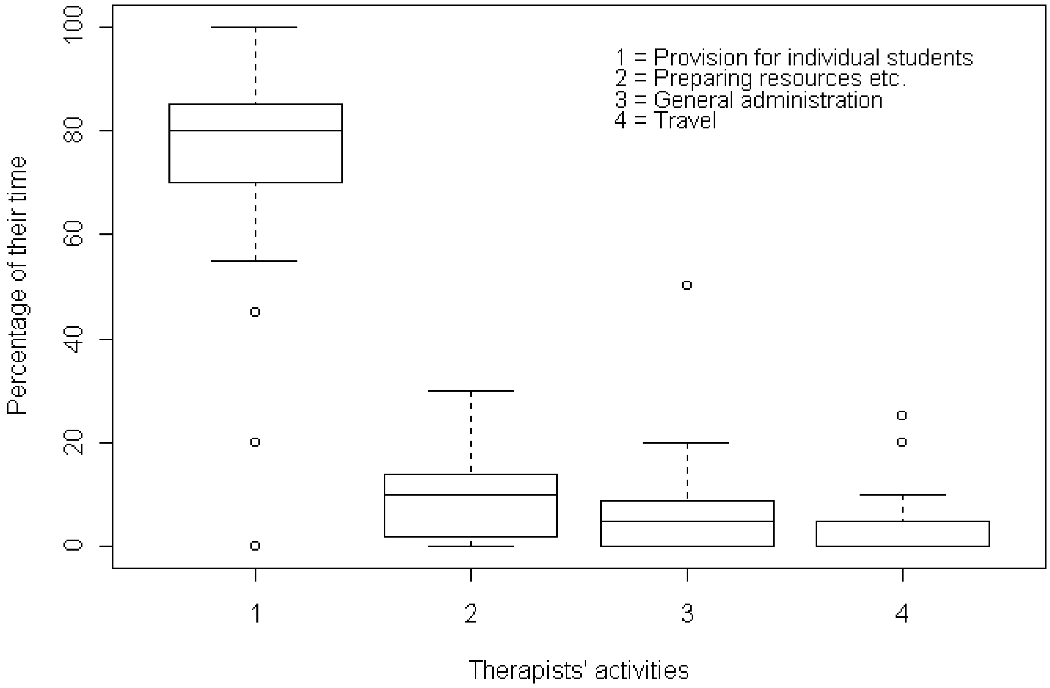
[4] ACC = Accident Compensation Corporation

There was significant variation in the frequency with which students were seen for speech-language therapy, with ‘weekly’ being the most common answer. In a few instances respondents indicated that ‘weekly’ actually signified twice or three times weekly. Significantly more schools provided speech-language therapy in groups than did not. Significantly more schools had speech-language therapy occurring mainly within regular class activities than did not.

ORRS funding, moderate contract funding, and the SEG were funding speech-language therapy services for students in more schools than not, but the split between those schools with and without students receiving ACC-funded therapy was fairly even. Very few schools mentioned that any students were receiving speech-language therapy services funded through Health or 'other' means.

Figure 1.19 shows respondents' estimates of the proportion of time that speech-language therapists spent on various tasks.

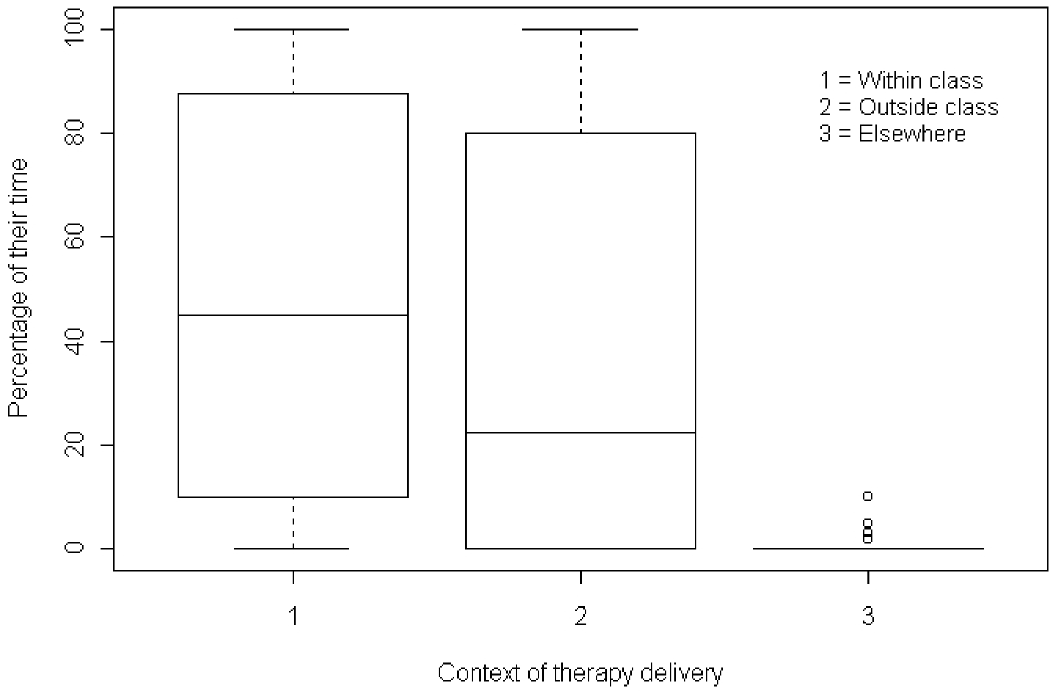
Figure 1.19.: How did speech-language therapists spend their time, Term 3, 2002?



Speech-language therapists were reported to be spending the vast majority of their time on speech-language therapy provision for individual students.

Figure 1.20 shows the proportion of time that the speech-language therapists spent in various settings (within regular class activities, outside regular class activities but still on the school site, and elsewhere – meaning outside any school site, e.g. at home, or 'other') when providing therapy.

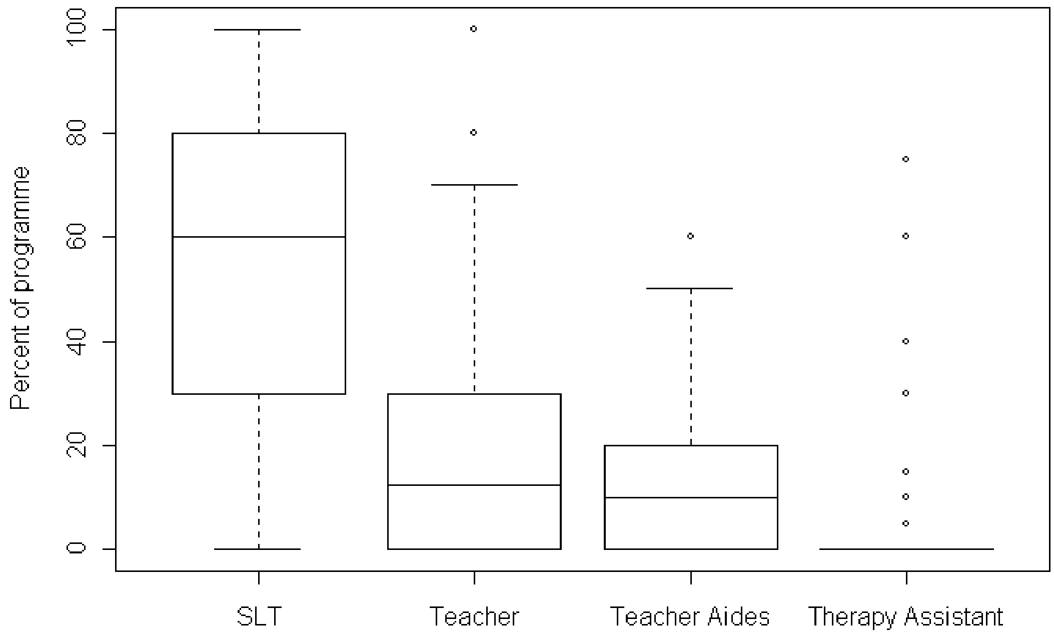
Figure 1.20.: Where did speech-language therapists provide therapy, Term 3, 2002?



Schools indicated that the proportion of time that speech-language therapists spent within regular class activities and outside regular class activities varied widely. A higher median proportion of time was spent within class activities than outside regular class activities. The estimated proportion of time spent on speech-language therapy provided in sites other than school, such as home, was negligible.

Figure 1.21 shows how much of the speech-language therapy programme is provided by people in four different roles: speech-language therapists, teachers, teacher aides and therapy assistants.

Figure 1.21.: Percentage of the speech-language therapy programme provided by speech-language therapists, teachers, teacher aides and therapy assistants, Term 3, 2002



Note: SLT = speech-language therapist

Figure 1.22 summarises the contribution that people in four different roles made to speech-language therapy programmes in schools. Further analysis of the data, which came from the 42 schools that responded to this question (except where otherwise stated), revealed the following.

- In 40 schools, speech-language therapists provided some of the speech-language therapy programme. The percentage of the programme they provided ranged fairly evenly from 5% to 100% (median 60%). In six schools, between 90% and 100% of the programme was provided by the speech-language therapist.
- In 30 schools, teacher aides contributed between 5% and 60% of the programme. Usually their contribution was small: half the schools estimated that teacher aides provided 10% or less of the programme.
- Therapy assistants in seven schools provided between 10% and 80% of the programme (median 20%).
- In 31 schools, teachers were estimated to be providing between 5% and 100% of the programme (median 20%). The school in which the teacher provided 100% of the programme commented ‘no SLT provision available, national shortage’. The school estimating that the teacher provided 80% of the programme indicated that the term in question had been a typical term for them.
- Therapists other than speech-language therapists were involved in 11 of 43 responding schools. These schools estimated that they provided between 4% and 10% of the programme; half said 10% or less, the rest said 10%.
- Special education assistants contributed to the programme in only four of 43 responding schools and were estimated to provide only 2% to 15% of the programme (median 3.4%).
- Respondents indicated that parents had a bigger role than in other therapies. In 13 of 43 responding schools they were estimated to be providing between 1% and 20% of the programme (median 5%).
- A communication support worker was estimated by one of 45 responding schools to be providing 5% of the programme.

- In two schools conductors were estimated to be contributing to the programme: 30% of the programme in one school and 40% in the other.
- Three schools estimated volunteer workers provided between 1% and 2.5% of the programme.
- Two schools mentioned someone else was involved in providing the programme. One of these identified speech-language therapy students.

Was this a typical term for speech-language therapy provision?

As indicated in Table 1.31, five schools said that Term 3, 2002 – as the term on which this analysis focused – was not a typical term. One of these schools mentioned that it was 'difficult to be accurate – because of roll growth our school has two full-time SLTs as from Jan 2003. In 2002 we had one'.

Do therapists need to know about the New Zealand Curriculum framework and SE2000 framework?

The questionnaire asked, 'Do therapists at your school need to know about the New Zealand National Curriculum framework and the SE2000 framework to provide education-related therapy services to students with physical disabilities that impact on learning and access to the curriculum?' In response, 86% (or 39 of the 45 respondents) stated 'Yes'.

Comments from those who agreed that there was a need for knowledge of these frameworks included:

> *They need to have a good knowledge of the essential skills areas as our IEPs [Individual Education Programmes] are based on these. Also a good understanding of how teachers and schools operate.*
>
> *Knowledge is necessary as a member of a transdisciplinary team. Programmes are interwoven with curriculum and all therapies enhance access to curriculum learning [school philosophy].*

Some were more cautiously supportive; for example:

> *An understanding of this documentation is preferred. However, more importantly [therapists] need to be familiar with the school philosophy etc, and how each teacher manages their learning environments and how they can generalise therapy where possible into the classroom setting.*

Comments from those who said that knowledge of these frameworks was not necessary varied from 'Teachers keep this responsibility and therapists 'hook in' to teaching programmes', to 'We have teachers to do that'.

Estimated workloads of therapists

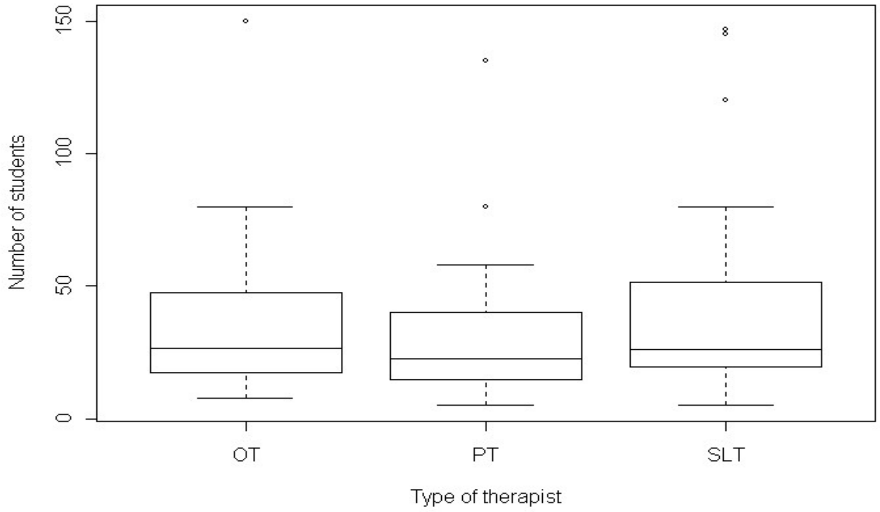
Respondents were asked to state the actual number of occupational therapists, physiotherapists and speech-language therapists employed, and the number of full-time equivalent therapists of each type employed. These two forms of information were sought, first, to assist estimates of therapist workloads, calculated as the number of children and young people who were receiving that type of therapy per FTE therapist. In such calculations, FTE-based information was clearly needed as two half-time therapists would be the equivalent of one full-time therapist. In addition, information on the actual number of people in the team would be important when addressing the practicalities of communication among team members. The question on the hours worked by an FTE therapist caused a lot of confusion, such that it was felt the responses were not reliable. When calculating workloads, therefore, only the number of FTE therapy positions in each type of therapy in each school was used.

The maximum number of students receiving occupational therapy during Term 3, 2002, was 120 (for schools where some students were receiving it, range = 1 to 120, median = 25, n = 43). The number of occupational therapists per school ranged from 0 to 3.9 FTEs; the position with the fewest hours was 0.06 FTE and the median was 1 FTE.

The maximum number of students receiving physiotherapy was 64 (for schools where some students were receiving it, range = 2 to 64, median = 19, n = 43). The number of physiotherapists ranged from 0 to 4.2 FTE; the position with the fewest hours was 0.05 FTE and the median for those schools with at least one physiotherapy position was 1.

The maximum number of students receiving speech-language therapy was 130 (for those schools where some students were receiving it, range = 2 to 130, median = 25, n = 39). The number of speech-language therapists ranged from 0 to 4 FTEs; the position with the fewest hours was 0.05 FTE, and the median for those schools with at least one speech-language therapy position was 1. The workload could be calculated only where there was information on both the number of students receiving therapy and the number of FTE therapists in a given school. For two schools the number of children and young people receiving speech-language therapy was not known.

Figure 1.22.: Number of students receiving therapy per full-time equivalent therapist, Term 3, 2002



Note: OT = occupational therapists; PT = physiotherapists; SLT = speech-language therapists

In Figure 1.22, the data are based on 29 responding schools for the workload of occupational therapists, on 30 responding schools for physiotherapists, and on 23 responding schools for speech-language therapists. Some of the highest workloads related to schools with only a few hours of therapy provision a week. The data in the figure show the estimated therapist workload in the responding schools. If any therapists worked elsewhere, their workload per FTE in the other setting may have varied. For this reason the analysis describes workload per FTE therapist, rather than per therapist employed or contracted by the school.

Vacant therapy positions

Respondents were asked to identify any vacant therapy positions in their school, and to express any vacancies as FTE positions. Two schools had vacancies for occupational therapy, physiotherapy and speech-language therapy positions. Two other schools described vacancies for speech-language therapy only. These numbers were too small to usefully compare the workload in schools with and without vacant therapy positions. One school described doubling the number of speech-language therapists employed the following term as the shortfall in therapy provision had become apparent. There had not, however, been a vacant position in the term on which this analysis focuses.

Professional development for therapists

Table 1.32 summarises the responses to the question on provision of supervision and professional development for therapists.

Table 1.32.: Provision of supervision and professional development for occupational therapists, physiotherapists and speech-language therapists, Term 3, 2002

Q41. Does your school make provision for ... (n = 46)		**Occupational therapists**		**Physiotherapists**		**Speech-language therapists**	
		Number (%) of schools	p value	Number (%) of schools	p value	Number (%) of schools	p value
Formal supervision with a supervisor	Yes	13 (28.3)	0.003	14 (30.4)	0.008	14 (30.4)	0.008
	No	33 (71.7)		32 (69.6)		32 (69.6)	
Informal supervision	Yes	37 (80.4)	< .0001	35 (76.1)	0.0004	32 (69.6)	0.008
	No	9 (19.6)		11 (23.9)		14 (30.4)	
Professional development	Yes	39 (84.8)	< .0001	37 (80.4)	< .0001	33 (71.7)	0.003
	No	7 (15.2)		9 (19.6)		13 (28.3)	

Formal supervision was provided in fewer than one-third of schools for each type of therapist. Schools with extra funding for therapy provision are meant to provide formal supervision for their occupational therapists and physiotherapists but were no more likely to do so than schools without this funding (p = 0.6 and 0.8 respectively). Informal supervision was provided in significantly more schools than not for all three types of therapist. Professional development was provided in most schools. Some respondents commented that they did not directly employ the therapists, and so were unsure about whether supervision was being provided elsewhere.

Students with physical disabilities that that had an effect on their learning or access to the curriculum

Respondents were asked, ‘During Term 3, 2002 did you have students enrolled at your school with a physical disability that impacted on their learning or access to the curriculum?’ (Q44). A total of 1,239 students – 737 girls and 502 boys – were identified in this way, out of 17,947 on the combined rolls of responding schools. This number represents 6.9% of students attending these particular schools.

Who is typically involved in designing and in updating a package of therapy?

The responses to the two questions on who was involved in designing and in updating a package of therapy (46a and 46b) tended to be similar for each respondent. There was a strong theme of a range of different professionals and parents working together. For example, one respondent stated that the following were involved in updating therapy programmes: ‘All therapists, teacher, parents, specialists (vision, drama, music, art, horticulture, transition). Senior management (curriculum leader)’. Among those identified by the majority were therapists (as would be expected), teachers and parents. Teachers were sometimes described in more specific roles, such as ‘senior management (curriculum leader)’ and ‘special education teacher’, and principals were mentioned specifically. Some schools mentioned the involvement of students, sometimes with a proviso of ‘where age appropriate’. Some schools mentioned involving professionals from outside the school, such as Ministry of Education, Special Education (GSE) advisors, paediatricians, general practitioners, advisor on deaf children, orthotic services and orthopaedic surgeons.

The Individual Education Programme meeting was clearly seen by many as key, particularly for updating programmes.

Where do parents get information from?

The questionnaire asked, ‘From where or whom do you think parents of students with physical disabilities get most of their information about services, entitlements, funding sources?’ (Q47). The majority of respondents saw the school as one of the places from which parents get most of their information. In only six cases did the respondent fail to include school, school teachers or school therapists as an important information source. It is encouraging that most schools see an important broad role for themselves here. Indeed, in at least two schools there is a parent–school liaison person whose role includes informing parents on just such issues as services, entitlements and funding sources.

A variety of other sources of information were mentioned. Only four schools identified needs assessment services specifically. In one case the needs assessment service was mentioned as being relevant for community-based services. This is perhaps a useful distinction.

What is going well with therapy service provision in schools?

In response to the question of what is going well with therapy service provision in schools, consistent themes emerged in regard to the advantages of having therapists on-site, and the advantages of being in control of how money is spent.

One of the advantages of having on-site therapists that was frequently alluded to was that it strengthened the ability to work as a team. This view is reflected in comments such as: ‘Being on site allows therapists to be accessible, available and flexible’, and ‘Good accessibility to therapists having them in school. Good relationship and communication between therapists and teaching support staff’. The following response was typical, emphasising the benefits to students that flow from having therapists on-site, with consequent closer liaison with staff and easier accessibility:

> *On-site employment of therapists enables interdisciplinary service [therapists/teachers]. On-site employment of therapists give[s] students access to immediate support in a crisis (e.g. aug. communication device breakdown). On-site employment of therapists allows immediate support/changes to strategies according to often suddenly changing needs of students.*

Another respondent underlined this point by describing the contrasting situation where therapists were based off-site:

> *The calibre and work ethic of the PT and OT [are] excellent, we just rarely get to see them. Being based in [name of city], travel uses a large percentage of their time. Funding restraints make it impossible for [school name and area] to offer an attractive package to employ therapists ourselves.*

Two respondents mentioned that the flexibility to employ therapists and other staff directly – ‘getting the right ratio and skill mix’ – was working well. In contrast, ‘In previous years – prior to having the capacity to directly employ therapists – the service was abysmal.’ Under the more flexible arrangements, one respondent noted:

> *All of it works well. We as a fund holder are at long last able to preside [over] a comprehensive therapy programme, with easy access to many facilities, e.g. orthotics, specialists, hospital consultants.*

Other positive themes linked to therapy service provision were the quality and expertise of therapists, and the supervision that the school was able to offer.

What aspects of therapy service provision in schools would respondents like to improve?

In response to the question on aspects of therapy provision where respondents would like to see improvement, a number of issues were raised by more than one respondent. These included issues in regard to: the funding of therapy, recruitment and retention of appropriately trained staff, accessing equipment for students, and areas where communication was perceived as being less than optimal.

Funding

Some schools perceived a need for funding for more therapists or more therapy hours. The need for more speech-language therapy and for speech-language therapy to be funded in a similar way to physiotherapy and occupational therapy was also a recurrent theme.

Some schools felt that the available level of funding did not allow them to meet the needs of their students. One respondent mentioned a need for funding to cover the costs of therapists travelling to off-site clinic appointments with students, which were costs ‘not included in the ORRS contract’. Others wanted more flexibility; for example, reporting that the ‘rigidity of ORRS [is] resulting in needy children not receiving necessary support’. Another school, which was providing therapy for students who were not ORRS-funded, noted that:

> *Criterion for ORRS funding is not meeting a considerable portion of children’s needs. A number of our children do not receive funding and are unable to access the curriculum and cope with the mainstream. Approximately 15–20% of children on our roll do not receive ORRS funding but they do receive therapy intervention because they need it, e.g. dysphagia.*

Respondents also noted that a regular review of allocated resources was needed to allow for the fluctuation in student numbers.

Recruitment and retention of staff

Recruitment and retention of staff were problems for some schools. There was both a perceived dearth of therapists with appropriate skills and training, and insufficient funding in many schools to allow them to employ therapists for the amount of time that they would have liked. Thus several schools had had or were having difficulty finding staff with school-based experience – that is, with knowledge of working within an education model. There was a perceived need for therapists who were well versed in education rather than health culture, and respondents identified a need for professional development to increase the pool of trained/qualified therapists to work in schools. There was also a perceived shortage of speech-language therapists.

Several other issues were seen to impact adversely on staff recruitment and retention. There was a perception that job security for therapists was poor, in some cases because of uncertainty of funding. The issue of a career path for therapists was raised, perhaps indicating the lack of a generally recognised one within the education sector. Difficulties with paying salaries that would attract therapists, or with affording pay rises as staff became more experienced, were also cited.

Access to equipment

Accessing equipment for students was cited as a problem by some respondents. Another issue raised was the need for appropriate physical facilities to house therapy staff, and for classrooms that were big enough to allow a ‘transdisciplinary model to be more fully implemented’.

Interface with other services or service providers

In a number of areas where services came into contact with one another, some respondents saw room for improvement. The home–school interface, the health–education interface, and transition into school were examples raised. Another need identified was for others to show respect to alternative therapy providers such as conductors.

Discussion

The 81% response rate for this survey was very good. The questionnaire was designed to be as quick and easy to fill in as possible, as this was likely to improve the response rate. The less advantageous side to this design was that certain important questions, which might have elicited revealing responses, were not asked. In particular, the questionnaire did not obtain data on the mix of the special education needs of the students in the schools surveyed. Additionally, in retrospect, it is acknowledged that respondents should have asked to provide data on school roll numbers.

It needs to be remembered at all times that the data reported in this section provide the picture as painted by the respondents. They have described what was happening in their schools, often with several different people collaborating in order to answer the different sections of the questionnaire. Schools were not asked to collect these data prospectively. Indeed, it is likely that much of the data is an estimate rather than a record of exactly what happened during the term on which this analysis focuses.

Information on who provides what proportion of the therapy programme is of necessity a description of a school's practice 'in general'. One respondent refused to apportion percentages to reflect the contribution that different people made to the provision of therapy programmes in that school, on the grounds that 'it will be different for each student'. This respondent makes a good point, namely that the data reported are a summary of what is believed to have happened, while the experience of different students within one school setting will, of course, vary.

On the other hand, the good response rate lends credibility to the findings, within the constraints identified above.

Some schools who responded to this survey had a high percentage of students with physical disabilities, and some had very few. Thus schools varied widely in the kinds of students and special education needs that they were set up to work with in particular, such that it would not always be appropriate to simply summarise data with one measure; for example, the range of responses might be more informative than the 'average'.

Occupational therapists, physiotherapists and speech-language therapists worked differently in different schools. Overall, working within regular classroom activities was more common than working predominantly outside regular classroom activities but still on the school site. Therapists spent most of their time with individual students. They spent little time on travel, in contrast to anecdotal reports of extensive time spent travelling by Health- or Education-funded itinerant therapists.

The finding that travel generally did not take up much of therapists' time is most likely to relate to the fact that many therapists worked on-site in the schools surveyed. There were other perceived benefits of having therapists on site. Respondents clearly felt that it promoted good teamwork and good liaison between therapists and teachers. Perhaps an example of this teamwork is that, in many schools, therapists, teachers and families were reported to be working together designing and modifying therapy programmes.

In estimating the frequency of therapy provision, schools most commonly reported it to be weekly or slightly more often. This survey shows, however, that the therapy programme is provided by a number of different professionals and helpers, not just by the therapist. The ORRS data reported in Section 1.6, on the other hand, related to therapist contact time only and did not take into account programmes put in place by the school. The two sets of figures are therefore not directly comparable.

The data on workloads for school therapists show a huge range; around three-quarters of schools have ratios of 50 or fewer students per FTE therapist. Data on GSE therapist workloads were not available for comparison. Similarly, moderate contract data were not collected in such a way as to allow workload calculations.

In two-thirds of the schools responding, fewer than half the students on the roll spent time in a regular school during the term on which this analysis focused. Indeed, as might be expected from the status of many schools surveyed as self-contained special schools, in almost half the schools 10% or fewer of their students had spent some time in a regular school during the term.

In some cases the percentage of students spending some time in a regular school may be an underestimate. The school roll data were obtained from the Ministry of Education, while the reported number of students spending some time in a regular school may have referred to only the number from the attached unit. For this reason, even if all the students in an attached unit spent some time in a regular classroom, the percentage who appear to be doing so will be low because as yet there has been no correction for the fact that a large part of the roll of a school with an attached unit is made up of students in regular classes anyway.

The case study research project discusses in more detail the various ways in which self-contained settings try to implement the indicators of integrated effective practice. The results of this survey are likely to provide useful background information to that discussion. In turn, a discussion of integrated effective practice provision across a number of different educational settings puts the information from this survey into a broader context. This context reflects the current reality that students with physical disabilities receive their education in a wide range of settings.

This section has given detailed information on aspects of therapy provision in a particular group of schools. It would have been useful to have equally detailed information on therapy provision for students in other educational settings and for students funded through other means. Information on occupational therapy and physiotherapy provision through Health was not available (Section 1.8). What we have recorded elsewhere in this report, however, is some information on therapy input for students receiving ORRS funding, in particular those who received therapy through the Ministry of Education, Special Education, and those who received therapy organised through specialist service providers.

Part 2: Case Studies

Jude MacArthur, Trevor McDonald, Carolyn Simmons Carlsson, and Pat Caswell

Section 2.1: Introduction to the Case Study Research

The purpose of the research

The purpose of the case study research was to contribute to improving service provision for students with physical disabilities, their families and whānau by informing both policy development and decisions about resourcing. The Ministry of Education and its Advisory Reference Group for Students with Physical Disabilities (the Reference Group) commissioned a scoping project, *Integrated effective service provision for children and young people with physical disabilities: Report to the Ministry of Education's Reference Group on Physical Disability* (McDonald et al., 2001),[20] to design a research programme that would answer questions in two key areas:

1. What is the current range and level of therapy and other services provided to overcome barriers to learning for students with physical disabilities in New Zealand? What are the characteristics of current users and what are the perceived levels of 'unmet' need?
2. What would coherent and effective models of therapy and other service provision for students in the compulsory school sector look like? What would such integrated models, with the student at the centre, look like across a spectrum of services, settings and locations (home/school, health/education/welfare/ACC)? The Ministry of Education's Reference Group was particularly concerned to ensure that these models reflected an holistic view of outcomes, focusing on life outcomes rather than just disability.

The case studies discussed here address this second research question.

The Ministry of Education's *Summary report: Scoping project on integrated effective service provision for children and young people with physical disabilities*, a summary of the scoping project (Ministry of Education, 2002)[21] suggested that 'identifying the principles of integrated service provision is more critical than developing a specific model of service provision' (p. 8). Equally importantly, the *Summary Report* suggested that integration needs to be at a number of levels and across agencies, and is about more than just the integration of services around individual students. These points were endorsed by the Reference Group.

Based on the relevant literature and on interviews, the scoping report identified the characteristics of integrated effective service provision. These support an approach to the research programme which:

> *seeks to clarify the characteristics of integrated effective service provision, with the understanding that such characteristics could be found in a range of models of service provision, not just in one type of setting or model. (**Summary Report**, p. 9)*

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[20] McDonald, T., Caswell, P., & Penman, M. (2001) *Integrated effective service provision for children and young people with physical disabilities: Report to the Ministry of Education's Reference Group on Physical Disability*. Wellington: Ministry of Education. See: www.educationcounts.govt.nz/publications/schooling/integrated_effective_service

[21] Ministry of Education. (2002). *Summary report: Scoping project on integrated effective service provision for children and young people with physical disabilities*. Wellington: Author. See: **www.educationcounts.govt.nz/publications/special_education/15734**.

The scoping report suggested that detailed case studies from a range of settings be undertaken to explore integrated effective service provision in greater detail.

A case study involves an in-depth study and analysis of one or several ‘cases’. The ‘case’ in this project refers to either a school setting with on-site therapy, or to a school or schools in which students are supported by a service provided by the Ministry of Education, Special Education (GSE) or by a Health-funded Child Development Services (CDS) team.

Case study research questions

Main research questions

The main case study research questions were:

1. What do models of therapy and other service provision for students with physical disabilities in the compulsory school sector look like across a spectrum of services, settings and locations (home/school, health/education/welfare/ACC)?
2. To what extent do these models reflect the components and principles of effective integrated practice as described on pp. 93–94 of the scoping project report (McDonald et al., 2001)?
3. What is the impact of therapy and service provision through the support team on the life and quality of life of the student with physical disabilities and their family?

Research questions relating to therapy and service provision in each case study

- How is therapy and service provision related to the principles and components of effective integrated practice, as identified in the scoping project. (McDonald et al., 2001, pp. 93–94)?
- What do members of the support team understand effective integrated practice to be?
- How do therapists, teachers and other professionals describe their approach to service provision?
- What are the key principles and components underlying the support team’s approach to service provision?
- What are the barriers identified by the support team to achieving effective integrated practice as they see it?

Research questions relating to focus students in each case study

- What services are students receiving (including Education, ACC, Health-provided services)?
- What is the cost of these services to individual students?
- Why are students receiving these services? What is the rationale for provision, and what is the process involved in making decisions and choices about service provision?
- How are the therapy and services provided to the focus students related to the features and characteristics of integrated effective practice, as identified in the scoping report (McDonald et al., 2001, pp. 93–94)?
- What is the impact of services and supports on student outcomes?

Research questions on the experiences and life outcomes of students and their family/whānau

- How do the student and their family/whānau understand and view the student's everyday life at school, home and in other settings?
- How do the student and their family/whānau view the contribution of and role played by the support team of therapists, teachers and other professionals to their overall quality of life (at school, home and in other community settings)?
- What are the post-school experiences of recent school graduates with physical disabilities? (Post-school experience may be seen as a critical outcome measure of effective services.)

Research questions on funding and resource use

The case studies considered how resourcing at the macro level affected the focus children and their families. An analysis of the funding and its use was undertaken for the 16 focus students (two in each case study site) in an attempt to provide a picture of funding use and impact across a range of children, sites/settings (special, integrated, urban, rural), and funding streams (e.g. ACC, Ongoing and Reviewable Resourcing Schemes, Special Education Grant funding only). Data collection and analysis focused on the various ways in which resources were used, the effect resourcing had on decisions about supports and the actual supports for children, the extent to which they were considered to support integrated effective practice, and the perceived and actual gaps between resourcing and service provision.

The main questions relating to resourcing were:

1. For each focus child, what is the impact of resourcing (funding) on the provision of effective integrated practice and on child and family outcomes?
2. How well does the focus child's resourcing (including funding, provision of and access to services) meet their identified and perceived needs?

Related questions included:

- How much funding goes to the child, and through which stream?
- How is the funding used: which services and supports is it used for and at what level of support?
- On what basis are decisions made about the allocation of funding and resources to services and supports (e.g. based on the amount of money available? the child's needs? family preferences? teacher preferences?), who contributes to these decisions, and how are the decisions made (e.g. a team approach? individual decision? parent/child involvement?)?
- Do the resources and associated services/supports for the child result in integrated effective practice (according to the principles and components described on pp. 93–94 of the scoping report)?
- To what extent are the needs of (the child) met within available resources/service provision?
- Are there perceived areas of funding shortfall, and if so, where are these?

Defining integrated effective practice – the scoping project

This section provides a brief overview of the material reviewed for the scoping project for this study on integrated effective practice with respect to services and supports for students with physical disabilities in educational settings.

The move towards models of inclusive education for children and young people with physical disabilities internationally has meant that physiotherapists and occupational therapists have become members of special education teams. This has resulted in much discussion about the role these specialists might play in this new working environment and about the best ways to integrate practices from a number of occupational groups within an educational model.

The aim of any therapeutic intervention is to make recipients full participants in the world (Rothstein, 1994), and while the same can be said of educational endeavours, there have been concerns about the application of medically based descriptions, assessments and treatment regimes to educational settings (Wylie, 2000). Within a health-based model, therapy has traditionally been 'hands-on' and provided for intensive periods, whereas therapies in education are focused on increasing students' participation in learning. The tension between two such different systems has the potential to frustrate therapists, teachers and parents, who may feel that in educational settings their child's therapy needs are not being adequately addressed.

Central to any discussion relating to the integration of therapeutic and educational practices for students with physical disabilities are the needs, rights and experiences of the recipients of such services (Sullivan, 1998). As was noted in the *New Zealand Disability Strategy* (Ministry for Disability Issues, 2001), people have impairments, but disability is the process that happens when other groups of people create barriers that limit the opportunities available to people with impairments. Thus, in using the term 'physical disability', a variety of meanings is possible. These arise either from the personal experiences or perspectives of the individual, or from the expectations or 'attitudinal barriers' that create difficulties for people in the first place (Gething, 1992; Sherry, 1999).

In addition, and in recognition of the extent to which disability has an effect on people's lives, the context in which an individual lives and works is also a critical component of the experience (Craig et al., 1999; Haley, 1994). This means, therefore, that any discussion regarding the integration of therapy and education must also focus on the practices and attitudes prevalent in the settings in which services are provided that have had the potential to lead to the exclusion of people with disabilities from the mainstream of life (Shakespeare, 1994).

What does 'integrated' mean?

In the scoping report, McDonald et al. (2001) noted that within the range of definitions of the terms 'integrated' and 'effective practice' a number of specific issues were relevant. The first concerns 'integrated'. This term has become widely used in education to describe the extent to which children and young people with disabilities are a part of their school communities. Increasingly, the term has become synonymous with inclusion.

Dunn (1991) has identified four uses of 'integration' in the literature:

- *Peer integration* is where typical children and those with special education needs are placed together in a range of social, educational, recreational and vocational settings.
- *Functional integration* is where therapeutic strategies are applied in a natural environment.
- *Practice integration* refers to interdisciplinary collaboration in the development and provision of services (between individuals).
- *Comprehensive integration* is a combination of all three forms.

In *Making a World of Difference: New Zealand Disability Strategy Discussion Document*, the Minister for Disability Issues (2000) discussed the need for New Zealanders to work towards 'a fully inclusive society, where our capacity to contribute and participate in every aspect of life is continually being extended and enhanced' (p. 4). In order to achieve this, she identified the need for collaboration between agencies providing a wide range of effective services. In particular, she noted the need to involve young people, Māori, Pasifika peoples and women in decision-making processes. In the present context, then, the term ‘integrated’ refers to professional and programmatic integration in addition to the integration or inclusion of young people with disabilities and their families in school and community settings.

What does ‘effective’ mean?

The second issue concerns the use of the term ‘effective’. Dunn (2000) has noted that best practices are those that contribute to effective practice. However, the discussion relating to this term has taken the view adopted in the bulk of the literature that the terms ‘best’ or ‘effective’ practices can be used interchangeably to describe a variety of approaches relating to methodologies, guiding principles, practices, outcomes and technological advances.

Peters and Heron (1993) suggest that best or effective practices need to be defined within the context in which they are to be used. To this end they suggest addressing the following questions when considering whether or not any particular approach might contribute to discussions of best or effective practice:

- Is there a sound theoretical base?
- Is the methodological integrity convincing?
- Is there consensus with existing literature?
- Are desired outcomes consistently produced?
- Is there evidence of social validity?

Dunn (2000) has concurred with Peters and Heron’s (1993) contentions. She notes that effective practices are those that concur with the literature in the field, provide consistent outcomes and are socially valid.

In the area of therapy intervention for children and young people with physical disabilities, effective practice focuses on the active role of the client and family (Gallegos & Medina, 1995) in the problem-solving process, and in the use of non-standardised observation and interview, assessment and treatment (Westcott et al., 1998; Wishart et al., 2000) in natural settings (Bundy, 1995). Measurable quality of life outcomes identified by students and their families and friends, along with an ecological[22] perspective to problem-solving, assessment and analysis of the factors contributing to outcomes, are further important issues that need to be taken into consideration (Borkowski & Wessman, 1994; Davies & William, 1994; Graves P, 1995; Graves K, 1999; O’Grady et al., 1997; Snell, 1997).

There is relative consistency in the literature concerning the need for effective practice to be based on the development of functional skills (Scrutton, 1984). In conjunction with this is the need to develop therapeutic interventions that can be applied within daily activities in natural settings (Wylie, 2000; Hayes et al., 1999; Larin, 1998), including educational settings (Lambert, 1992) and with respect to interactions with the curriculum (Ministry of Education, 1993).

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[22] The term ecological refers to an approach that recognises that the student does not operate in a vacuum, but that surroundings and context also have an effect on abilities and needs. Ecological assessments include a study of the student’s physical environment and their interactions with the people in close contact with them.

In terms of therapeutic interventions, best or effective practices are those that:

- foster children's competence in their own environments
- prevent secondary complications and disability
- acknowledge periods of personal stability when changes do not occur
- promote home- and community-based programmes (Coolman et al., 1998).

It is suggested in the literature that this holistic approach offers the most promise for change (Hedges, 1988; Larin, 1998; Rab & Mako, 1996) and development over the long term (Baum & Law, 1997; Case-Smith, 1997; Demchak et al., 1995; Doty et al., 1999; Graves P, 1995; Karnish et al., 1995; McEwan, 1994; Peters & Wright, 1999; Randall & McEwan, 2000). Indeed, O'Grady et al. (1997) make the point that the less functional an intervention, the greater the likelihood that hope, determination and a sense of accomplishment will suffer.

Interestingly, a focus on the development of functional skills is also seen as offering the potential for developing an educational model of therapy service and provision in a range of settings (Coles & Zsargo, 1998; Stile & Mitchell, 1995; Wylie, 2000). Also, such a model supports the engagement of teachers and support people who would ordinarily be excluded from participation in therapeutic interventions (McEwan & Sheldon, 1995).

The point must also be made, however, that despite the recognition of a number of components that could be said to constitute integrated effective practice, there can be no fixed way of describing such a thing. It can be argued that the specifics of any model must be dependent on the individual characteristics of the child and family in question. No approach should be rigidly followed at the expense of any opportunities for the child to maximise their assets (Scrutton, 1984). The need for collaboration between therapists, teachers and families in order to incorporate opportunities for routine and play activities throughout the day at home and school is therefore essential (Baker, 1999).

Integrated effective practice

As a result of identifying the issues facing individuals and the agencies that support students in educational settings, the potential for the views of all stakeholders to be represented in developing models of integrated effective therapy provision in educational settings needs to be considered. The first such consideration must focus on the central role of the client and family in the assessment of need, development of interventions and monitoring of outcomes.

There is little doubt in the literature as to the unique role of parents in the assessment and intervention processes (Graves P, 1995; Hanson et al.,1999; Wolfendale, 1996). However, parent–professional relationships can be both problematic and complex. Professional intervention has tended to come from a white, middle-class Western perspective and the assumptions common with this perspective may not be shared by the families involved (Dennis & Giangreco, 1996). In New Zealand, the desires and needs of Māori are also critical in establishing effective models or descriptions of best practice. The beliefs of many Māori are not consistent with those of the dominant Pakeha culture, and this has resulted in the alienation of Māori from services that could otherwise be useful. Perceptions of health and of the effectiveness of services common among some Māori include the need to refer to all aspects of a person's life (well-being), the use of a number of modalities, and the emphasis on tino rangitiratanga or self-determination (White et al., 1999). While it is important to note that cultural beliefs will not necessarily be common to all people of the same ethnicity, these issues are important to any discussion of effectiveness, or of the use of standardised measures of effectiveness.

Measuring outcomes

A number of protocols have been developed to facilitate interaction with and information gathering from families, and central to these protocols is an awareness and appreciation of the many factors that can influence the values and perspectives of individual families and children (Graves P, 1995; Piggott, 2000; Wolfendale, 1996). The factors recognised as critical to professional sensitivity (particularly in cross-cultural situations) are an awareness of the impact of the following on families:

- discrimination and acculturation
- poverty
- family composition
- work practices
- living arrangements
- experience of disability.

Further considerations recognised in the literature on integrated effective practices concern the use of a range of non-standardised ecological observation, assessment and treatment methodologies that are consistent with the ways in which we understand learning to occur *and* which measure change based on mutually agreed outcomes (including the individual, their families and peers) in all the settings in which an individual participates.

In the past there has been a tendency to rely on standardised assessment data for developing intervention plans, because subjective information was regarded as ‘soft’ or ‘unreliable’. While it has been suggested in the health sector that there is a need to move away from past practices, there has been an ongoing expectation that such tools should be standardised; that is, rigorously tested for reliability, validity and responsiveness over settings, students and time. The use of such tools in educational and social settings is problematic given that unexpected outcomes of intervention specific to individual contexts and perspectives are frequent (Barnard, 1993; Duckworth, 1999). Also, the demand for intervention to be functional and related to an individual’s daily life has made the question of measuring effectiveness using standardised comparative data difficult because their validity cannot be guaranteed (Hartigan, 1994; Kientz & Miller, 1999).

New measures for outcome assessment

In response to this issue, a small number of measures have been developed to provide the type of environmentally based assessment that can be used to measure and record change over time. Features of these tools include:

- criterion-referencing of key functional capabilities and performance outcomes (Simmons-Carlsson, 1999)
- consideration of the context of movement within functional activities and in the context of an individual’s daily life (Giangreco, 1986; Haley, 1994)
- recognition of the student’s ability to participate in various settings subject to the support and adaptations that are required, and the performance of skills (Bailey et al., 1993)
- collaboration in assessment and programme planning (Coster et al., 1998).

There are difficulties, however, with respect to the necessary involvement of the client in the process of identifying goals and for measuring the success of intervention, when concepts such as well-being become essential components of an evaluation (Enderby & Kew, 1995; Hemmingsson & Borell, 1996; Jewell & Roush, 1995; Mawson, 1993).

In response to the difficulties associated with assessment and the measurement of effectiveness, Wilkins (1995) has identified a range of questions that could lead to the development of an appropriate audit system. She asks:

- How can quality be defined?
- How can outcomes be measured?
- How can measurable goals be set?
- Has the intervention produced the change?
- Will this system challenge professional independence?

Integrated effective practices should lead to quality-of-life outcomes that promote adaptation within an individual's environment and functional skills *and* that lead to interventions becoming natural activities in an individual's life. Central to these issues is the need for planning for interventions to identify outcome measures that can be used in a number of settings and across different domains of learning. As an example, preferred outcomes now include maximising function and social integration (Dabney et al., 1997), the integration of therapeutic goals across an individual's day (Bell, 1987) and the maintenance of independent function and good quality of life (Carter, 1997). These sorts of demands on effectiveness measures provide further impetus for the use of ecological inventories over and above standardised measurement devices (Kientz & Miller, 1999; Watling, 1999).

Hunt and Goetz (1997) completed a review of 19 papers investigating programmes, practices and outcomes for students with severe disabilities. The themes that emerged as being important in the development of positive outcomes for students were:

- parental involvement
- achievement of positive and academic learning outcomes in inclusive settings
- acceptance, interaction and friendship
- effective collaboration at all levels
- adaptations of the curriculum as essential components
- multiple measures of success, multiple perspectives from all stakeholders and multiple-component interventions to address multiple needs.

Inter-agency and professional collaboration

The final issues of importance in the literature on integrated effective practice refer to the need for inter-agency and professional collaboration that:

- addresses issues of overlap in order to avoid problems of communication, continuity and transition
- reduces pressures on families
- is client centred and culturally sensitive.

Wylie (2000) highlighted the issue that in New Zealand there are a number of overlapping services to support children and young people with physical disabilities and their families, but the services operate without any clear areas of responsibility. She suggested that if greater co-ordination were achieved then services should become more accessible to families (Wylie, 2000).

O'Connor (1995) has noted that in order to develop true co-operation between agencies and individuals, agencies need to demonstrate 'trust, respect, and mutual dependence' (p. 105). To this end, the adoption of common goals and the recognition of the strengths of each agency will enhance the level of understanding. Similarly, membership of teams needs to be stable in order to overcome the inevitable side-effects that occur as a result of staff turnover. Flexibility in relationships is also seen as a crucial aspect when service provision issues are discussed, because rules can sometimes hinder the adoption of sensible solutions to problems. As discussed by Coster (2000), when inter-agency collaboration is working effectively it should remove the need for parents and caregivers to be the main link in the chain of communication.

To facilitate the development of services as outlined previously, Fowler et al. (2000) argue the need for agencies to have agreements to allow for the smooth transition of children between services, and suggest that such documents provide blueprints for change away from the informal processes currently in existence. The importance of the local 'ownership' of such agreements is also emphasised by Fowler et al. (2000), Durie (1998), and Ratima et al. (1995). Coolman et al. (1998) also argue for consultation and a balance between fiscal responsibility and advocacy.

Giangreco (1995) maintains that the use of client-centred functional and meaningful goals provides the best opportunities for enhancing students' educational achievement. An essential element of this is collaborative models of service provision, requiring shared frameworks for decision-making by related services personnel, educators and parents.

Despite the absence of descriptive and experimental data on decision-making in the literature, a number of guidelines do exist (Giangreco, 1990; Randall & McEwan, 2000). In all of these guidelines the critical factors appear to be:

- the centrality of the child in the process (Law et al., 1995)
- clarity of role and relationship to other team members (Llewellyn, 1994) to stimulate effective teamwork, integrated therapy (Kasser et al., 1997) and collective decision-making (Muhlenhaupt, 1998)
- role release, or the sharing of the knowledge and skill traditionally held by therapists as part of their professional role (Mackey & McQueen, 1998)
- commitment to teamwork (Giangreco et al., 1998) and the development of collective knowledge (Rainforth & York-Barr, 1997) and communication (Kasser et al., 1997)
- the identification of individual needs using curriculum-based assessment and observation (Giangreco et al., 1993; Vandercook & York, 1989).

Table 2.1summarises the indicators and outcomes of integrated effective practice evolving out of the literature review and research undertaken for the scoping project for the present research. Note that the indicators of integrated effective practice, as identified by the scoping project, have been modified for use in the present study. The modifications were made to provide a manageable summary of the indicators for use during the interviews. This has involved a slight rewording and summarising, but the essence of the indicators of integrated effective practice as identified in the scoping report has not changed.

For example, the original two criteria relating to funding (sufficient funding, flexibility and transparency of funding) have been rewritten as one (sufficient, flexible and transparent). Similarly, the eight original points relating to agency functioning (local control, consistency, bureaucracy, collaboration, co-ordination, transition, workload management and role clarity) have been combined as three points stating that:

- 'there is local control, development and management of services'

- ‘agencies collaborate, co-ordinate and manage transitions successfully’
- ‘workloads are managed to enable enduring relationships with clients and families, effectiveness of service and individual role clarity’.

Similarly, and in order to reduce replication, the indicators of effective integrated practice used as section headings in sections 2.4, 2.6 and 2.7 follow the modified format described above.

Table 2.1.: Summary of integrated effective practice

Integrated effective practice	**Integrated effective practice**
Services and provision can be said to be integrated and effective when: • sufficient, flexible and transparent funding is available to meet individual, programmatic, organisational and monitoring needs • there is local control, development and management of services • agencies collaborate, co-ordinate and manage transitions successfully • caseloads are managed to enable enduring relationships with clients and families, effectiveness of service and individual role clarity • families are informed about options and alternatives, and they are respected team members • there is a focus on changing attitudes and environments • the IEP [Individual Education Programme] is the focus of contact and planning, changes are recorded and documents are regularly reviewed • physical and educational needs are balanced • flexibility in programme model, location and provision occurs • staff are familiar with the educational context and the curriculum, and have on-going professional development, supervision and mentoring.	The literature has identified the following components of integrated effective practice. • Inter-agency and professional collaboration, which helps to reduce overlap and avoid problems of communication, continuity and transition. • Services aim to reduce pressures on families and work in a client-centred, culturally sensitive manner. • Clients and families are central in the assessment, development and monitoring of interventions, and there is recognition of disability across people’s lives. • A range of developmentally appropriate, non-standardised ecological observation, assessment and intervention methodologies are used. • There is a focus on quality-of-life outcomes that promote adaptation and functional skills. • Change is measured by the analysis of school, home, health, community and vocational factors. • Interventions become natural activities in an individual’s life. • Intervention plans are designed for implementation in natural settings across an individual’s day.
Measuring outcomes Effective services are said to have been provided when programmes focus on: • inclusion, including access to peers and minimising differences • equalising opportunities for students with/out disabilities • self-esteem, confidence and learning • meaningful and beneficial goals • a long-term view, and practical and easily maintained goals • input from clients and families • using relevant assessment and monitoring approaches.	**Measuring outcomes** The literature has noted that the indicators of effective outcome include: • extensive family involvement • client learning and achievement • acceptance, inclusion and friendships • supports for curriculum adaptation • interventions that focus on quality of life and include multiple measures, perspectives and components • built-in accountability measures based on the definition of outcomes and the purpose for which the information is to be used.

In summary, the literature review completed for the scoping project from which this study stems, and that has been briefly reported here, identifies the following components as contributing to integrated effective practice:

- inter-agency and professional collaboration that:
    - addresses issues of overlap
    - addresses problems of communication, continuity and transition
    - aims to reduce pressures on families
    - works in a client-centred manner
    - is culturally sensitive
- the central role of the client and family in the assessment of need, development of interventions and monitoring of outcomes to ensure:
    - respect for, and recognition of, cultural differences, understandings and treatment preferences
    - recognition of disability in the wider context of people's lives
- the use of a range of non-standardised ecological observation, assessment and intervention methodologies that are consistent with the ways in which we understand learning to occur
- a focus on quality-of-life-outcomes that promote adaptation within an individual's environment and functional skills
- some method for measuring change based on mutually agreed outcomes (including the individual, their family and peers)
- indicators of change being based on an analysis of relevant factors related to school, home, health, community and vocational settings
- change can be said to have taken place when interventions become natural activities in an individual's life
- therapy/intervention plans are designed for implementation in natural settings across an individual's day.

Section 2.2: Method and Methodology

Case study settings

Case studies were completed in eight case study sites and a total of 11 schools. The case studies covered a range of models of service provision. A description of the settings is given below.

Case studies with on-site therapy

There were four case studies in sites with on-site therapy: a self-contained school, a primary school with an attached unit, an intermediate school with an attached physical disabilities unit, and a secondary school with an attached unit. Each case study included two focus students, and all the schools were in urban locations.

In the self-contained school, the focus students, aged 13 and 18 respectively, were both resourced through the Ongoing and Reviewable Resourcing Schemes (ORRS) as very high needs.

In the primary school with the attached unit, the focus students were aged 8 and 11 respectively: one focus student was in the regular school and had ORRS high needs resourcing, and one student was in the unit and had ORRS resourcing for very high needs.

In the intermediate school with an attached physical disabilities unit, the two focus students were aged 11 and 12 respectively. One student was in the regular school and one was in the unit; both were resourced through ORRS as high needs.

In the secondary school with an attached unit, the two focus students were aged 14 and 16 respectively. One was full-time in regular classes and one had a combined regular school/unit timetable; both were resourced through ORRS as high needs.

Case studies with itinerant therapy

There were four cases studies which involved itinerant therapy provision: a Child Development Services (CDS) team providing services in an urban setting, a CDS team providing services in a rural setting, a Ministry of Education, Special Education (GSE) team providing services to a rural area, and a GSE team providing services an area school.

The two focus students receiving services from the urban CDS team were aged seven and eight respectively. Both children attended regular primary schools. One received ORRS high needs resourcing, the other received support through the contract for provision of therapy for services for students with moderate physical disabilities (the moderate contract).

The two focus students receiving services from the rural CDS team were aged 6 and 11 respectively: one student was in a regular rural primary school and received Resource Teachers: Learning and Behaviour (RTLB) support only plus monthly monitoring by a CDS team leader; the other students attended a regular college and received RTLB support and physiotherapy/occupational therapy from a Health-funded service.

Two focus students receiving services from GSE team supporting a rural area were aged 8 and 12 respectively. Both students attended regular primary schools and both were resourced through ORRS as high needs.

The two focus students receiving services from the GSE team that supported an area school were aged 10 and 16 respectively. One student was in the primary section and was resourced through ORRS as high needs, and one was in the secondary section and resourced through ORRS as very high needs.

In total, 16 focus students were observed and two school-leavers were interviewed (one from the secondary school with the attached unit, and one who had been supported by the rural CDS team). There was an even gender mix, and schools covered a range of deciles. The characteristics of each student, and their resourcing stream and supports at school, are provided in Appendix H at the end of this document.

Selection of case study sites

Sites were selected on the basis of the opportunity afforded by the site to learn about effective integrated service provision across a range of different services, settings and locations. Stake (2000) argues that 'potential for learning is a different and sometimes superior criterion to representativeness' (p. 446). Sites were also selected to provide a range of settings across decile, level (primary/secondary), location (rural/urban, South Island/North Island), school type (regular/special unit/self-contained), and support service (on-site therapy teams; Ministry of Education, Special Education teams; and Ministry of Health-funded CDS teams).

Sites were initially approached through the school principal and board of trustees. A 'Brief for Schools' (Appendix I) was sent out and their permission was sought to participate in the project. A similar approach was used with CDS teams, using a 'Brief for Child Development Teams' (Appendix J). Services that agreed to participate selected students and schools which they felt would best inform the case study research. The principals and boards of trustees of these schools were then approached and their permission was sought to participate. All schools and CDS teams approached agreed to be part of the project.

Focus students

Focus students were selected in consultation with a key participant in each case study site to include gender, age and ethnic diversity. An attempt was also made to include diversity in disability and resourcing streams (including high and very high needs under ORRS, ACC funding, moderate contract resourcing, and funding from schools' Special Education Grant). Because the primary focus was on sites that were considered to be providing support consistent with aspects of integrated effective practice, however, this spread was not easy to achieve. The range of disabilities included cerebral palsy (12 students), spina bifida (one student), hemiplegia (one student), and low tone with sensory and motor-planning challenges (two students).

Informing participants and gaining consents

Following each school's agreement to participate, a key person on each case study site informally approached the parents of potential student participants and gauged their interest in being involved in the project. Those interested were then sent information sheets and consent forms for themselves and their sons and daughters to complete and return to the researcher responsible for that case study site (see Appendix K for information sheets and consent forms). Team members on the school site were also sent information sheets and consent forms to read, sign and return.

Case study methodology and method

Case studies are one way to undertake qualitative enquiry. Case study is not so much a choice of methodology as a choice of what is to be studied. The 'case' becomes the focus for learning, and the design of a study aims to optimise understanding of what happens in that case or setting, rather than generalisation beyond it (Stake, 2000). The aim of these case studies, therefore, was to get a greater understanding of the practice of integrated effective provision in terms of the principles identified in the scoping project.

Consistent with the concern of the Ministry of Education's Advisory Reference Group for Students with Physical Disabilities that the research project be student-centred, with a focus on the rights and voices of the student and their family/whānau, case studies focused on the support teams working with two students with physical disabilities and their family/whānau.

Each case study involved a five-day site visit across one working week (Monday to Friday). Fieldwork for each case study included:

- *key informant interviews* with focus students, their parents/caregivers/whānau and a friend, where possible
- *key informant interviews* with all members of each student's support team, which included the school principal; unit directors; heads of department for special education needs in secondary schools; class teachers; therapists; teacher aides; and any other person considered to be part of the student's support team
- *key informant interviews*, where possible, with a recent school graduate (within two to three years of completing school, predominantly from sites where the support team is working with secondary-age students)
- *observations* that focused on the daily life experience of the two focus students at home and school, which involved the researcher spending one to two days moving with the students through their day at school, home and other settings
- *archival searches* of relevant documentation relating to the student's education (including their last Individual Education Programme [IEP] document), level of need, range and type of needs, funding and support.

Interviews were tape-recorded and transcribed. Observations were recorded in field notes and relevant archival material was photocopied. The research data therefore comprised transcribed interviews, field notes and printed archival material. Participation in the project was informed and voluntary for all participants. A small number of participants chose not to be interviewed or were unable to be interviewed, and students who were unable to communicate their experiences to the researcher were not interviewed.

The project used qualitative methods of enquiry to collect and analyse the data. Qualitative enquiry is built on a concern with understanding what others are doing or saying, and constructivism is one philosophy used to explain the aim and practice of understanding human action through qualitative enquiry. Constructivism acknowledges that people do not find or discover knowledge in a passive way; rather, they are active in constructing and making knowledge:

> *… we invent concepts, models and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experience. (Schwant, 2000, p. 197)*

Knowledge is seen as constructed not in isolation but against a historical backdrop of shared understandings, practices and language. Consistent with this perspective, the present study used methods to collect and analyse data that focused on various participants' experiences and understandings of effective integrated service provision and its relationship to quality lives for children with disabilities and their families. The project used qualitative methods to undertake a collective study of eight sites.

Generalisability

A sample of case study sites was drawn in this project to build in variety and to acknowledge the opportunity for intensive study and opportunity to learn (Stake, 2000). As noted in the *Summary Report* of the scoping project, different models of working with students with physical disabilities may have the potential to reflect integrated effective service provision. Each site was unique and covered different settings and models of service provision, and each included a range of students with different needs and strengths. Nonetheless, each setting still has a generalising capacity (Eisner, 1991). Those qualities of teaching and team support identified as comprising integrated effective service provision can be secured and applied to the worlds of other students with physical disabilities where they are believed to be relevant. Within this working context, members of the research team were prepared to enter each site with an idea of what to look for in terms of current theory and research on integrated effective practice.

Data collection strategies

Qualitative interviewing

Semi-structured, face-to-face interviews were conducted with participants. Semi-structured interviews allow researcher to explore a range of question areas which are shared across participants, while also pursuing questions specific to participants' individual roles and experiences (Fontana & Frey, 2000; Patton, 1990). This approach also allows the researcher to pursue those issues salient to participants that arise during the interview.

Support team members were asked the same questions in relation to the function, operation, philosophical basis and framework of 'the team', while additional questions were framed to meet each person's individual role (e.g. as an occupational therapist, or as a classroom teacher). Interviews with students and parents focused on learning about the daily life experience of the student and family, and the role and impact of services and supports in shaping that experience (see Appendix L for interview guides).

Interviews with children were carefully designed to ensure the children were informed and comfortable about speaking with the researcher. Some unstructured interviewing was also conducted in the field as part of the process of observation (described below). Researchers encountered opportunities as they moved through the day with students and others to talk about actions and issues as they arose or were observed. These unstructured interviews were recorded in field notes.

A reflexive approach was maintained, an approach which respects the individuality of children and their experiences, and their fluid roles as social actors (Davis et al., 2000). The work in this area was guided by the researchers' own experiences working with and interviewing children, and by the ethical and procedural guidelines established in the literature (e.g. Davis et al., 2000; Smith et al., 2000).

Observations

Two children in each case study site were observed as they moved through one to two days at home, school and in other settings. Observations were designed to provide a snapshot of the way in which students and their families lived and experienced daily life, and the support services that went along with that experience. The observations attempted to provide as full and rounded account of the daily life of the students and their families as was possible in the time, with a focus on the individuals themselves and their relationships with others who provided support (Fontana & Frey , 2000). The personal meanings and understanding that participants (children and their parents) ascribed to their own experiences were explored, examining in particular the ways in which services and supports worked to either enhance or inhibit the achievement of a quality personal and family life.

Observational research involves interpersonal interactions between researcher and participant, and the nature of this relationship can affect the data, so it was important for researchers in the present study to be aware of these factors and their likely impact.

Data analysis

Discussions among team members, and later with the Ministry of Education's Reference Group on Students with Physical Disabilities, formed the basis for the initial identification and development of key themes relating to the three main research questions. A key theme identified in these early stages related to the relationship between integrated effective practice on the one hand, and school type combined with service provision model on the other. In particular, schools with therapy and services located on-site shared some common experiences in their implementation of integrated effective practice. Schools receiving itinerant therapy and supports shared a somewhat different set of experiences. Also, the particular philosophy of each setting had a bearing on the way in which therapy and teaching staff supported and taught students with physical disabilities.

The data were analysed for each set of sites (on-site therapy and itinerant therapy). This organisation of the data facilitated the management and analysis of a large amount of observational, interview and archival data. There was no intention to evaluate or draw comparisons between these two types of settings. Two researchers read and re-read transcripts, observation notes and student-related archival material to identify and extract themes relating to the three main research questions. A third researcher undertook to read most of the interview transcripts across sites, and to code the data according to the research questions. Authenticity in the data was established through a process of ongoing scrutiny, and review and discussion of emerging themes and draft material by all researchers working on the case studies.

Ethical procedures

The project was reviewed and approved by the Ethics Committee of the University of Otago. Critical ethical processes of informed consent, anonymity, confidentiality and right of withdrawal were adhered to in this project. Particular care was taken to ensure that children in the project understood what the project was about and what their involvement would entail. Parents first explained the project to their son or daughter, and the researcher carefully went over the information sheet and consent form with each student. No real names of schools and individuals are used in this report, and any identifying features have been removed or changed. To further protect anonymity, some genders have been changed, and data have been combined in places to ensure that sensitive issues can be raised without being linked to case study sites or individuals.

Section 2.3: Description of Case Studies in Schools with On-Site Therapy

The case studies in this section involved schools where therapists were located on the school site. The four sites with on-site therapy comprised one special school and three schools with attached units (a regular primary, a regular intermediate and a regular secondary school). The three attached units received resourcing for occupational therapy and physiotherapy positions from the transitional fund. The majority of students attending classes on these sites received Ongoing and Reviewable Resourcing Schemes (ORRS) resourcing at the high or very high levels.

These case studies describe the daily life experiences of Simon, Selena, Ian, Isobel, Harry, Heather, Paul, and Penny from the perspectives of their teachers, therapists, aides, and one, and sometimes both, of their parents (with the exception of Selena's, who did not wish to be interviewed). Harry, Heather and Ian were also interviewed for their views on what their lives were like. Heather's older brother was also interviewed. Neither Simon, Selena nor Penny had access to the communication augmentation that would have made it possible for them to talk about their lives. Isobel used an Alphasmart[23] for basic communication.

Case study 1: Self-contained school

The first case study site was a self-contained school for children and young people with a wide range of needs. Most students attending this site were described as having more severe learning and often multiple disabilities. All but a very few of these students received resourcing through ORRS at the high and very high levels. The school acted as its own ORRS specialist service provider,[24] and was the specialist service provider for students in a number of local regular schools. Therapists from the school travelled to these other schools in the same urban area as needed to support students.

The school did not receive the transitional funding for therapists that the other schools and units for students with physical disabilities received. Staffing at this school included teachers, special education assistants, teacher aides, occupational therapists, physiotherapists, speech-language therapists and a part-time psychologist.

For those students with significant physical disabilities, the school followed an integrated model of therapy and education provision. Students were not withdrawn from classes for therapy interventions. Therapists, teachers and others worked alongside each other in classrooms to address students' physical, sensory and educational needs.

Focus students: Simon and Selena

The two students identified for this study received ORRS resourcing at the very high level. Simon, who had a Pasifika background, was 18 years old at the time of the study and lived at home with his family. Simon had a range of needs, including cerebral palsy (spastic quadriplegia), epilepsy and learning disability. Simon travelled between home and

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[23] An Alphasmart is an electronic notetaker or word processor – essentially a simple computer for writing.

[24] Specialist service providers were formerly known as fund-holder schools.

school by Ministry of Education-funded taxi and received occupational therapy, physiotherapy and speech-language therapy support.

Simon previously attended a regular school, but was withdrawn because the school seemed unable to meet his needs. He was subsequently enrolled at a school for students with physical disabilities, but was withdrawn from that school as it was felt that his learning needs were too great, and thus was enrolled in the self-contained school that was the focus of this case study. Attendance at the school for students with physical disabilities and the self-contained school required a great deal of travel to and from home.

The second focus student, Selena, also had a Pasifika background and was nearly 13 years old at the time of the study. She lived at home with her family and came to school each day in a taxi. As with Simon, Selena had a range of physical and learning needs, including scoliosis, for which she had had surgery. She also received support from all three therapies. In addition to therapists who worked in her classroom, Selena had support from her teacher, a special education assistant and an aide.

There was a daily and weekly curriculum timetable posted in Simon and Selena's classrooms. For all students the day began with a visit to the toilet. The class programme comprised individual programme time, during which students used a variety of equipment related to posture, mobility and communication. This was followed by a morning tea break, lunch from 11:00 to 12:00, toilet, and a break for staff. The afternoons were often filled by swimming and perhaps time in the sensory room. Student breaks were taken in the play area, either under cover or in the open.

Simon and Selena's school days tended to look similar, but their individual learning needs were catered for by individual programmes and the adult support they each received. Students arrived at different times at the beginning of the day, and as they arrived, they were assisted to walk or were taken to the classroom in their wheelchairs by way of the toilet. As they arrived at the classroom they were asked to transfer out of their wheelchairs and on to individual chairs. Simon did this himself after a verbal prompt to do so, and Selena was physically assisted to move from her wheelchair to her own chair. The students were then grouped around in a circle so that they could all say hello to each other and observe what was happening in the room. Wheelchairs did not remain in the classroom during the school day.

While students were arriving and going to the toilet, one of the school staff either asked the student to take their lunch and home notebook from their bag or it was done for them. At this time the teacher also discussed the plan for the day's activities with the special education assistant and the teacher aide. Once the students returned to sit on their chairs, the staff in the room interacted with them one-to-one, and as other students arrived they were greeted by name by staff and students. In Simon's case it was clear that he had particular friends in the group whom he was happy to see.

The session began with information for students on the day's events. After this a sensory activity that had been jointly planned by the occupational therapist and teacher took place. On the day of observation this activity related to planning a video sequence for a film being made by the students. The teacher and occupational therapists had written a script for a royal party. The script was written out on a board and narrated by a staff member. All of the students including Simon and Selena played a role, and as they took their part the teacher videoed their performance. Students were supported by the other adults in the room to attend to the video sequence, to take turns, interact with peers, move about or participate in activities using pens and crayons to make invitations. Students were also videoed making sandwiches for the party.

On other days this session was given over to music, at which time a part-time teacher took the class, relieving the teacher for planning with therapists. Music sessions followed a similar pattern to that described above and provided opportunities for movement, listening, turn-taking and general interaction between staff and students.

The next activity involved the students matching photographs with their names. As this was completed, each student pressed a 'Big Mac' switch to say hello to their peers and staff. The teacher and occupational therapist, assistant and aide were observed to use a range of prompts and guidance for each student, depending on need.

Once this activity was completed, the occupational therapist left the room and students moved to their equipment for individual activities. In Simon's case this meant crawling to his 'easy stander', getting into it and, with some assistance, standing up. For Selena this time was given over to practising standing transfers from wheelchair to seat and some stretching exercises on the floor. Once this was done, the students were wheeled down to the play area for morning break, which lasted for 15 minutes. At this time the staff debriefed the morning session and took a break themselves. Other staff were on duty in the break time and they interacted with students. Although they facilitated some interaction between students not a great deal happened.

Back in the classroom Simon was assisted out of the standing frame and was asked to go to his seat for lunch. The special education assistant sat with him and ran through a visual sequencing book that pictured the steps he needed to go through to prepare for and then eat his lunch. To do this he sat with two other students with whom he seemed to have a good relationship. Beyond opening packages or heating food, Simon ate and drank independently with the aid of a cup and straw, and a plate with a shaped lip that helped him to load a spoon. He also used the 'Big Mac' to request more food or to ask if he could move on to the next food item. After eating, Simon and Selena went to the toilet again and were taken outside for a further 35-minute break while staff debriefed and ate their own lunch.

After the lunch break, swimming with the physiotherapist took place. The students were assisted to walk to the pool, where they changed into swimwear and waited for their one-to-one time with the physiotherapist in the pool. After the session the reverse sequence was completed and students returned to the classroom for a further one-to-one session, this time with the special education assistant on the computer, during which Simon used a 'Jelly Switch'. Different students used different software according to their information processing skills.

Once all of the other students returned from swimming they sat in a circle, said goodbye, returned to their wheelchairs and moved to the common area to wait for the taxi van.

Case studies 2, 3 and 4: Attached units

The other case study sites with on-site therapy were all units attached to regular primary, intermediate and secondary schools. Each regular school was in an urban area. For the sake of clarity, these settings are referred to as 'units', to reflect their physical and funding status. However, it should be noted that in some schools, units were referred to by other terms, such as Learning Support Centres, to reflect their primary role as a support centre for student learning.

In two of the units involved in this study, students were withdrawn from classes to a therapy area as and when required. The other unit used an approach emphasising the maintenance and development of gross and fine motor skills in the context of functional activity, although therapy occurred on the same withdrawal basis as the other settings.

Students in each of these units had a range of needs, but by and large were all ORRS funded at the high or very high needs levels. A number of the students in each setting would be described as having multiple needs, while others spent varying lengths of time in regular classes, returning to the unit only occasionally for therapy or life skills-type programmes.

Staffing in these units was very similar in make-up to that in the self-contained school, although one unit used staff who were trained to teach and provide occupational and physical therapy. In addition, one unit employed special education assistants and a therapy assistant. Each of these sites received the transitional staffing allocation for therapists in schools and units for students with physical disabilities.

Schools hosting two of the three units were ORRS specialist service providers and the remaining unit received resourcing from the Ministry of Education, Special Education (GSE), for the support of their students. Therapy staff in this last unit were spread between services for students on the roll of the unit and students in other schools on the contract for provision of therapy services for students with moderate disabilities (the moderate contract) (0.6/0.4 split).

Focus students: Penny and Paul

The attached unit from which Penny and Paul received therapy and education services used an integrated approach to therapy and education. The unit was part of a regular primary school and was established as a result of parental advocacy for this approach to intervention. At the time of the case study there was a waiting list for the 22 places on the roll. All of these students were resourced at high or very high needs levels through ORRS. In addition, as a unit for students with physical disabilities, the unit attracted transitional funding for the employment of therapists. Staffing included three full-time teacher positions, two-and-a-half therapy positions and 20 part- and full-time teacher aides.

Penny

Penny lived at home with her mother. Although her home was some distance from the school, the programme offered meant that Penny's mother felt it was the best option for her. Penny had previously participated in an early intervention programme but her mother felt that this was insufficient, so when the approach to intervention used in the school was offered at an early childhood level she took it and followed this with enrolment in the primary school programme. As she said:

> *I just felt that Penny needed more. She wasn't getting anything out of the groups and [name of programme] seemed to be where she just thrived. Even though she fought it, she just loved it.*

Penny's mother was aware that attendance at a school so far from home limited the opportunities available for social interaction. She, too, would have liked the chance to interact more with other parents of children with disabilities at the school. To try to alleviate some of these difficulties, Penny's mother involved them regularly in activities initiated by local church groups and by CCS.

Penny had multiple needs and used a wheelchair independently for mobility. The house had been modified to meet her needs. In the bathroom, a wet area shower had been installed and there was a lift to allow access to the house. Some other equipment funded by Health was also used at home. Penny had a carer in the evenings to help at meal and bath times and in the weekends to provide her mother with some respite.

Penny's needs included those associated with young people with autism. This meant that because of her susceptibility to noise, the number of options for participation was limited. As an example, static in the speakers in the assembly hall meant that she could not attend assembly. Her mother felt that the school sometimes lacked an awareness of Penny's needs in this respect and that her daughter should have greater access to help and support.

Penny spent only about one hour per day in the unit, at which time she participated in the integrated therapy programme used in the school. She began at the school in a full-time placement in the unit but was seen to need greater academic challenges than were available to her there. Penny's mother said:

> *She started off in the unit and then, you know, they sort of gradually realised that she needed more. She actually reverted back because she was in the unit, of needing to be fed, drooling, dribbling which*

> *she was copying off other children. And, not actually talking, she was imitating the children. And they said, you know, it's not good for her. So, put her in the mainstream and she hasn't looked back.*

Paul

Paul also lived at home with his family some distance from school. Paul said he would like to be closer to school. Paul's parents also felt isolated by distance and had tried to alleviate this in numbers of ways. For example, his mother made a point of collecting him from school at least once a week, although this was difficult since their other child attended school closer to home and was too young to come home alone. At other times Paul was transported to and from school by taxi. Paul was collected from home at 8:00am and returned home at about 3:40pm.

Paul's mother discussed the difficulties she had with having children at different schools on different sides of the city in which they lived, and in particular, about the demands on her as the parent of a child with a disability:

> *It's the tripping to and from. I work and my husband's a traveller. He's out of town every two weeks for a full week, so it's the to-ing and fro-ing. Children in two different schools on different sides of the city, to get them both together and then to get to an appointment is a reasonable marathon. It ends up being the parents that are doing the chasing around which sort of – as parents you are happy to bring your child up, it doesn't matter what the disabilities are. I feel if a few things were streamlined it would make, it would have an impact on the child because the child is the one being carried around in a vehicle when they could be at home unwinding from the school day.*

Paul's parents were very aware of the potential for strain from Paul having to travel so far from home to get to school but made their decision on the basis of their son's progress and from the pleasure he got from participation in this programme before starting school. His mother said:

> *He did flourish in that time. Initially he was very stubborn and didn't want to do what [his therapist] asked, but it came around and I could see that every time we went, it got to the stage where we'd actually turn in the drive three or four times a week and he was squealing with delight because he could do these things … and he roared into school. I was gobsmacked with what he wanted to be involved in. He was always first to put up his hand for news and all that sort of thing.*

A further factor in their decision about where Paul should go to school came from the visits Paul's parents made to local schools:

> *… all my local schools. Responses were very mixed as you can imagine, from reasonably welcoming, to this is a very small school and the cost of putting in a ramp for your child if he went to this school would be three or four hundred dollars more than we've got here.*

Paul's schooling had been disrupted over the past two years as a result of serious illness. Paul continued with treatment and had to deal with the associated side-effects. His mother said:

> *The school was brilliant in that time when he was going for treatment and the support from the other parents. I mean it was probably one of the biggest things for us as a family being involved in a group of people that have got a similar situation happening. He had really good wee friendships and little notes coming home and school did everything to keep his morale up and even to the stage where the kids all have their news in the morning and they would record it on a tape and the teacher aide would bring it into the hospital in the afternoon so he could catch up on what was happening with everyone. That made a big difference.*

Paul was resourced through ORRS at the very high needs level. Even though this school was a specialist service provider, it used an 'unders and overs' method of apportioning,[25] as did GSE. As a result, Paul had 30 hours a week of aide support. His mother reported that she felt his needs were:

> *… very very high because he has a lack of mobility, he has toileting issues, he has visual impairment, he needs communication advice and help and assistance, total assistance at all times.*

While happy with the support Paul received at school, his mother felt that he needed more speech-language support for his communication. She said that she understood that this was difficult to provide in school and as a result, and with the assistance of an outside agency, the family was receiving private speech-language input at home.

Focus students: Ian and Isobel

Ian and Isobel attended an intermediate school with an attached unit for students with physical disabilities. There were 31 students on the roll of the unit, although a number of these students were placed in regular classes. There are one-and-a-half occupational therapy positions, a part-time speech-language therapy position and the equivalent of a full-time physiotherapist. The school employed a therapy assistant to support therapists' work. In addition, there were three teachers and a number of aides and special education assistants to support students in unit and regular classes.

Ian

Ian was 11 years old and a student in Year 7 at the time of the study. He had needs associated with cerebral palsy (spastic diplegia) as a result of a premature birth. He lived with his parents and younger sister. Ian had recently had surgery and was receiving post-operative support from health agencies. He received ORRS resourcing at the high needs level and also got Ministry of Education funding for transport to and from school.

Although he was on the roll of the attached unit, Ian was fully integrated into a regular class. In class he was supported by a teacher's aide at times and received occupational therapy and physiotherapy in the unit. It is somewhat unclear what services Ian received prior to moving to intermediate. The school received little information from the contributing school even though they had convened a transition planning meeting prior to his enrolment.

Although he missed his friends who had gone to other intermediate schools, Ian was very happy with his new school. In relation to friends he said:

> *I consider I had good friends at [the other school] but I don't like to play with them a lot. I am not a person that likes to play. I sort of like to hang around, maybe talk to a few people and sort of watch other people do whatever they want to.*

In particular Ian liked the fact that he was not the only student in the school with a physical disability:

> *… at the other school I was the only one with a walker, even though everything was accessible for me, but I was the only one with wheelchairs or walkers or anything and I know I won't be looked at like I am completely from, from planet Mars or something like that you know.*

He said that having other students in wheelchairs at the new school meant that there would be options for him. At his other school, being the only one meant that when the class did something he could not do, he was simply left alone.

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[25] Funding for ORRS-verified students is managed at the local level by a range of specialist service providers. Each provider pools all the funds for the students and allocates according to changing student needs.

Ian usually arrived at school by 8:30am for class to begin at 8.50. Generally the taxi-driver assisted Ian with the 'K-walker' he brought from home. He was independently mobile in his wheelchair.

Ian's classroom was small and there were approximately 25 other students in the room. The desks were grouped in small pods and Ian sat with his peers near the front of the room. There were three other students with disabilities in the room and much of the aide's time was taken with them. Her responsibilities to Ian seemed to relate to the organisation of equipment and providing limited physical support. The aide also checked the home–school notebook each morning for news from home. Ian was clear that he did not like being 'helped' but that it was a fact of life: 'I want to do it myself, like everybody else, but I can't. I physically can't'.

Ian did not use his wheelchair in the classroom. At the door, he got up and cruised, using the furniture, to his desk. Since having surgery Ian had not used the K-walker much and his current focus was on building the stamina necessary to use that device for the majority of his mobility needs.

The classroom teacher was flexible in her approach. Students sat where they liked, and since it was early in the year, much of her time involved assessing students' strengths and needs and on getting the programme up and running. On the first day of observation it was clear that Ian was a full and contributing member of the class. He participated as others did and appeared to be treated in much the same way as any student in the room. Ian also moved about the room at times of transition, and while somewhat reticent about engaging with other students, he was as much a participant in activities as they were.

The days of observation were somewhat out of the ordinary in that a number of assessments took place and Ian spent a good deal of time away from his class at physiotherapy. On one day Ian met with school and health physiotherapists for a 'hand-over', and he attended a wheelchair group with some other students where they learned about wheelchair maintenance and care. In total, and apart from returning for reading just before lunch, Ian was away from his room from just before morning break till approximately 2:00pm. While these events were more a product of the 'settling in' period at the beginning of the school year, Ian's teacher was concerned that he had missed the assessment work his peers completed. Although it did not bother him that he had to have therapy during the day, Ian felt that it was something completely separate from his school work and that it should come second to academic learning. He said that he thought that it was better 'to sit in a wheelchair and know your maths than to walk'. He was concerned that frequent absence from the class would also mean that he missed important work. He said that his father had similar concerns.

At morning tea break Ian joined a group of students from the unit. He later said that he felt safer with these students because out in the play area he could be hit with balls or knocked over by other students. He said he also preferred to stay close to the buildings as he was often late for class if he had to travel far. He reported that at his previous school he had been bullied on numbers of occasions: 'I got dragged around the classroom and kicked up the field and all sorts of things like that'. He noted that he thought it was very important for other students to know something about disability:

> *They need to know more, even if I am not in their classroom. They need to know what, like not in their faces, just a bit like, disabilities, or anything, but in the fact that I can't just walk through anything.*

At the end of interval, Ian returned to his class but was immediately removed by the physiotherapist, who informed the teacher that this period was a scheduled physiotherapy time. The teacher did not know this and, as noted already, expressed concern about Ian missing an assessment. Ian participated actively in the physiotherapy session, which focused on home-based physiotherapy activities. At the end of this session Ian was due to go swimming with his class, but because the pool was inaccessible he remained in the unit until it was time to return to his class for reading until lunchtime, which he spent in the library.

After lunch, Ian went with the physiotherapist to attend the wheelchair group. This was a joint occupational therapy–physiotherapy group for students who were active wheelchair users. The goals for the group included safety and awareness, problem-solving and social skills. Ian returned to his class at 2.15 to be told to read silently until the class returned from assembly. When the class returned, he rejoined his group from the morning and continued work on a shared project. At 2.40 Ian had to leave to wait for his taxi home.

On the second day of observation Ian was late to school because of the taxi. He went straight to the therapy room. His class was completing a further assessment task at this time. Ian was receiving intensive physiotherapy intervention as a result of the recent surgery, and two therapists worked with him for up to five hours per week. They had also visited his class to make recommendations to the teacher as to how to accommodate his physical and learning needs in the classroom.

After the morning break, which Ian spent with students in the unit, he went to music with his class. Ian appeared to enjoy this class: He participated actively and took something of a leadership role in one activity. He was learning to play the cello outside of school and this session was clearly an area of strength for him.

Isobel

Isobel was 12 years old at the time of the study and in her second year at the unit. At that stage it looked likely she would remain in the unit for a third year also. Before coming to intermediate, Isobel attended her local primary school. Her parents sent her out-of-area to the intermediate because they felt that their daughter was missing out on the services she needed by being in a regular school. They had ongoing concerns that there were services available in the community that could be beneficial to their daughter but that they had been unable to access them through a lack of knowledge, or the 'right' professional contacts. For them, ensuring the availability of resources and supports has been an experience fraught with difficulties. They said:

> *… all through the past you are always concerned whether you are going to get it or not, because you always fear, like we said, you always have to fight for everything all the time or you are not told and you have to find out for yourself … it is demoralising. I don't know, it is kind of a feeling like, you know, I find that we are OK with it, because we have a sense of ourselves and we are strong people you know, who can put our case across. But, sometimes you worry in particular about people that can't and other people you know.*

While they felt somewhat distanced from the school, they were very happy with her current placement as they felt that her needs were being well addressed without them having to constantly monitor what was happening.

Isobel had a right-sided hemiplegia as a result of a stroke and in the last year she had begun having seizures, for which she was taking medication. In Year 7 Isobel was integrated into a regular class, but because of her seizures and the potential for them to recur it was decided to place her full-time in the unit. Her parents had also become concerned that she was beginning to struggle academically and that it might be better to place her with a peer group in the unit and to focus on life skills. Isobel received resourcing through ORRS at the high needs level. She received occupational therapy, physiotherapy and speech-language therapy.

Isobel was in one of the two classes based in the unit. Her class was staffed by a teacher, teacher aide, and a special education assistant. However, Isobel was out of this class for a good deal of her time, when she went to Ian's class for reading, to the other unit class for maths or across the hall for therapy.

Isobel had one hour of individual speech-language therapy per week, and another three 'oral–motor' group sessions with four other students. These sessions were taken once per week by the speech-language therapist and on the other two occasions by the therapy assistant. She also attended a 'community integration' occupational therapy group on a Monday from 10.40 till lunchtime at 12.30 with a group of other students, and she had one other joint occupational therapy and physiotherapy session per week. In addition to this, Isobel had a 'hydrotherapy' session once a week, and twice a week she attended a group for children who have hemiplegia. As her teacher noted, 'she is away from my care for quite a lot of her time'. Once a week Isobel went to Riding for the Disabled during school time. She was an accomplished rider and really enjoyed this activity. Her mother said that this was a special time for her. Her family felt very strongly that it was important for her to do this.

Two of the therapy sessions that Isobel and her classmates attended were organised so that teachers could have release time. At these times teachers prepared and organised for new work. As Isobel's teacher said:

> *… unlike other classroom teachers, we can't set work for children to do and leave them to do it while we mark work and prepare. We can't do any of the administrative work at that time, so, it's either after school, before school, or during either of those two periods.*

In class Isobel was supported by the teacher, special education assistant and by an aide at various times during the day. Isobel was placed in a class with students who were described as somewhat challenging. She was a very quiet student and on occasions it was clear that the behaviours of others were quite distressing to her. In the classroom Isobel did not initiate contact with others beyond attempting to make eye contact with adults. She tended to wait to be told what to do.

In her regular class, Isobel sat at the back with three other students from the unit. The teacher aide worked with these students as a group. As was the case in her unit class, Isobel waited to be told what to do. The class teacher also interacted with these students to talk about their work and to hear them read. She felt that Isobel was really only 'finding her feet' at the time of observation.

Isobel used an Alphasmart for written communication so carried this between classes.

Focus students: Harry and Heather

Heather

Heather, a student with cerebral palsy, was 14 and in Year 10 at secondary school at the time of the study. She lived in her school zone with her mother and brother. Their house had incomplete renovations in the bathroom area, and the family was waiting for funding to be approved for a bath hoist. A caregiver assisted with bathing in the mornings, but at other times the family got by on their own. Heather's mother had back problems and lifting at home was an issue of concern. Heather's 19-year-old brother helped with lifting, but Heather's mother felt increasingly uncomfortable with this level of personal support as Heather grew into adolescence. Heather's brother said:

> *I do all the lifting at home to save Mum's back. Mum does the paper work [toileting]. I'd like to see as a good goal for Heather teaching herself to toilet herself. Maybe the physiotherapist could help with that in terms of mobility. I have taught her to move from chair to bed. She's not keen, but she can do it. Sometimes it's easier and quicker to just lift her but it's better for her to do it herself. She doesn't like it. But I'd like to move out next year and I'd like to know Mum can manage on her own with Heather in terms of lifting. It's not good for her back.*

Heather had resourcing under ORRS at the high needs level. She previously attended her local primary school, which had a number of itinerant staff attached to it for supporting students with a range of needs. At primary school, and with the support of a teacher aide, she received physiotherapy and occupational therapy input, but the therapy programmes were provided by teacher aides.

During her early years Heather also participated in conductive education, and she had surgery that her mother said left her unable to stand unsupported. She remained adamant that this surgery had a significant negative effect on her daughter's quality of life and long-term options. Also, access to resources and supports had always been a problem.

In her first year at secondary school, Heather spent much of her time in the attached unit. Her timetable included a combination of mainstream education in subject classes alongside her same-age peers. In the regular part of the school, Heather participated with her form class in social studies, practical maths, science, phys-ed, animal studies and drama. In the unit, Heather took an independent living class, life skills, cooking, literacy and craft classes. Twice during the week she also went swimming, and she had one one-to-one physiotherapy session.

The remainder of Heather's therapy was provided in a variety of ways. Occupational therapy was sometimes provided in the regular classroom, when the therapist observed and assisted with seating and writing. The occupational therapist also ran the life skills and independent living class that Heather took with other disabled peers. During these times Heather was also supported in working towards her own goal of becoming more independent and mobile in the community using her newly acquired power chair. Heather had asked to be able to go outside with her friends at lunchtime, and this request highlighted some problems with mobility and independence. An Individual Education Programme goal was drawn up to support her to do this independently using a power chair. Heather had achieved this goal very quickly and the goal had recently been extended to include independent mobility in a range of community environments. On the day of the observation they were off to the Four Square shop to buy milk.

Heather's weekly physiotherapy took place in the unit. The area designated for physiotherapy was the corner of a room used for group and one-to-one teaching, screened off with a curtain and surrounded by standing frames and wheelchairs. The area was described as 'totally inadequate' by the physiotherapist, who envied the specially designated room of a colleague working in a similar school, which had specialist service provider status.

Heather's future and employment prospects were a source of great concern for her mother.

Harry

Harry was a 16-year-old in Year 12. At the time data for this study were collected he was at home recovering from surgery due to spinal problems associated with spina bifida, and he had missed three months of school.

His primary education was in a small rural school, but his family moved with him to the city so that he could attend a school understood to offer good curriculum options and access to therapy. His parents also felt that city living would offer him more opportunities as a young adult, and they had bought a house which they were doing up for him.

Harry's programme at school was academic, and he was in regular classes for the whole day. His subjects included English, maths, tourism, computing, and two study lines in which he worked on homework and caught up on class work. Teacher aide support was available during the study-line periods if he needed it. He also had one senior module and could choose from a list of subjects, including theatre studies, craft, remedial maths and English. Teachers had selected these for him but he did not know what these choices were. He knew that if he did not like an option he could change it. He had seven hours of teacher aide support each week. Some of this was used during the study lines, and some in the classroom. Harry described teacher aide support as 'Help with cutting out, writing stuff neatly, understanding if I look confused, then they know. I'll ask the teacher for help if I need it'. He valued the teacher aide support and the support he received from staff in the unit:

> *Teacher aides should be given more money, and schools need more money for equipment. Schools are under-rated, especially the unit [staff]. Without them I'd be a mess. It'd be hell.*

He spent break times and lunchtimes in the unit. Harry attended the unit three times a week for occupational therapy and physiotherapy. Post-surgery breaks from school were not uncommon for Harry, and had had some impact on his learning. During the observations for this project, one of Harry's regular teachers decided, for example, that Harry had missed too much of the Year 11 curriculum in her subject and would need to repeat the course.

Summary: Description of case studies in schools with on-site therapies

The students described in these case studies were all resourced through ORRS at high or very high needs levels. Simon and Selena spent their days in a self-contained school, during which they participated in a number of activities in which therapy and educational goals had been integrated. These activities included social/communicative activities, movement/drama, music, self-care, computer activities and swimming.

Ian, Harry, Paul, and Penny spent significant periods of the day in regular classes, where they participated with their peers. Although observations were taken early in the school year and students were still 'settling in', Ian's teacher was worried about the amount of time he was withdrawn for therapy and Harry had yet to attend school that year because he was recovering from surgery. Heather spent similar amounts of time in unit-based activities and in regular classes, and Isobel spent most of her days in the unit.

Most parents expressed satisfaction with the therapeutic services their children received despite shortages of therapists at the primary school. Heather's mother felt Heather needed more therapy at her school.

With the exception of Harry and Heather, all of these students lived out of their school zones and all were ferried to and from school by taxi. In most cases going to and from school by taxi meant that the day was shortened, and in Ian and Isobel's cases it seemed that lateness in arriving was a common occurrence. A number of the parents interviewed also expressed concern that living so far from school was very isolating for their children and for themselves.

Section 2.4: Models of Therapy in Schools with On-site Therapy

This section describes the approach to therapy provision in the self-contained school, and in the three schools with attached units. Discussion of the models used in these settings centres on the indicators of integrated effective practice described in the scoping project for this research (McDonald et al., 2001).

Organisational matters

Principals as leaders

The principals of both the self-contained school and the primary school hosting a unit felt that the leadership role was critical to the success of any programme of intervention. They also felt that leadership had to be accompanied by professional development. Given that both settings provided an integrated therapy and education service, there was a clear feeling that a strong philosophical basis and support from the top for staff to develop their expertise were also essential components in the development of that model. As the principal of the self-contained school said, ‘It starts and stops with the principal through the senior staff. Without the principal driving things, nothing will change’.

More pragmatically, the primary school principal spoke of the need for:

- the delegation of areas of responsibility to a management team
- sufficient release time for management personnel to do their jobs
- regular meetings and engagement with the principal of the wider school
- a clear focus on ensuring that the regular and special education staff were unified and cohesive
- an ongoing focus school-wide on the integration of therapy and education in all environments in which students participate.

In support of this position, two other interview participants added that when staff had positive attitudes about the work they did, they were more likely to be effective in their practice. To this end, shared planning, organisation and a focus on improvement were seen to help to keep staff engaged. One of the therapists said that such a focus ensured that staff had regular access to professional development within and outside the school, and within and outside their own discipline.

The intermediate school principal added that policy to support the special education unit located in his school was an essential element in the development of the work of the unit. He said that within his school this policy ensured that, to the greatest extent possible, unit staff and students were fully involved in the life of the school. To enable policy to be ‘living’, however, annual reviews were necessary, as were regular visits to and reports from unit staff to the school’s board of trustees. As he noted, board members were ‘lay people’ and needed to be shown the work of the unit and brought up to date with changes to education practice. Without that input, this principal suggested that it would be difficult to maintain the financial and organisational support necessary from the board of trustees.

The secondary school principal made the point that the philosophy guiding supports for students with physical disabilities was the same as for any other student in the school:

> *… we want to make certain that they're intellectually stimulated, that they have access to whatever subjects they choose and that when they leave and go on to tertiary or to employment that they'll – I mean it's exactly the same for all the other students in the school – that they get the best out of being here and feel confident and ready to go off on the next stage of their training or education.*

The principal saw it as her role to:

> *… hold to the philosophy and to make certain that what we agree on we do because there's such a long history [in the school] I think it would be easy to deviate from our original view about inclusion and you know, people come and go. For years and years my role has been in a sense to protect what we've got.*

Each of the case study schools identified a staff member who had overall responsibility for the development, management and co-ordination of services, as follows.

- The self-contained school's deputy principal acted as service co-ordinator in the school. She described her primary focus as, through the Individual Education Programme (IEP), to link the developmental programme necessary for many of her students with the national curriculum in order that they could 'make the million and one steps these children need in order to get there'. To this end she managed the use of Ongoing and Reviewable Resourcing Schemes (ORRS) resourcing and she co-ordinated therapy and education services. Within these sets of responsibilities she also had a curriculum responsibility and deployed ancillary staff around the school.
- The deputy principal of the primary school hosting an attached unit was also the manager of the unit. She was a regular class teacher but also facilitated the unit management committee. This group had responsibility for the approval of spending, addressing parents' concerns, employment and deployment of ancillary staff, and the functioning of the team.
- A senior teacher position in the intermediate unit was given over to the management of staff in the unit along with the relationships with the main school. A staff member described this person as 'setting the standard … laying out the approaches and guidelines'. She also had a teaching role in technology, and since she had completed a 'module' on counselling while on a course for special education teachers, she ran a group and saw students individually when they were experiencing difficulties. Her areas of responsibility included monitoring the progress of all of the students on the roll. She also organised resources and managed the work of the ancillary staff. She saw a significant part of her roll as maintaining harmony within the team.
- A staff member with senior management responsibilities was in charge of the management and organisation of the secondary school unit. She was responsible for liaison with outside agencies, the organisation of responsibilities of resource teachers, and liaison and support of regular teachers who had students with disabilities in their classes.

In each setting there were a number of committees and groups overseeing various aspects of the programme. At one of the schools, therapists met once a week to review their work with students and to collectively problem-solve. In addition, all of the staff in this unit (with the exception of teacher aides) met daily after school for 15 minutes to review the day's work. Regular classroom teachers with students with physical disabilities in their classes were also invited to attend these meetings and unit staff attended full staff meetings when appropriate. Although sometimes onerous, several staff members at this school commented on the value of regular interaction. One said the meetings helped because:

> *… listening to their points of view and I mean I do a lot of that at the moment because I am learning how to do different things myself. And yeah, learning from their experiences …*

The principal of this school added that he met with the unit director weekly and that an advisory group met once a term to review the work of the unit. He said:

> *They do a great job. You know exactly what's happening because they have weekly meetings. They have IEPs at regular intervals, you get all the feedback from them.*

A regular classroom teacher said about the decision-making process within this structure:

> *Well, they are variously decided, depending on whether they require extra funding and that sort of thing. In the case of funding, then some of the decisions are made by little groups, or they are made directly by the director of the unit. Some decisions are made or arrived at, during the conference of the IEP meeting.*

Flexibility of resourcing

Regarding flexibility of programme development and provision, the principal of the self-contained school said that Special Education 2000 (SE2000) had been 'wonderful' for special schools, in that increased levels of resourcing had enabled schools like his to employ therapists and others directly. He said that the bulk funding approach of SE2000 had enabled him to address local needs. Similarly, the deputy principal noted that the flexibility of staffing under SE2000 had made a huge difference to the way such schools worked. Despite this flexibility, the principal maintained that they continued to experience problems when therapists moved 'up the scale' and sometimes became too expensive for them to afford. In relation to resourcing, one of the therapists also noted that it was difficult to work within allowed resourcing to maintain and develop resources. This person felt that the situation could easily be alleviated by a therapy assistant position.

Other principals did not agree with the views regarding SE2000 that were expressed by the principal and deputy principal of the self-contained school. Two felt that current resourcing, attached as it was to individual students, was an inappropriate way to fund their facilities. They said that it created uncertainty from one year to the next because income could vary according to the needs and numbers of students. One of these principals also maintained that his board of trustees 'provided a large amount of additional resources'. The other noted the anomaly in resourcing between students receiving money through ORRS and one student who was funded at a much higher level by ACC as a result of the student having acquired a disability as a result of an accident.

The previous point notwithstanding, one of these principals noted that changes brought about with SE2000 had enabled many more students to attend their community schools than had previously been possible under the old system. He also noted that the bulk-funded nature of SE2000 made it possible to hire teachers, therapists and aides over and above Ministry allocations, such as the 0.1 and 0.2 full-time equivalent (FTTE) teachers allocated through ORRS, and therapists provided under transitional funding arrangements.

One principal with an attached unit said that while resourcing for students through ORRS might be sufficient, students identified for resources under the contract for provision of therapy services for students with moderate physical disabilities (the moderate contract) were ill-served:

> *We've got the contract with […] to bring therapy to the moderate needs students in … and I suppose one thing it's taught me is this school is very well served. We've had access to therapists and resources that other schools don't have … and I don't know enough about occupational and physiotherapy to know what is the optimal use and what is optimal contact but it seems to me that one*

> *visit a term and then hand over the programme to someone inside the school is perhaps not the best way to go about it. We need trained people.*

Control and local development of services

While SE2000 had made it possible for schools to develop their own services according to local needs, one principal felt very isolated from the services that had been available to schools prior to Tomorrow's Schools. He felt that services could easily become inequitable, and that in respect of difficult situations and students, schools are very much on their own.

Inter-agency and professional collaboration

Therapists, in particular, seemed to have a great deal to do with agencies both inside and outside schools. Two of these people cited the following as the individuals and agencies they regularly deal with:

- other education-based therapists, such as speech-language therapists
- teachers, aides and special education assistants
- families
- community services providing respite care
- surgeons
- orthotic services
- dieticians
- community occupational therapists for the likes of housing alterations and wheelchair support
- Ministry of Education, Special Education, for assistive equipment
- physiotherapists post-surgery
- transport providers
- other schools where therapists also worked on the moderate contract.

One student's parents said that even though there had been changes towards a more 'seamless service', there was considerable frustration in having to deal with a large number of providers themselves. They said:

> *… all these different agencies, they all have this sort of path going out and saying well, it is all client centred. Well it's not! It is coming, it is coming from individual agencies according to their abilities, philosophies and whatever, and their competence and going to the individual. It is not coming back the other way in terms of what does the individual require. All these people are trying to do it their own way instead of putting it back to the individual who is the recipient of the service.*

One therapist recognised these parents' issues by noting the difficulties in trying to work collaboratively given the tension between the health model that many therapists worked within and an educational model. She described this issue in relation to a student who had just had surgery:

> *… because he is recovering from surgery we need to apply those principles of health rehab, so I think we are applying a mix at the moment and you know, as his surgery needs lessen, obviously more of the school needs will come to the front. We try very hard to link in with the school.*

This person felt that collaboration had to go further than therapy, but that:

> *There is a lot of liaising. I personally have strong involvement with our school production and I work in very closely with a lot of staff on that and I think it's important for relationships. We have morning teas and lunches up in the staff room; we have staff dinners that we always make sure we attend.*

An occupational therapist discussed the importance of in-service professional development as a tool for establishing collaborative relationships. She described her relationship with a food technology teacher as having arisen from professional development, and how this had meant that this area of the school was now equipped with a range of tools for use by individuals with disabilities. She also described the increase in this teacher's skills for supporting students with a range of needs.

A therapist providing support for the student who had just had surgery noted that, in her experience, the relationship between Health and Education was relatively new. She said:

> *We basically didn't have any before [liaison between Health and Education] … I think that is our weakest link … It is something we're trying to develop, it's not something we're good at yet. As part of our pre-admission process that we are working on, one of the aspects is to be contacting physiotherapists, occupational therapists and the teachers so that we can try and keep that smooth flow through.*

This person noted also that liaison and information were until recently a responsibility that parents had to pick up, and that only 'proactive' therapists, alerted by families, were likely to establish any collaborative relationship with outside agencies at all.

Team functioning

Families as essential members

All of the professionals interviewed for this study were clear that the educational needs of the students, as identified by their families, had to drive their work. One therapist in particular talked about 'unit policy, to try and take as much of the load off the parents as possible'. Without a focus on the needs of families, one therapist noted, the team could not function effectively. As was noted by one unit manager:

> *It could be summed up that parents come first really. Parents are right even if we might not think they are. I say to parents when they first come here that they must express what they want for their children … we have their children for two years, three at the most. They have them for a lifetime.*

A teacher described families' input as coming from the daily 'contact book' and from the focus of the Individual Education Programme (IEP). A therapist in the same setting saw this contact as 'really neat', and that it was important for school-based staff to know what parents wanted before they put their own opinion or goals forward. This therapist added, however, that she felt that 'the students could maybe be consulted a little bit more about what they want'. Another therapist talked about the ways in which school staff had been assigned key worker roles for individual students, and that along with 'keeping track of things' the key worker had been a positive contact point for families.

As in the case of the school described previously, daily notebooks went between home and the self-contained school and each of the units. In Harry's case, however, this did not happen because he was fully mainstreamed, going to the unit only for therapy. Heather, who attended the same school as Harry, was in Year 10 but spent her time in both the regular school and the attached unit. She carried a notebook with her between home and school daily. Most frequently the notebook was read and filled in at school by one of the teacher aides. In one setting this situation was seen as somewhat problematic in that aides were often untrained, and as a result would not know how to deal with issues of confidentiality. As the senior staff member noted, 'parents communicating information to the wrong people … like the teacher aide who then gets hold of a whole lot of information that they shouldn't get'.

Teachers at the self-contained school also did home visits, and therapists in each of the settings visited homes regularly and as necessary. In a number of instances therapists would also attend health and medical meetings and appointments with families if requested.

One unit manager described the liaison between home and school as crucial:

> *If the family doesn't have a realistic view or set of goals for the students by the time they get to [name of school] it isn't just a matter of having difficulties with the system. I think it is often a matter of having difficulties accepting things about their children's differences.*

Not all parents wanted a great deal of information from or interaction with the school, however. Harry's parents said that they were by and large happy with what the school provided, that they could get information if they wanted it, but that in reality, as his mother said, 'I see my role as just being a parent'. In addition, and since their son was at secondary school and proceeding well with a regular education, they felt that it was his responsibility to monitor his own progress and to involve them when and if he wanted.

In the self-contained school, teachers and therapists met monthly to discuss the progress of individual students. At these times parents were invited to phone in or to attend meetings if they had any concerns. The deputy-principal saw this access as important for parents, especially since 'they can access the therapists here, in an environment where they feel comfortable, which is not what they always feel at an outside office or even a hospital'.

Simon's mother felt very much like a member of the team. As the principal said, Simon had made the progress he had because 'the school's doing what Mum wants and Mum's doing what the school wants. There's that partnership'. Simon's mother said:

> *At home, I do what they tell me … I have to support them, for his good and for my good … I've just got to carry on with what they say … it doesn't feel like too much [and] always they say it to you nicely, you don't ever get offended.*

Isobel's parents saw their role as team members differently to Simon's mother. They felt that since Isobel had gone to the unit she could be a 'kid' at home:

> *It has taken the pressure off us so that we don't feel so guilty about maybe not giving her physiotherapy or not doing her speech all the time and things like that, and she can come home and relax and be a normal kid.*

In some cases, however, families' priorities were seen to lead to compromises. As one therapist said:

> *Prioritising academic and therapy needs, and you know, there are times when I know the classroom teachers feel like the children spend more time in therapy than they do in the classroom and sometimes I think they are probably quite right. But, other times I feel like the child needs this and*

> *again, a lot of that is dictated by the parents. We have some parents that have said, I don't really, I am not worried about the academic performance. I am more worried about this child learning or maintaining their function or learning to do this.*

In another case parents were not so sure that their views were important. As one father noted:

> *I have a feeling that you've really got to thump the table at some of those meetings to get through. Some of those problems you're talking about are quite important really … The problems turn up again next time don't they?*

IEP: The focus of contact and planning

School and home communication appeared to occur across all settings more or less regularly, with the annual or biannual Individual Education Programme (IEP) process being the most common communication tool. There was some variation in the way in which schools operated their systems for IEPs, but most often schools reviewed progress towards goals on a regular basis and in some cases invited parental input at reviews. At the time new IEPs were set, therapists and teachers normally prepared by reviewing their own goals, determining where they thought a student could go next, and writing goals for review at the IEP meeting. Where students spent all or part of their time in regular classrooms, there seemed to be little input from those teachers to IEPs, although such involvement was seen by one teacher as 'just great and not at all time-consuming'. Another teacher in a different school mentioned that she had attended only one IEP meeting in her time at that school. Only one of the case study sites asked parents to engage in a review process such as school staff did. Students were not generally involved in the review or setting of their IEPs.

The IEP was seen as an important document for a number of reasons. Firstly, therapists saw it as a useful tool for helping to understand some of the differences between health-based and education-based philosophies. As one therapist noted, the IEP helped her to understand the needs and demands of the classroom environment on students. She also described the IEP as underpinning the concept of the key worker as someone who 'has that vision of where the child is going'. A further and important element of the IEP was the extent to which the document could help to avoid fragmentation of services to individual students. Although this person said that there was still a good deal of fragmentation in her setting, the notion of the 'common goal' was helping to break it down.

A principal noted the value of IEPs for her staff:

> *… I understand because we have a lot, with 21 ORRS-funded kids in the school, that's a lot of meetings, but the benefit of there being a shared pathway, and everyone's contributed to it, and you hear what the family has to say, you hear what the student has to say and then choose a direction to be working towards, it's just huge. So, the time to do that is really important and I think we're probably short on that one. I think we just have to keep trying to make it happen because it's incredibly important.*

Professional development

The key people in each setting mentioned the importance of professional development to their work. However, such support was seen as scarce. For teacher aides, most professional development was on-the-job; for therapists, the supervision process and their national associations provided some support, although limited.

In one school, a teacher aide discussed on-the-job training from teachers as the most professional development she got. However, all the aides in this school also met with the unit manager twice weekly while the rest of the school was at assembly. At these times professional development appeared to be a priority. As this aide said, ‘We talk about the curriculum that we need to know … other trainings we need and if there are courses we want to do’.

In one school, therapists participated in the same appraisal process as teaching staff but, as was reported by one therapist, this did not necessarily relate to therapy work. Teachers in attached units received the same professional development as their colleagues in regular settings, but there was seen to be little available in relation to the education of students with disabilities. One teacher noted that she had completed two postgraduate university papers in ‘special education needs’. She saw these as ‘brilliant … just for opening your eyes as to how you can do things differently’.

Teachers and aides also received in-service support from therapists in some of the schools in the study. Topics for these sessions included correct lifting and transfer techniques and, in the case of aides, support for therapy inputs. One therapist noted the importance of time to enable aides to understand why a particular approach might be appropriate. She talked about the value of teacher aides attending therapy sessions for this purpose:

> *They can actually see what you are doing and the reason behind it as well. Because I think often the problem is that you don’t get a chance to explain why you are doing what you are doing.*

Two of the case study sites ran integrated programmes. One of the managers of these services made the point that a diversity of professional background could sometimes make the development of a shared vision problematic. She noted the importance of collaboration in decision-making, and of ongoing opportunities to engage in dialogue about professional practice as essential to the development of a shared vision. A therapist in one of these schools noted:

> *I find the way I’m working at the moment immensely satisfying because I’m working with a team which includes the teachers, the aides. So, all staff that’re working with a particular child are involved in their care and their programme implementation. And, also in problem-solving. We have regular meetings and all of the staff throughout the school, they come together and they discuss each student in class.*

She went on to say:

> *Amongst ourselves we discuss those kinds of philosophical issues and we debate a lot. We share ideas and information that we’ve gained from all sorts of different sources … and through these discussions we find that our vision will evolve further.*

Another therapist described the in-house professional development programme she was involved in. In this school, meetings were scheduled so that therapy staff went to full staff meetings as appropriate, and during the time regular syndicates met, therapy staff got together for an in-service professional development programme. At these meetings each therapist took a turn at presenting either information from courses they had attended or case studies of students with whom they were working for staff to discuss treatment and problem-solve difficult issues. At this school the annual practising certificates for therapists were paid for by the school. In addition, this school was seen, in the words of one therapist, as ‘very good with professional development from outside courses’.

At this school, there was also supervision for therapists. Every two weeks therapy staff from other local units got together to discuss their work and to give and receive peer supervision. Time was made available during the working day for this to take place. Unfortunately, this process did not seem universal. As noted by one therapist who had graduated two years previously:

> *… I have had very minimal supervision which I don't like to admit. But that is the way the ball is rolling unfortunately. So, as far as my competence, I feel sometimes I am not always providing the best that I could.*

Roles and responsibilities

Aides

Teachers' aides in one school saw themselves primarily as that: aides to teachers. One aide described her role as 'getting them settled, ready for the teacher to explain what is happening'. She said that 'by being there' she supported the teacher in being able to get on with teaching. Other responsibilities this person had concerned mobility and, in respect of the four students she supported, to make sure that they were organised and prepared for the work they had to do.

In one setting an aide's position had been given over to assist therapists in their work. This person supervised students with the likes of treadmill programmes, and they did stretches and other exercise and intervention programmes with specific individuals and groups of students.

Teachers

Ian's teacher talked about her role as 'facilitating Ian's learning'. She said that she did not see this responsibility as any different for Ian than for any of her other students, but she did note the difficulties inherent in Ian's frequent absences for therapy and the need for her to ensure that Ian kept up with the classroom programme. In this respect she was trying to ensure that whatever she did to help Ian keep up did not make him look too different from his peers. In addition, she made sure that other students in the room supported Ian as and when necessary by getting his wheelchair for him, or moving equipment to facilitate transitions and the like.

This teacher was aware that Ian's experience, because of his disability, was different from that of other students. She said that she was trying to work with Ian to learn more about his needs: 'I will say to him, you teach me cause I am not quite sure. And every child that comes in to your room is different and they all have special needs'. This teacher was also very aware of the need for her to be constantly checking in with her students with disabilities. Her comments suggested that in addition to the tasks assigned to the aide, it would be very easy to forget their educational needs as well. About Ian's learning, this teacher said the following:

> *I have this thing where he is actually doing really well as part of my class. And I think that if everyone treated him with kid gloves because he has got special needs that he wouldn't be, wouldn't be, like socially, he is doing really well with the kids. Whereas, if I put him at the back of the room where the teacher aide is … he wouldn't be flourishing, he'd be a bit more isolated and a little bit more, not part of the group.*

Another teacher made similar comments:

> *When he comes in I always welcome him but I don't make a fuss over him and try to make him feel different from the rest. I think it's really important that he just feels like he's one of the crowd. But, as I say, I always have my aerials up as to where he's at and how he's coping with the work.*

When talking about organisation, Isobel's teacher identified a number of issues:

> *There is a lot of juggling and shuffling around and juggling and shuffling the therapists too, fitting them in. So that we don't have a situation, well we did have a situation last year, where Isobel was not getting a lot of reading time. She got maths, but she was out for therapy when she was due for reading. Now, we didn't worry about that too much because her reading was so far up the scale, we just gave her lots of reading homework.*

In the secondary school system, issues of keeping up with academic work become significant because students face the examination system. At these times, teachers saw it as important that students were more proactive about seeking assistance when necessary:

> *He's quite often not there and I think that creates difficulties for him because he then needs to catch up, or he's missed chunks of work that we need to, to keep helping him. But, fortunately, because we're doing unit standards, a lot of that work can be taken away and done sort of off-site. I mean as long as he's getting the necessary teaching … I must say that about Harry, he's very good at asking for help, you know, he's quite up front and he'll say, 'Look, I've done this much but I just couldn't do that, can you help?' And, that's good … he's quite independent.*

Therapists

In order to support students in their learning, the majority of therapists interviewed for this study saw as part of their role the need to ensure that teachers had few 'worries' about their work in the classroom, and that where necessary they were supported by the therapists. One therapist cited the following concerns as issues for teachers:

> *… seating, environmental issues, talking with the teacher with regard to presentation of material which the teachers here are quite good on because they have done it for a few years now, so they have built up their skills. And that is part of our role as well: to educate the teachers.*

With the exception of the self-contained school, therapeutic interventions generally occurred outside the classroom. In most instances this seemed to be the preferred way of working. As noted by Isobel's teacher:

> *… we have had some therapies conducted in the classroom at times and they have proven to be a little cramping as far as space goes. They have been a bit disruptive with other children and so on. We have things like some of the speech training where some of the children are blowing bubbles, or sucking through straws and things like that in the classroom. Or, making strange noises and it just doesn't work.*

As has been noted elsewhere in this section, withdrawal for therapy seemed to be the preferred option for a number of students also. However, therapists did note that this sometimes made it difficult for 'carry over' into other settings. In recognition of this, a number of therapists talked about the importance of liaison with teachers and others, but that there was often little time to ensure that this occurred sufficiently. A number of the therapists interviewed also worked on the moderate contract. Although they recognised that the students they saw in the schools in which they were based had much higher needs, they talked about there being significant differences in the way they worked on the moderate contract. One therapist said:

> *There is a lot more consultation and a lot more upgrading of skills. We do a lot of hands-on work in our moderate contract and we see students for a block of therapy once a week and then a block off. They don't get as much hands-on therapy and I don't necessarily think they need as much, but the model is more educating the people that are working with the child daily.*

In the case of Selena, the speech-language therapist interviewed for this study spoke about a focus on recreational skills as most appropriate for meeting her needs, and of a sheltered environment as most appropriate for learning. Regarding communication, and to support classroom staff in developing their skills around communication, she discussed her own role as one of:

- regular monitoring of the use of Selena's communication equipment
- empowering and enskilling staff in their learning about communication
- developing a system for organising common therapy goals
- integrating therapy and education goals to focus on the natural rhythm of Selena's day
- supporting staff to learn about Selena's unique communication style.

Time to be a team

One therapist said of her situation:

> *I think that we have a great therapy team. I couldn't ask for a better therapy team and we have a developing relationship as a unit team if you like. So that there is still that classroom therapy thing but we are working hard on that one and it is getting better. Teachers aren't afraid to walk in here anymore.*

Staff at the self-contained school were clear about the benefits for students of working together. As was noted by the deputy principal:

> *It's very important, I think, for the teachers to learn what is required of them in order to fulfil programmes that the therapists provide, and I think it's important for the therapists to understand the constraints of a teacher within a timetable and to see that because people work together there's good vibes and a good environment.*

One of the therapists agreed. She said that since the focus of all staff was on accessing the national curriculum and on increasing a student's ability to interact with the environment, it was essential that staff feel comfortable about crossing professional boundaries if it resulted in functional gains for students. To this end she cited the terms 'trans-disciplinary' and 'multi-disciplinary', where the former term referred to working within each others' area, and the latter to the sharing of information and interaction between professional areas. Another therapist used the term 'intra-disciplinary'. She said:

> *I think an intra-disciplinary focus from the therapy department is pretty important. I also think that intra-across from the teachers and the therapists is very important.*

A support staff person agreed, suggesting that if therapists knew more about each others' fields, along with specific information about students, it would be possible to reduce lost time when personnel changed. One teacher suggested that this approach was also important because often she felt that, along with her teaching, she had the responsibility for getting 'the adults humming along and happy'.

One of the support staff in Selena's classroom added to this by suggesting that having therapists in the classroom was 'really good. I've always got someone there to find out'. Of her own work, she said that at every point she had the support as needed and that she was a part of the planning and organisation that went on in the classroom. She said:

> *I've just been here a long time … I'm not a teacher, but I do understand what they're talking about … It's like we, the teacher and I, share ideas on what we're going to do.*

A therapist in one of the attached units was, however, cautious about a 'trans-' or 'multi-disciplinary' approach, and another raised the issue of the Health Practitioners Competence Assurance Bill[26] and the implications of this for a therapist's practice. These people raised concerns about students' safety and the potential for litigation arising from an intervention going awry if the individual completing the work lacked the relevant professional background.

Time for teaming was a significant issue for many staff, with the possible exception of those in the self-contained school, who had frequent opportunities for debriefing and planning built in to their days. This issue seemed to be most significant in relation to the need for time for teachers and therapists to work together to plan schedules and interventions and to learn about each others' expertise. Ian's teacher made the point that she had previously been quite inflexible in her interactions with therapists, but that this was more a function of her lack of knowledge about the need for such interventions. She said she could now see that although she had doubts about the extent to which therapy aided access to the curriculum, it was nonetheless important.

Isolated service along with time constraints meant that some staff felt isolated from their colleagues and unable to ensure that therapy helped students to access the curriculum, as was explained by one member of a therapy team:

> *In terms of the time I have here I would say that I feel very isolated because the time I have, I have to give to the students. I can't broaden it so I feel very disjointed from the school.*

Not surprisingly, a number of unit heads focused specifically on the liaison role and saw it as their responsibility in order for the team to work as cohesively as possible. To this end, the provision of resources and supports for regular teachers was an important element of the work of unit heads. In one school the IEP document had recently been revised to make it more user friendly. Finished documents were also available to teachers on the school intranet

Interventions

Assessment

All of the staff in the self-contained school spoke about the importance of relationships with students and of knowing them and their families individually. Various members of staff spoke about being 'encouragers' and 'friends', and individual staff members seemed to have special relationships with individual students. In other settings, therapy staff and others completed playground duties with students during breaks as a way of getting to know students better. In one instance a teacher aide talked about the importance of just having time to sit down and talk with students in order to get to know them. In each case, personal relationships were seen as the way to improved learning outcomes for these students.

In all instances – and in addition to relationships with students – a range of assessment tools and approaches were used to learn about and to identify needs for students. As was noted by one therapist, without such information, 'effective treatment' is impossible. This person talked about the choice of assessment tool being driven by 'functional outcomes' for students. To this end she talked about the use of observation in real environments, and of the importance of feedback from teachers about classroom activity.

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[26] Enacted as the Health Practitioners Competence Assurance Act in September 2003.

One therapist who was unit-based talked about the Move Programme as being a useful tool for assessing a student's functional needs and for providing pre- and post- measures. This person also talked about assessment information from families and students themselves as essential to the development of interventions. She saw the use of a wide range of assessments as essential to ensure the appropriateness of her work:

> *It doesn't matter how physically disabled a child is, they need to be able to do some things and I think that is where we come in as we need to look at what they need to do and we are function-based. We look at what the child needs to do to survive their everyday environment right now and also in the future.*

Approaches to teaching and learning

In respect of Ian, a therapist talked about a dual focus to her work, comparing long-term and more immediate issues in terms of 'shooting for the stars as much as we can' as against just 'getting around the school'. To achieve this balance she said:

> *… because of the fact that we can integrate the therapy into the classroom programme and we can link in very closely with what's happening on a daily basis then we can give Ian a more rounded approach to his total development. I strongly believe that he is more than capable of being a very productive member of society when he gets out of school and I see the team's role and my role in being one that allows him to develop life skills, academic skills, physical skills, all of those things that he needs to survive in the real world.*

An occupational therapist saw it similarly. She noted:

> *… a huge and varied role in the school setting. Helping the kids access the curriculum whether that be handwriting or visually being able to see the boards or all those kinds of things. But also equally, I see my role … at this age … as being really vital for developing their confidence in their abilities and their independence with tasks … all those other tasks of daily living like dressing and grooming and looking after yourself.*

The class teacher of the focus students in the self-contained school felt that her work within the national curriculum became much more focused and appropriate once therapy and educational goals were co-ordinated. To this end she described a daily programme that was developmental in nature and moderated by IEP goals. She gave the example of moving towards augmenting a student's communication through a process of having them become familiar with matching like objects, matching objects represented in a number of ways, including symbolically, and then, finally, introducing a symbolic communication strategy. Similarly, an aide talked about the importance of knowing about a student's goals and needs in order to tailor her assistance appropriately.

In the primary school setting, one speech-language therapist spoke of the value of linking the communication work she did with students with the curriculum and the classroom focus at any one time. Similarly, a teacher aide saw growth in Penny's skills when she was able to integrate the therapy work she did in the unit into her regular class programme.

In Harry's case, therapy occurred outside the classroom, a practice he felt entirely happy with. At this stage his only needs were for physiotherapy and limited occupational therapy. The practice in the secondary school environment also seemed to suggest that the most appropriate way of providing therapy services was by withdrawal. At the same time, though, a number of personnel cautioned that staff needed to be clear that such withdrawal from regular classes should not compromise that student's access to their education.

Case study sites providing on-site therapy services tended to have students with more severe disabilities. As a result of this, and of the sometimes competing educational, physical and social needs of students, there appeared to be a perception among some staff that the importance of the national curriculum related more to the essential skills than to the learning areas.[27] As one staff member said:

> *So my own personal feeling, this is my personal philosophy coming in, I think for students with disability there is a good argument for having a greater emphasis on the [essential] skills than on the learning areas [in the curriculum documents] … probably because ultimately you are looking at vocation more for students with disability because it takes them much longer to get there.*

Others saw it similarly:

> *… involving … in para-sport and the cross-country and all that sort of thing. I think that is what I would see as the main academic-based focus for her … I definitely think mainstreaming all the time wouldn't be beneficial for her. She's in one of our community integration groups at the moment … learning how to catch the bus, how to operate a telephone book. So, some really basic skills that are required, but stuff that will hopefully give her a kick start.*

A common issue regarding teaching and learning, especially for regular class teachers of students with physical disabilities, was time to plan for individual needs. Heather's phys-ed teacher talked about her work with Heather, and while she felt that her programme provided Heather with some functional gains, she was concerned that her learning could be better if she had more time to plan for Heather's needs rather than simply 'fitting' her into the existing programme, as happened now:

> *I don't know if it's actually helping her physical ability an awful lot because, like I said, I'm doing my own programme and adjusting it for her rather than looking at her and seeing what she needs. So, she's running with a programme that's for the rest of the class – it's not designed for her.*

Heather's brother felt that it would be useful for her to learn more functional maths at school, and this point was reiterated by her teacher aide. Her brother said:

> *I'd like to see her doing more useful maths. It's a bit basic … She can't tell the time. She'll look at the clock and say 5 o'clock, but it's only 9 o'clock. With money, she recognises money but she couldn't work out the change, and I think it is important for her to learn about money. If she gets a benefit she needs to know how much she should get otherwise people will take advantage of her. It's very important for the school to focus on her independence.*

However, the perception that functional skills were perhaps more important than academic gain was not shared by all staff. Paul's teacher experienced ongoing frustration at the difficulties of trying to deliver the curriculum in addition to skill building around functional needs. She said:

> *And things like getting to and from the toilet takes ages. I start morning tea in that classroom usually at quarter-to-ten or ten-to-ten to have the children out by quarter-to-eleven so that they can have a play. And then, at lunch time again, it's starting about quarter-to-twelve just to get the children out by one.*

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[27] Consultation is under way to replace the curriculum's essential skills with key competencies.

Outcomes

Friendship

Harry was, until coming to secondary school, always in a regular school setting without any real support. When interviewed, his most significant memories of school before secondary were of bullying and teasing from other students. It was different at secondary school. He talked about one friend in particular with whom he has contact outside school, mostly by email. At school he said he tended to go to the unit at break times even though he received no instruction there. Harry felt that the school should take a more proactive role in raising the profile of people with disabilities:

> *They should have, like, people with disabilities in, like, in prefect roles, like that, or head girl or boy or something like that. You kind of feel left out, like, all the popular students in that year get a role and we don't.*

Harry's parents were concerned about his general lack of a social life outside school. They dreamed about the possibility of nights and weekends out on the town with his friends:

> *Leave on Friday night, leave on Friday afternoon and come back, you know, Sunday night, three o'clock in the morning or something like that … That would be good wouldn't it?*

The lack of friends did not go unnoticed in the classroom. One of Harry's teachers described him as a positive young man with a delightful personality highly suited to working in an industry which involved good people skills. Her only concern was that he appeared in class to be socially isolated from the group, and did not interact much with others unless group learning situations were deliberately structured in the class. When these were set up, he participated happily and contributed well.

The senior management of the school Harry attended recognised issues around friendship for some students, suggesting that sometimes friendship had to be 'supported and mediated' and that it simply could not be left to chance.

Isobel's experience was similar to Harry's. She had one friend with whom she remained in contact from her previous school. They did things together outside school and at holidays and weekends, and they phoned each other. Isobel also reported having experienced some bullying at school, although not from other students in the unit. Her teacher saw the development of relationships as central to his work:

> *Well, I feel that Isobel has a lot more potential than she is showing at the moment and I would like to see that developed … I try to see that each child has the best that we can provide in the way of support in their accessing of the curriculum and in socialising. A lot of the children who are here, realistically, can't deal with a great deal in terms of the curriculum at all. And so, their main purpose of being at school is for the social interaction, development of relationships with their peers and so on.*

Heather spent a good deal of her learning time in the unit while at school. At break times she generally preferred to stay in the unit, but often friends came and took her out. Her mother reported that friends from school called at home to take Heather out at weekends, and she had arranged for some friends to come for a sleepover party to celebrate her birthday. She said that she sometimes felt nervous about Heather's safety when she was out with friends, but that in order for Heather to be part of her community she needed to let this happen.

Penny was described as something of an 'isolate' at school despite spending most of her time in a regular class setting. Her aide said that despite her inclusion she was a child very much 'on the edge'. One of the therapists at this school said that she felt that most of the students with disabilities would prefer to be full-time in regular classes because she saw them as more alert and happier around their able-bodied peers. The principal of the school described the positive impact of students with disabilities on the rest of the school population and felt that other students were more positive and caring in the behaviour towards each other as a result of the unit.

Learning gains

Isobel was happy with the move to the intermediate unit. She felt that she had made some good physical gains since being there, saying: 'I think it helps me a lot. No one thought to help me at the other school. There was only a teacher's aide.'

Simon's mother was very happy with the support and learning her son has had from school:

> *You see, he wasn't like he is now. He just flopped around. Now he stands. He supports himself from place to place … He's really quite good, even showering now, he doesn't want to sit … He can eat, not like before, he was always choking. I was, like, a nervous wreak, sitting and watching his every mouthful. He's good.*

On the basis of her son's enrolment at other schools she was in no doubt that it was the programme in this school that had helped her son. She felt that the outcomes her son experienced were as a result of the staff of the school working together with her and her family:

> *They work together, that's why it's a success story because they're all working together for the children's good … It's good, we can, you can be open with them. If you're uneasy about one certain thing you can just ask.*

At the self-contained school students participated in a range of individual and group activities such as sensory programmes, cooking, computer, art or unit studies, or self-care activities for up to three hours daily. Toileting, feeding/eating or break times took similar amounts of time.

Heather's brother was well-informed about the school's work with Heather's seating position and posture in her wheelchair, and at every opportunity he carried over the advice of the physiotherapist to the home:

> *When her feet are on her footplate [on her chair] she sits straight. The physiotherapist said it's very important to sit up straight to keep her hips in position. If she doesn't, she'll end up in hospital again and we don't want that. It's also really important for her independence.*

Social versus learning outcomes

Despite gains, Simon's mother was unsure about the future. She said that Simon would just stay at home with her. Like a number of his peers, Simon was had severe physical and learning disabilities. With respect to Simon's future, the principal had the following to say about outcomes:

> *To have gone as far as their physical ability – because that has a tremendous spin-off into the rest of their health. Since we bought the … programme and got the kids actually moving, their health has improved … I hope that by the time they leave there when they're 21 I'm hopeful that they can have quite a bit to do in their surroundings and that might be only in the home. The other thing we try to do*

> *is to make sure they can do as much as they can without support. I've always said the simple things. Like these kids, the more capable ones I'm thinking of, if they can get around the house, or just sit quietly watching TV while Mum gets the dinner, it's a major thing in a house.*

These sentiments seemed to be echoed by staff in a number of settings with on-site therapy staff. One hands-on staff member talked about the assistance she provided Simon to work within his programme. She described him at 18 as a 'sociable young child' who was learning to write his own name and work independently. She said he liked puzzles and that it was important to 'do mobility and feeding stuff that will help his parents in the long run'.

Other therapists described their programmes as revolving around the development of behaviours 'to make it easier for the family to manage home'. These people also talked about the importance of recreational skills, and of socialisation:

> *I believe socialisation, I believe being part of your wider community and all those things that are very very important issues and I believe that we work on issues here to try to integrate our students and give them skills that will enable them to integrate as part of their immediate communities.*

The future

Regarding the future, the therapy staff employed in the secondary attached unit were focused on life beyond school for Harry. In trying to achieve this they felt very constrained, however. The physiotherapist said:

> *It's problem-solving, especially with Harry, and it's the wider community issues. So, we're looking at him fitting in the community, what he can do, how he can use his disability and fit within. So, we're looking at, he wants to swim, and so we're looking at swimming. He wants to get fit so we're looking at other sports. He can do track and field and he's really into basketball and things. He wants to drive so I'm helping him to set that up. So, even though I see him for half an hour a week I can't do all that in half an hour, so there's a lot of in-between time as well. Looking at the funding and helping to get that as well because it's too much for one family to get their head around, they don't have the resources to do it.*

The occupational therapist added:

> *I think we need to ensure that, it's just that when you leave school you haven't got a unit and I think we need to equip kids to feel good about themselves and to be prepared to meet a variety of situations … I would be encouraging them to do lots of things like sports that make them feel good about themselves.*

Isobel's parents echoed the sentiments of the high school staff. Like the unit manager who talked about seamless transitions, they wanted links between school and post-school options for their daughter, and they wanted her to be a self-starter, to be 'self-motivated'. The primary school principal said:

> *So the whole aim … is to improve the quality of life for these kids to allow them to communicate, to allow them to go as far as they can in terms of knowledge and to be as independent physically as it is possible to make them.*

Penny's mother was worried about the future, but as her daughter's time at primary school neared its end she was more concerned about transition to the as yet unopened secondary facility using the same therapy approach to the primary school. This point notwithstanding, her greatest fear was that her daughter would end up in an old-people's home when it was no longer appropriate or possible for her to stay at home. Paul's mother had similar fears about the future and was very concerned about what would happen when the family had reached the limits of what they could or should do to continue to support him.

The school-leaver interviewed for this study had, in 2001, done a one-year business administration course at the local polytechnic. In spite of a number of applications and the support of a community worker, she was still job hunting. This person had been in a regular school all through her school years. She said that at secondary school, in particular, there had been in-class support for her, which she needed during her first two years, but that during fifth and sixth form extra support had not been available.

At school this student had participated in a mix of classes, both in the regular school and in the unit attached to the school. She also received regular physiotherapy and support from an occupational therapist for in-class adaptation. As well as the academic classes that were part of the curriculum, the student also participated in a number of classes related to home economics and life skills. In addition, in the six months before she left school, her teachers ‘sat down with me and went through all the things I could do’. Despite not yet having employment, this person felt that the education she had received at secondary school had prepared her very well for life beyond school.

Summary: Integrated effective practice in schools with on-site therapists

The attached units discussed in this section were all funded through ORRS and through the transitional funding for therapists, in addition to resourcing received through the schools’ operations grant and Special Education Grant. The self-contained school was not funded for therapists because it was not designated as a school primarily for students with physical disabilities. (Prior to the introduction of SE2000, this school was resourced as a school for students with learning disabilities).

In general, principals were happy with the level of resourcing and with the flexibility of resourcing possible under SE2000, despite some reservations about the tagging of resourcing to individual students, which could lead to employment uncertainty for some staff. In instances where students in schools with attached units spent significant amounts of time in regular class settings, demands for aide support for individual students put a strain on resources.

The self-contained school used an integrated model of therapy and education for its students with physical disabilities, based in the classroom and in other places such as the swimming pool. The primary school used an approach to therapy where physical skills were taught in the context of functional activity, although therapy occurred on the same withdrawal basis as in other settings. A number of people noted difficulties in providing sufficient therapy for students, and the inadequacy of resources to provide what students needed.

Most schools had policies to support the working of their units in the school and a number of management and organisational structures were in place to support staff and students. Staff in all of these settings saw value in collaboration and the integration of services. In the self-contained school this was readily achieved due to manageable workloads and teacher–student ratios, and time to collaborate and consult.

Different settings placed different priorities on learning or educational goals, therapeutic goals, and social goals, however, which suggests sorting out the relative priorities of the goals could be an area for further professional development. In some instances, concerns were raised about the extent to which students were withdrawn from classes for therapy. Everyone recognised that collaboration was important, but for a range of reasons this was not always realised in practice in some contexts. Teachers and therapists frequently referred to the lack of time to consult as the primary reason for this. Relevant professional development for teachers, in particular, was difficult to access and a number of therapists expressed concerns about the availability of adequate supervision for themselves and for opportunities to work with teachers and aides.

Parents were generally happy with the services their children received, and each of the schools said that they put parents needs and aspirations at the forefront of their planning. In the self-contained school, parents were actively involved at several levels, and the school provided many opportunities for formal and informal involvement by parents, with a particular emphasis on culturally responsive service provision.

Students in these settings varied in the amount of contact they had with the curriculum. In some settings, involvement in regular schooling seemed to depend on the student’s ability to interact with the curriculum, although the secondary school was exploring ways to include students in regular classes and to involve class teachers more actively. Those students who spent all or most of their days in self-contained settings participated in programmes that were described as relating more to the essential skills identified in curriculum documents than to the essential learning areas.

Friendships and relationships were an area of concern for most participants, as most students were fairly isolated in the schools they attended and in the communities in which they lived. While this aspect of students’ lives was sometimes addressed in the context of social skills, school-based staff found it difficult to support the development of friendships and positive social relationships.

The next section of this study describes the daily lives and experiences of students who attended schools in which therapy was provided through an itinerant service.

Section 2. 5: Description of Case Studies in Schools with Itinerant Therapy

This section describes the daily experiences of students who attended schools in which therapy was provided through an itinerant service.

Caitlin and Christopher attended their regular school and received support from the Child Development Services (CDS) team located in the urban area in which they lived. Ricky and Rose were also supported by a CDS team in the rural area where they lived. Ashley and Alan attended their local rural area school, but their therapy needs were supported by the Ministry of Education, Special Education (GSE), as were those of Leah and Laura, who attended regular schools in a country town. Caitlin, Leah, Laura, Alan, and Ashley were funded through the Ongoing and Reviewable Resourcing Schemes (ORRS) and Christopher through the moderate contract. Ricky and Rose did not receive resourcing support through either ORRS or the moderate contract.

In each case, relevant therapists were interviewed for their perceptions of the daily lives of the focus students, as were the students' teachers, aides and principals. Each of these students' parents were also interviewed, as was a friend of Caitlin's, Hannah, and a friend of Alan's, Max. Alan, Caitlin, Leah and Laura also contributed their stories, and Ricky spoke with the researcher at the time his mother was interviewed.

Each team selected two focus students, and the researchers conducted observations and interviews in seven schools. Schools included two city primary schools, three rural primary schools, a rural college, and an area school.

Case studies 5 and 6: Health-funded CDS teams

Four students received services and supports from Health-funded CDS teams. One team provided supports across a large rural area, while the other provided support in an urban location.

The rural team of five full-time therapists and several contracted part-time physiotherapists supported more than 100 families across a very large geographical area with a large number of small schools. Therapists resided in several towns, which cut down on travel, but most of the team were centrally located in a hospital. Although the CDS team was funded by Health, it also held the GSE contract in its area. This meant that children turned down for funding under Education could still be supported by the same therapists. Staff worked across the health and education sectors, in homes and other community settings. Because they held both contracts, staff had well-established relationships with families, which continued through the transition periods from early childhood to school, and from school to adult life.

The rural team used Bronfenbrenner's ecological model to focus on children's experiences and development within the contexts of their families and support networks. This meant focusing on context as well as on the child's skills and physical development.

This functional and ecological approach to therapy through role release was described by an occupational therapist as therapy 'in the school and in the home, and the people who are around them are being supported and empowered actually to do the work'. This involved:

> *Educating parents, supporting them and giving the teachers ideas that support them, because they actually carry it out all day, and I think at the end of the day, that's more effective than coming in for an hour session, probably.*

The urban service also covered a wide geographical area, and involved significant travel for staff. Five staff supported between 350 and 400 children in educational settings and in homes. Since Special Education 2000 (SE2000), the team's client group had changed: the CDS team's work focused primarily on children of early childhood education age, with support for school-age children being transferred to GSE services. There were some exceptions where support continued into the school years for students who were pre- and post-surgery, had minor physical challenges such as handwriting and co-ordination difficulties, or had neurological difficulties and did not meet the criteria for ORRS or moderate contract support..

In the case of the two focus children, the team's involvement had been intensive during early childhood education and around the time of transition to school. Informal support to Caitlin's family continued into her school years because of a lack of physiotherapy support from GSE. The CDS team also maintained contact with Christopher's family as the parents went through several unsuccessful ORRS applications and a successful application to receive moderate contract services.

The urban team felt that since SE2000, its approach had been dominated by the co-ordination of services for families. This was not the therapists preferred approach. They aimed to provide a family-oriented service which built on families' aspirations for their children. In their services for children aged 0 to 2 years, they were working towards a seamless service, with an integration of the various specialists involved to support families, particularly in the early stages following diagnosis. Flexibility was considered important in relation to the age cut-offs traditionally used in their service, and in relation to approaches to service provision. The latter, they suggested, should respond to the actual needs of children and families, and not be 'set in concrete'. They maintained good links with GSE and CCS, with regular meetings each term. This was particularly important around the transition to school, when funding for equipment came from both health and education sectors.

Of the four focus children supported by these two teams, Ricky and Rose had neither ORRS nor moderate contract resourcing to support their education, Christopher had just been accepted under the moderate contract at age seven, and Caitlin received ORRS resourcing. The extent to which the teams could support children and families according to their preferred model or approach differed in response to these variations in resourcing levels.

Focus students: Ricky and Rose

Ricky and Rose were supported by the CDS team located in the rural area in which they lived. Ricky was receiving occupational therapy and physiotherapy through Health, as was Rose, whose support from an occupational therapist was provided in school.

Ricky

Ricky was 11 years old at the time of the study and in his first year (Year 7) in a rural college (Years 7 to 13). He had very low tone, an unstable gait with poor motor skills and poor visual-perceptual development. He also had significant delays in his learning and was working at level 2 in most areas of the curriculum. His handwriting was very difficult to read. In addition, he had skin grafts on a third of his body following an accident. His behaviour had been an issue of concern over the years and he had been described as having Attention Deficit Hyperactivity Disorder (ADHD). He found it difficult to participate in any sports or physical activities, and this added to his already compromised social life. Ricky lived with his mother, grandmother and two siblings.

Ricky had received occupational therapy support from the CDS team since he was five. At primary school this amounted to about half an hour every two weeks, and although the occupational therapist tried hard to liaise with the school, Ricky's mother thought that the limited time available for Ricky made adequate liaison difficult to achieve. For a year prior to the accident, he received half an hour per day teacher support for reading and maths. After the accident, at age seven, he received physiotherapy support and teacher aide support funded through ACC. This had since stopped. Physiotherapy had been provided for about a year, and varied from three times weekly to once fortnightly to coincide with hospital operations. However, over the years, physiotherapy had been particularly difficult to access, despite concerns by Ricky's mother that it was a major priority for him. The 12½ hours per week of teacher aide support was to help compensate for a six-month period of school absence and some memory loss, and was also provided for one year. The teacher aide used Correspondence School resources, both at home and then in the classroom once Ricky was back at school. After one year ACC indicated that the support would be stopped. According to Ricky's mother:

> *They wanted to cut it off, snap, like that! I complained and I said to them you can't do that because Ricky is still not up to where he was before the accident. And they said his [problems now are from] his ADHD … and I said instead of being one year behind in his learning he's three years behind … so we got it back … I told them, you can't cut him off cold turkey. He's a special needs kid, and because of the accident he has even more special needs, so they weaned him off … In term one it was 10 hours, term two 7½ , then 5 hours a week, then it was 2½ hours a week. Then for the last term of school [he] didn't have any [teacher aide time] … he was piggy backing with another boy who had special education services [they shared a teacher aide] … [The school] didn't even apply to SES [Specialist Education Services, now GSE] for him for that last term so he had nothing. Whereas before the accident – that's what I couldn't understand – before the accident he had half an hour a day.*

At the time of the case study research, Ricky received no additional resourcing through ORRS or the moderate contract. He had occupational therapy at school once every three weeks, and had recently had some physiotherapy made available through Health outside of school as a result of his mother's advocacy, based on her concerns that physically he was 'going backwards'. Both his occupational therapist and physiotherapist were provided through the CDS team. Some Resource Teachers: Learning and Behaviour (RTLB) support was also available. A new occupational therapist had just begun working with Ricky during school time, both in and out of class. He also attended Riding for the Disabled during school time. His mother felt it was a shame that he had to go in school time but wanted to continue with it because 'he really enjoys it, he's getting exercise and it's helping his muscles'.

The CDS team had supported Ricky and his family since he was diagnosed with ADHD at the age of six. Although he could now be supported through the Education-funded moderate contract, it was acknowledged that the contract would provide few therapy hours (two to four hours of occupational therapy a year), and that a better level of support was available under Health (occupational therapy once every three weeks). Nonetheless, although it was decided to stay with the CDS team, applying for moderate contract funding was felt to be important because without this process he would not be known to GSE.

Ricky's goals in occupational therapy were originally focused on a very broad range of skills and issues. These included work on visual-perceptual development (copying, writing, angles and background-foreground) and on self-care, self-management, and attention in class. Discussions with Ricky's mother led to a focus on grief issues, confidence, self-esteem, leisure activities, peer support, and friendships, 'a mixture of psychiatric and physical occupational therapies, a very broad occupational therapy thing but I could do that through Health'. The occupational therapist fed back information to the teacher from her observations of peer relationships in the playground, and maintained close contact with the hands-on staff at school (the RTLB, teacher and principal).

While meeting Ricky's physical challenges did not appear to be a high priority at his new school, the college had, according to Ricky's mother, taken a real interest in both his behaviour and academic status. She particularly valued their desire to raise the level of his learning rather than focusing only on behavioural issues, and 'they're prepared to listen'. A priority for Ricky's mother was supporting him to learn to read, and she acknowledged that having physiotherapy at school now would help him to access that area of the curriculum: 'The physiotherapist helps Ricky with that too. The hand–eye stuff and the fine motor skills with the pencil and stuff.'

Ricky's teacher felt that top priority should be placed on his social behaviour at school because 'he hasn't got the social skills', and the teacher saw this as a primary barrier to his learning in other areas. She struggled to find ways to meet his behavioural needs in the classroom and felt that 'it needs someone far higher qualified than me to be able to work with him'. His learning needs were also significant, with his reading and written language work at the upper end of level 1[28] on the curriculum. He had difficulty putting words on the page, placing words in any meaningful order, and spelling was a huge challenge. While his teacher appreciated the learning challenges Ricky faced, it was difficult for her to know how much she could achieve in terms of supporting his learning needs, particularly when there were significant demands from other children in the class. He received some remedial reading and maths support at school, and his teacher also had some support from the RTLB.

At school Ricky had a lot of difficulty making and keeping friends. His physical challenges make it difficult for him to participate alongside his peers, and according to his mother, consequently he 'makes a fool of himself, so the other kids look down on him'. However, she felt that the change from primary school to college had been good for him in this regard:

> *He's actually made friends and kept them and this is like, wow, month four kind of thing! … there's all these different people … he's got new people to associate with. The change to college has been a very positive thing for Ricky.*

Out of school he enjoyed a range of activities including riding his bike off-road, watching television and swimming, and he had recently taken up sailing, which he loved. Much of his out-of-school time was spent alone, but his mother had insisted that if he went swimming at least two others must be with him. He often swam with two other boys in the neighbourhood, and an older sister or two.

In terms of the future, Ricky's mother focused on reading and academic outcomes as a top priority. He recently went off to camp with a book in his bag:

> *I could have hugged him, actually I did … I says to him, where's my hug and he goes ooooh, and gives me a big hug …. I'd like to see Ricky being happy, I think that would be my main focus, above even reading, because he's never going to learn unless he's happy. But to be happy, I'm not sure what he needs.*

Rose

Rose was six years old and in Year 2 at her local rural primary school at the time of the study. She had sensory integration, motor planning and significant social challenges. She spoke a little, and her use of language was improving

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[28] Curriculum levels indicate progressive achievement within the essential learning areas of the New Zealand curriculum.

with attendance at school. She started school at 5½ and as a new entrant attended mornings only for two terms, with 1½ hours of support each day from an RTLB. The decision to start school later than usual and to initially only attend half-days was based on two unsuccessful applications for ORRS resourcing. Her family had been participating in a home-based learning and behaviour programme, which they paid for themselves, and this approach had continued for the remaining half-days when Rose started school. The intensive work undertaken by the family at home, could, in their view, have reduced the chances of Rose receiving ORRS resourcing, because she had achieved so much over this period. The occupational therapist who had worked with Rose and her family in the early childhood education years agreed: 'The family have put a tremendous amount in and it was like a slap on the wrist in a way.'

Rose and her family received good early intervention teacher support and speech-language support at kindergarten, and occupational therapy support through the CDS team at home during her early childhood years. Occupational therapy support during these years focused primarily on preparation for school – skills that supported alphabet recognition and writing, using scissors, understanding of colours and shapes, dressing, and toileting. The occupational therapist identified Rose's social understanding and social behaviour, and her fine-motor and co-ordination challenges, as areas that needed a particular focus now that she was at school.

Rose was in a Year 2 class with 26 children. The increase in class size from a small new-entrant class concerned her parents, who felt that while she would be fine academically,

> *there's no way she was going to cope there. She hasn't got the social skills. She has trouble comprehending and decoding information and all that sort of thing. Keeping her on track …*

The decile 7 school was also struggling to see how they could fund sufficient teacher aide support from their Special Education Grant. Rose's parents decided at that point to fund the teacher aide themselves at $3,500 each term:

> *We said [at her Individual Education Programme meeting] 'she needs the aide so don't look at the money side, we'll get the money'. The support will be there … she needs it all the time until we can work out the areas where she doesn't need it.*

They sold their family business to support this financial commitment.

Rose had a first-year teacher who sometimes worried that she was not yet doing Rose justice:

> *I haven't honed in enough on Rose and her needs because in my first term at school I was having to deal with so many new things and so many needs of so many other children … knowing the teacher aide was there was essential for me.*

She valued the support she received from the teacher aide, and they were working out ways to support the classroom that would provide Rose with opportunities to become more independent. The realities of teaching without the teacher aide, who had recently taken some time off, had hit home to the teacher recently: 'It was an eye opener … Just not having her there drew so much of my energy and attention away from the rest of the class'.

The school had also secured approximately $600 to fund some RTLB support, which was available to Rose's class teacher 'on the end of the phone if I need her'. The teacher felt that she probably needed to speak with the RTLB more regularly, but establishing a relationship early in the year had not been possible because the RTLB had not been to visit and had had some time off work. The most helpful support had come from an independent support agency, which Rose's parents had associations with:

> *Her feedback of observations of Rose was incredible … She really knew where she was coming from and why she behaved in certain ways … it was somebody who really knew the nature of her challenge in particular. That was the most helpful support I felt we had.*

She was not familiar with the role of the CDS team or of the occupational therapist from this team who worked with Rose, although the occupational therapist had observed in the classroom for an hour and had attended Rose's Individual Education Programme (IEP) meeting. Addressing Rose's fine motor challenges was not deliberately planned for in the classroom, although her teacher was aware that this was an area she needed to work on, and handwriting activities were used to calm her when she needed some quiet time alone.

As a new teacher, it was difficult for her to feel well-informed about Rose's needs when she was overwhelmed with 'information coming from a hundred different directions about a hundred different topics and subjects', but as time went on she was aware of 'surfacing' and wanting more specific information to inform her teaching with Rose. She identified curriculum support as one area where Rose's support team might be able to assist her. The teacher did not adapt the curriculum or do any additional planning for Rose, and her goals for Rose at this stage were primarily social, since the challenges in this area made it difficult for Rose to access the curriculum. She expressed a hope that her academic needs were able to be met at home, at least for the time being.

Despite her teacher's concerns about academic learning, however, Rose was observed to be very much part of the class. She participated in the same curriculum work as her peers, settled well, and engaged fully in academic activities. The teacher aide was skilled at supporting Rose to work with other students in small groups, something the teacher described as an 'unspoken thing between us'. Group work was used a lot, and this had proven to be a challenge because Rose needed more support at these times, and her teacher felt that to access the curriculum she usually needed to be 'very focused and on her own'. She saw the support of teacher aide in her class as critical to Rose's learning:

> *Her disability means that she does need to have someone looking out for her specifically to make sure she is not getting stressed … I think that that is important to her whole well-being – learning to manage that, and mainstream classes are chaotic places, you now, they are, that's their nature … That concerns me for Rose because she does need a lot of down time, quiet, focused self-time.*

Rose's mother drove her to school each day because Rose became upset with the noise on the school bus. She checked to make sure that Rose was in the school gate and safe. Safety was an issue of concern in Rose's early days at school, and the school had set up a buddy programme with older students to keep an eye on her during break times because at that time there was no teacher aide. She had improved in this area, but safety remained a concern for her parents. After school Rose was picked up by her mother, once it had been confirmed that she had all her gear in her bag, a task which the teacher aide was very good at organising. Rose's mother went over the home–school communication sheet each day with the teacher and teacher aide to catch up on the day's events. At home there was homework to be done, and a friend might come home to play 'to work on the social side of things'. Rose's mother had seen a change in her play with individual children, a situation Rose seemed to find much easier than trying to relate with groups of children at school.

The team supporting Rose had changed from early childhood, where an early intervention teacher was involved, to having much less support at primary school. According to Rose's mother, Rose seemed to have 'lost that so-called 'special', if you know what I mean'. The level of support available through the RTLB did not make sense to her parents, and while there was some small sense of being part of a team supporting Rose's education, it was not clear where leadership responsibilities lay:

> *She's now grouped with not diagnosed kids, that are in the system with the learning needs kids, which I don't think is right at all. I personally think she should be ORRS because her disability and her*

> *needs are ongoing. It's just now we're sort of lost as to who takes the lead role in her special education. We have RTLB support, and I think she is supposed to be our leading GSE person, but, I don't really know – at the last IEP meeting she said if we were coping OK the way we are we don't need her. Now, my God, what do we do now? I thought, there's got to be something better than this.*

Rose's parents looked forward to a future where they could stop paying for a teacher aide:

> *We don't see why we should keep paying and as things go on, we've sold this place so we free up some money to work on Rose, but our goals are that she's going to be able to function to her potential within the school and at this stage that requires aided input to get her there and it's working … School presents all these different things for her – all these new challenges and if we don't have this help, she wouldn't cope because – well, normal children, they would approach the teacher if something was wrong, whereas Rose would just wander away.*

Focus students: Caitlin and Christopher

Caitlin and Christopher attended regular schools in their local urban areas. They received support from the CDS team in their area before and after the regular surgical interventions they had to ameliorate the difficulties due to their physical disability.

Christopher

Christopher was born prematurely, and was eventually diagnosed at the age of three as having cerebral palsy (spastic diplegia). He was seven at the time of the case study research, and attended a local decile 8 primary school, but his school life began in a special school, which his parents described as 'really good':

> *The special school had physiotherapy and occupational therapists and speech therapists. Everybody was there on-site. And very small classes. And it was actually very ideal at the outset because he had lots of one-on-one every day … they supported him for two years and we can't thank them enough.*

But Christopher's parents became concerned about the social and learning opportunities open to him at that time:

> *Midway through the second year, he just wasn't having the right interaction with able bodied kids … the choice became whether you want him to carry on down the path of the disabled or try moving ahead … so we decided to come to this [regular] school.*

Christopher was now settled into a class of 29, with no special equipment and, according to his parents, a 'wonderful' teacher. He worked quietly, diligently, and independently, often completing set tasks, but during the case study observations he rarely interacted with or sought out the company of his peers in class. His teacher was considered by Christopher's parents to be very understanding, supportive, and aware of his needs, repositioning him if he appeared uncomfortable and ensuring that he had something to support his back when sitting on the floor:

> *We don't want him separated out from the class but on occasions, particularly when he's had his legs in plaster, she'll allow him to sit on a chair. She tries her very best not to have him stand out from the group. She's very aware.*

His teacher described him as 'just another kid, no difference at all'. Some accommodations were made in maths, and he had some one-on-one work with a teacher aide on a remedial phonological reading programme twice a week for 40 minutes. In other areas of the curriculum Christopher worked with his peers. His teacher used group work in her classroom, and made sure that a peer in his group supported him to be involved in the activity. She received some consultative learning support from an RTLB. She also adapted activities involving physical movement so that he felt part of the group, rather than just ‘standing there like – not knowing what to do’. She tried hard to find the balance between ‘standing by him’ and helping him, and leaving him to try things for himself:

> *I just don’t want him to feel like – it’s hard for me to explain it. If I do stand by him and help him – how’s he going to feel with all the other kids having their buddies and he’s left with me all the time. And I think, well, if I was a kid I probably would prefer just to be left to it – if I can’t do it, I can’t do it, if I can, cool. It’s hard to find that line, though.*

Christopher’s teacher had also given some thought to his relationships and friendships with others and had tried to encourage supportive relationships with other boys in the class. She had also actively discouraged the girls from ‘mothering’ him. Nonetheless, during break times Christopher spent much of his time alone or on the edge of activities. The school principal had recognised this, and had noticed that his friends tended to be younger children. He commented that the building of friendships was an important goal.

Three applications had been made for high-needs ORRS resourcing since Christopher had started school, and all had been turned down. Christopher’s parents felt very let down by the application process:

> *You get a standard letter back each time … this letter to me is just – it’s not – it’s very impersonal – you don’t expect a handwritten letter, but it was like you’ve just gone through as a bit of paper … that group there we won’t have – so give them that letter. And that’s basically how it felt, you know, and that was the end of it. Filled in the gaps where the name goes. And basically [the verifier] said if he can come out of school being able to write his name and – you know – he was meeting some sort of curriculum … I think our standards are higher than the base standard of [special] education somehow … we were banging our heads against a brick wall.*

In his first two years at school Christopher’s parents were so desperate they had sought out occupational therapy and physiotherapy through the CDS team, but he now received support from the team through the moderate contract for therapy. This was provided through a joint session of one hour per fortnight. Some hospital-based pre- and post-surgery physiotherapy was also provided intermittently through Health. He received no support from GSE and was not known to them.

Christopher was withdrawn for therapy, and during the observations for this case study research, he seemed happy to leave the classroom. However his teacher did note that out-of-class therapy time had been reduced because Christopher had found it ‘too much’:

> *The therapists came in to get him and he shut his eyes and squeezed them tight – and he didn’t want to know – he didn’t want to leave – he was too interested in what he was doing in the room. I think at that stage it might have been more detrimental than actually helping him … he was going out for speech and didn’t like that disruption at all. He was going out for speech and language as well and he was going out for reading … and with the teacher aide for physical stuff, like 10 minutes of doing balls and running and jumping and hopping and that sort of thing … He didn’t like that disruption at all … I could see it in his face – I think he just wants to be part of the room – be in our room … you’ve got to be careful with these kids that they don’t feel like they are socially isolated.*

While his class teacher knew when therapy was scheduled, she was not sure what happened in therapy or what the goals of therapy were for Christopher. However, she had been told by the physiotherapist that long sitting with his back straight against a flat surface was important, and she encouraged this positioning whenever she could. The children also encouraged him to sit like this, and had learned to support him in other situations:

> *Physically, yes, I do know he's there and I do take his physical needs into account – sometimes I forget – like when I'm going downstairs sometimes I forget that he's there and I look around and there are two kids helping him down – and I think well that's so cool because kids can do more than I can – because they are at his level – they can see what he can and can't do.*

Access to therapy and support services had been an area of overwhelming concern for Christopher's parents. In terms of mobilising supports for Christopher, his parents experienced 'a huge gap' when making the transition to his regular school:

> *There was no help … I mean, it took us about six months to a year to continually push to get on board with the RTLBs … It was halfway through the year and he still didn't have physiotherapy at school to see if he was seated correctly, there were no handrails around the place to help him get around the playground … And now we have a physiotherapist and occupational therapist going into the school once a fortnight. It's debatable how much can be achieved in that one hour, but it's better than nothing – and it's all that's available ... And I mean we talk about funding for the physical side – we struggle to get any funding for the other side as well [his learning needs] – or anything – basically.*

Christopher's parents were committed to a regular education for him, 'because he does look up to the other kids, and he aspires to be like them'. Although he was reading well, his parents reported that Christopher struggled with handwriting and maths, and they had arranged for private maths tuition after school, to prevent him 'going backwards' in this area of the curriculum. The school, through the RTLB, had also provided additional support using a specially designed maths programme drawn up by the RTLB for Christopher's class teacher.

After school was a busy time, with homework from both school and maths tuition taking at least half an hour each night. One night a week Christopher went to swimming classes, and Christopher's parents liked to play games with him to support and reinforce his learning in maths. The computer was a favourite at home, and he had a wide range of learning-focused computer programmes. He did not spend much time with his peer group outside school hours and his mother described this issue as 'a hard one'. One friend had been to play at Christopher's house, but Christopher had not been to the friend's home. Another school friend used to visit last year, but this relationship seemed to have ended because the two were no longer in the same class. Much of Christopher's social time at home was now spent playing with a younger child across the road.

Christopher's physical needs were also a major area of concern for his parents. Small changes in surface height or structure caused him to fall, and he needed constant support around play equipment and at the swimming pool because he lost his balance so easily: 'You can't sit down on the park bench and watch him – you have to be with him to help him up – to make sure he does everything'.

He was encouraged at every opportunity at home to walk, and his mother did stretches with him morning and night before bedtime:

> *It's time consuming and he's got to be able – I don't care if he can't run fast and he can't play sport – I would love to have that, but we've got to make sure he's able to walk, and will always be able to walk.*

Caitlin

Caitlin received support from the CDS team before she started school, and now, at the age of eight, attended a Year 4 class in her local school. Caitlin was born very prematurely, and had cerebral palsy (spastic diplegia), and some difficulties in the areas of visual perception and visual memory. She lived at home with her mother, and older brother and sister. An application for high-needs resourcing under ORRS prior to starting school was turned down, making the transition to school stressful for her mother:

> *She couldn't put a bag on her back, she'd just fall over backwards. She couldn't walk to the classroom. She couldn't walk up stairs … oh, it was hard to leave her at school … she'd fall over the kids in the classroom, or couldn't get round the room, so everything had to be put close to her. If the class was doing phys-ed she basically couldn't do it. She had to stand away at the side.*

The school was under pressure as a decile 5 school to find adequate resourcing to support Caitlin, and at one point suggested that she might be better supported in a special unit. According to Caitlin's mother:

> *I went off there and had a look [at the unit]. There were kids at the unit and Caitlin says – 'I don't want to be here'. It was no big deal. She didn't actually see herself as different. So I thought no. She wants to go to that school and at that point in time we couldn't see anything majorly wrong with her that she couldn't go there … it's only her walking that makes her look different.*

Special education staff also suggested to Caitlin's mother that Caitlin start school the following year, rather than on her fifth birthday in October:

> *… because she could hardly walk from A to B … but I said, no. She wants to come. She knew she was coming up five, she just wanted to be at school and that was all there was to it.*

Caitlin's mother pursued the issue of ORRS resourcing with the verifiers in Wellington, and she then received ORRS resourcing because she was in receipt of ongoing surgery and Botox treatment:

> *… and the school patted me on the back and says – oh, thanks for doing that – you know, for getting funding for Caitlin … we wish we had more parents like you … because they know that there's a lot of parents that aren't capable of advocating for their children, don't know how to.*

Given that before she started school, Caitlin had received 'physiotherapy input, lots and lots of physiotherapy input, and occupational therapy input', Caitlin's mother found it 'bizarre' that to get support at school 'she had to have surgery to get any help … I don't understand it'.

Caitlin's day began with stretches at home, then she went to school where she participated in the regular class programme. On the observation day the teacher aide did 15 minutes of stretches first thing, then Caitlin joined her peers for handwriting. She moved around the class with a fairly unstable, rolling gait, and participated in the class programme with her peers. She had an adapted desk and chair and used her wedge when she sat on the mat.

The ORRS resourcing was used for five hours of teacher aide time and for some occupational therapy support. She received no physiotherapy support due to a shortage of physiotherapists in GSE, although she had regular physiotherapy in her first two years at school from a therapist contracted by GSE from Health. This had been a major area of concern for Caitlin's mother, because stretching at home and school was not monitored, and there was no regular process for monitoring deterioration. Caitlin received some physiotherapy from the CDS team around regular periods of surgery, which meant that her legs were in plaster for significant periods. However, Caitlin's mother was concerned at the lack of physiotherapy input in the school setting:

> *There's no physiotherapist goes to these IEPs, no occupational therapists go to the IEPs. You know, she's a physically disabled child, no one from the physical department turns up for her.*

Consequently, she felt that her role had become one of co-ordinator between Education and Health, a role she felt happy with at the time because ‘I want to know what’s happening’. She felt that it was important for the school staff to understand Caitlin’s physical needs and her needs for rest, and that since no physiotherapist was available to convey this information she needed to take on that responsibility herself :

> *I want to be there and have input … you know – I don’t want them to get lost, those things. Caitlin’s IEPs are totally different when physios are at them. Especially Health physios.*

Catlin’s mother had even suggested to the school that they become a specialist service provider and get the resourcing for physiotherapy, but ‘they said it was too big a job for them’. In the face of a lack of support in this area from GSE, Caitlin’s mother established some good relationships with the hospital, and the CDS team had offered ongoing, informal support.

Caitlin’s ORRS resourcing was also used to fund special education needs teacher time, a position the school changed each year. The school had six children with ORRS resourcing and the special education needs teacher had 3½ days to provide support and undertake administrative tasks. The teacher allocated 1½ hours per child per week for one-to-one support. She used this role flexibly to provide direct support to the child, or to free up the teacher to work with the child while she took the class herself. She described her role as one of a ‘key worker’: liaising regularly with families, supporting teacher aides with their work, and working directly with teachers, therapists and any other involved professionals. As ‘the base that everyone comes to’ she felt that she had ‘got to know my job as well as everybody else’s to actually see that whole picture’.

One-to-one work with Caitlin focused on remedial maths teaching, done in a group situation ‘so she doesn’t feel I’m solely with her’ and to support interactions with other children in class. She was planning a reading programme for the teacher aide to implement, which could also be used in a group situation in class. Socially the special education needs teacher supplied equipment and set up games in break times, which addressed physiotherapy goals and encouraged involvement with peers:

> *I’ve bought the hopscotch mat, which is like a giant jigsaw, and I just say to the class, ‘Come on … I’ve got this – who would like to play this game?’… they just sort of see me as another teacher – I don’t think they know that I’m attached to Caitlin.*

Teacher aide time was used both for stretching and for learning support to implement a special reading programme (not daily), with some one-to-one support in other areas in the classroom as needed. The teacher aide also encouraged correct positioning when Caitlin was sitting. There had been some discussion in the school about including physiotherapy in the classroom setting rather than withdrawing Caitlin from class, with a range of perspectives being offered. The special education needs teacher and the occupational therapist felt that classroom-based therapy was important because Caitlin would remain with her peers and would not miss out on events in the classroom. They were considering some of the ways that this might happen. Caitlin’s mother was not so enthusiastic, however, and suggested that Caitlin was embarrassed by classroom-based therapy, which made her feel different.

Caitlin’s mother had some concerns about Caitlin’s learning, particularly in reading and writing, and she raised these with the school. She undertook to do stretching at home, thus freeing up some of the time used for stretching at school for the teacher aide to support Caitlin’s learning. The special education needs teacher at school was supportive and sent home additional reading and maths work do be done at home:

> *So I got a lot of extra homework. We got so much extra I could hardly cope with it. You know. So I got what I asked for!… School’s just really good, really, really good.*

Caitlin's mother felt that Caitlin had not had a very happy Year 3, primarily because her friends had moved into other classes, but a change of teacher brought new life to Caitlin, who went from seeing herself as 'dumb' to being full of confidence and happy at school: 'When this new teacher came, she started writing. Just started writing things at home. I couldn't believe it.'

When asked what she liked best about school, Caitlin said 'we can play on stuff when it's lunchtime, and we like reading books and writing. I like writing too.' She had a good friend in class, Hannah, and whenever possible they worked together in class and played almost exclusively together at break and lunchtimes. They also spent after-school time together at each other's homes. Caitlin had a lot of friends as a six-year-old, some of whom, according to Caitlin's mother, 'wanted to help her because she had these plasters on and things'. In her third year at school she was placed in a composite class with another child with a disability. This arrangement was helpful in terms of organisation, because the same teacher aide could work with both Caitlin and the other child. However, socially, Caitlin's mother felt it had been detrimental:

> *She lost her friends that she made the year before … and she was really unhappy last year at the beginning of the year because all her friends that she's had for the two previous years had just gone.*

This year things were better because Caitlin had her best friend Hannah in her class.

In relation to the future, Caitlin's mother hoped that Caitlin could be 'part of the norm', but she worried about the transition ahead to secondary school and the possibility of failure:

> *I'd like to think that she was actually going to pass some exams. I just feel like school's going to be a waste of time for her. You know. When she gets to high school it's going to be a nightmare – there's just no way she is going to be able to even – because of her speed she can't keep up with the work now – what's she going to be like when she's 12, 13, 14? … she won't be able to keep up with the homework … so it means she's going to fail school and I – she would love to be a vet … she's animal mad. So that's what she'd like to achieve in her life and she's just not going to be able to.*

Case studies 7 and 8: Education-funded special education teams

Two GSE teams based in urban areas were included in the study. Both teams provided itinerant support to local and rural schools across the range of therapies. Distance and travel were an issue for both teams since large geographical areas were covered. Both used a clearly articulated consultative model of integrated effective practice.

Team members emphasised that therapy was not about giving people programmes, or about treating the child in isolation from school activities. Based on ideas about inclusion in education, therapists aimed to make the school and the class programme the basis for their practice, while maintaining some flexibility to meet individual needs. In practice this meant meeting therapeutic goals through natural and functional routines in the classroom and wider school environment. In this regard therapists tried to convey to school teams that in order to make the best gains for the students, what the school did itself was as important as the therapists being there. The social model of disability was described as underlying therapists' practice, with an emphasis on providing health-related support services in community settings.

The therapy teams described themselves as taking a collaborative team approach, in which a group of people with a range of skills (therapists), and the team at school (teachers, teacher aide and family) talked about and worked out the best way to provide a service. In practice, therapists described working predominantly with teacher aides and special education needs teachers in schools. There was an emphasis on working well together, and having a good understanding of each others' roles and responsibilities. In practice, the collaborative consultation model involved therapists working with the child and school staff, modelling therapeutic approaches, making suggestions, responding to questions and giving staff the knowledge, information and skills needed to work with their students**.** Principles of role sharing and role release guided their practice.

Focus students: Alan and Ashley

Alan and Ashley attended an area school (Years 1 to 13) in their small rural community. Both travelled to school on the school bus. At the time of the study Alan attended the primary school section while Ashley was in Year 10 in the secondary school section. Both boys had attended their school since the age of five, and were supported by a team of GSE therapists from a city approximately 1½ hours drive away. Their school had a strong community focus, with many of the school staff living locally.

Alan

Alan was 10 years old and in Year 6 at the time of the study. He lived on a farm with his parents and three younger siblings, and travelled to and from school each day on the school bus. He had cerebral palsy, which restricted his mobility in terms of speed and balance, and he had some needs in the area of fine motor control. He used a walking frame when he first started school, but had been walking since having surgery at the age of six. He also had visual challenges, with field loss and short-sightedness.

Alan had high-needs resourcing under ORRS. Funded at $8,300, his mother described him as an 'over' in an allocation system of 'unders and overs'. At school he had support from a teacher aide for 18 hours each week, and from a 0.1 FTTE specialist teacher for one-on-one reading and physical stretches. The special education needs teacher also had a wide range of responsibilities relating to programme assessment and planning, staff training and co-ordination, and IEP co-ordination for the three ORRS-funded students in the school. The school had a Head of Department for special education needs, who had been Alan's class teacher the previous year. She was released from teaching for two hours each week, and her role in relation to ORRS-funded students was to make decisions about the allocation and use of resourcing, to select personnel and match teacher aides with students, and to provide direct support to teachers. A GSE support team travelled to the school (a 1.5 hour drive), and included a physiotherapist, occupational therapist, speech-language therapist and vision support person. Alan accurately named by first name and surname all the adults who currently supported him at school, including GSE staff, and those who had supported him in the past. He said, 'They help me with things. They're nice to me'.

Alan enjoyed school and participated fully in his active and diverse Year 6/7 class. He was withdrawn for remedial reading with the special education needs teacher and for physical stretches, for one-on-one music with the music teacher, and for community-based instruction with the teacher aide in areas relating to vision and mobility. He saw the itinerant therapists each term, with the exception of the vision support person who came once a fortnight. His teacher aide also withdrew him at times, particularly for reading, if the class was too active or noisy:

> *I do take him out and we do one–to-one reading and I find that he concentrates a lot better when there's not a lot of noise or anything, but they might be doing things that he's kind of interested in and I decide that he could focus much better when there's one to one. It's quiet and we've got that time to discuss things together as well.*

His IEP was revised every six months, and the meeting was attended by the whole team, including his class teacher and parents. It covered all the curriculum areas, and also included communication, physical, mobility, self-management and vision goals. Teaching strategies relating to the goals were primarily classroom-based, with the exception of physical stretching, which was done by the special education needs teacher in the spare room. Fine motor skills were specified as being practised on a daily basis along with finger, hand, wrist and arm exercises.

With the exception of the vision support person, who provided both direct support to Alan and consultation with staff, the occupational therapist, physiotherapist and speech-language therapist visiting Alan's school used a consultative approach to service provision. According to the physiotherapist, in practice this meant:

> *I work with schools, rather than with the individual student – I do very little hands-on in the classroom. I try to do most of my work through consultation, direct and indirect service provision. So I might go in once and show the teacher aides how to do the programme and follow that up with monitoring visits, and resources and checking back to see that they are doing what was set up in the programme, whether it's been useful, or whether we need to tweak it.*

The approach to therapy was based on an ecological approach in which school staff were encouraged to use naturally occurring opportunities to practise therapy goals throughout Alan's day. For physiotherapy this included walking, using stairs, kicking balls with his friends, and adapting phys-ed lessons to enhance opportunities for participation. Therapists occasionally worked with the class teachers, although their work was described as mainly involving consultation with the special education needs teacher responsible for ORRS-funded students, and with the teacher aides. Often the teacher aides sat in on therapy sessions and the therapists modelled approaches. The occupational therapy focus for Alan was primarily in the technology area at this stage, and there had been a particular emphasis on providing equipment to support his participation and learning in food technology classes.

Finding uninterrupted time to talk with Alan's teacher was a concern for some of Alan's therapists, and even for the part-time special education needs teacher herself, who said:

> *I mostly work with Alan's teacher aide. I don't do a lot with his teacher. I pop up every now and then when I've got a minute, to see how his other subjects are going. But I don't have much time to do that. I would like more time. I keep thinking how's his writing going? I haven't seen him for so long. I have half an hour in the morning and that's set in concrete … and in that time he's not doing his writing … I do find it hard to keep up with that and that would be true for all three of the ORRS-funded students.*

Although the teacher and teacher aide had a good supportive relationship, time was at a premium for them as well. While therapists consulted with the teacher aide, there was not a lot of time for the aide to pass on information to the teacher. Alan's teacher said that the lack of time to meet with therapists meant that she was not always aware of his therapy goals herself, or of how to support him in meeting those goals in the classroom.

According to Alan, school was a great place:

> *School's really good, I like learning stuff … I like all of it … it's fun ….*
>
> *I like mobility because we go to the shop … I do maths, reading, mobility, heaps of stuff … we're learning about the war in Iraq just now, because they hate Sadam Hussein, and George Bush and Saddam Hussein must have had a fall out or something.*

His parents agreed, and felt that the school had supported Alan very well:

> ***Mother:*** *We're very happy with his learning at school. He's doing really well, now he has his glasses.*

> ***Father:*** *Yeah, really happy, but I'd like to see him doing a bit more writing, yeah, handwriting. His reading is really good. He's taken off since the special needs teacher has been taking him.*
>
> ***Mother:*** *We think the reading improvement has affected everything else. He's very happy there, it's a very secure place, he has lots of cousins there … he gets disciplined like other kids, he's not treated as if he is disabled.*

His parents' only major concern at school was friendships:

> ***Mother:*** *School's been really good for him. The only thing we feel a bit sad about is his lunchtimes isn't it? He spends a lot of time in the library. We think he is probably quite lonely a lot of the time.*

There were some things that Alan did not like: 'I don't like people being rude like yesterday. I just like if everything's good … I hate homework.'

Alan knew his timetable well, and was not usually concerned about being withdrawn from class for reading, special music and stretches. He particularly loved his one-on-one music session with the school's music teacher:

> ***Alan:*** *Sometimes. I'd rather not [go out of the class] on Thursday. Say for example if I was doing something fun, I wouldn't want to miss out on that.*
>
> ***Interviewer:*** *And does that happen sometimes*
>
> ***Alan:*** *In a way, yes it does.*
>
> ***Interviewer:*** *What would you not want to miss out on Thursdays?*
>
> ***Alan:*** *Special music – I wouldn't want to miss out on that because it's the only time I have music.*

His teacher agreed that it was appropriate for him to go out of class for some things, but she appreciated the special education needs teacher's flexibility and willingness to let him stay in class if he was enjoying an activity. Alan also declared that he sometimes felt compelled to go out of the classroom, and did not always like doing this. He said, 'I have to put up with it'.

Extra-curricular activities featured in his school day, and, being a music lover, he was a fully participating member of both the school choir and the kapa haka group. Some maths work was provided by the Correspondence School, although it was now recognised that some aspects of class maths were accessible to him and that a combination of the two would meet his needs. His family and the school staff felt that he was very well supported by the ORRS resourcing he received, and that in general the resourcing allowed the school to support Alan's access to the curriculum.

Alan's home was a busy place, with a younger sister and two early childhood-aged siblings. He had his own farm bike, which he was allowed to ride on the flat paddock, and he enjoyed playing on the computer and listening to music. He would like his own room, and frequently made reference to the fact that it was very hard to have privacy, peace and quiet with younger brothers and sisters around.

Outside of school, Alan had a busy social life in his small rural community. He was a rugby fan and an active and valued member of the local under-11 rugby team. He attended all practices and Saturday games, with his family driving up to an hour and a half to play against other rural teams. At practice after school he was greeted by his peers and by the coaches, who included and involved him in some throwing and catching, and gave him the notices for upcoming games. Alan was also responsible for putting out cones and collecting them up, and at other times he sat and watched, occasionally shouting advice and cheering the efforts of his team-mates. While he did not always have friends home to play after school, he had recently stayed over at a classmate's house and his classmate had also had a sleepover at Alan's house.

Although Alan was clearly well liked and very much a part of his school, lunchtimes and playtimes were not social occasions for him. He spent much of this time alone. During playtime he sat in class and ate his playlunch – an activity that took up the entire break time because 'I get really hungry!'. At lunchtimes he took quite a long time to eat his lunch. Afterwards he typically went to the library and looked at books. He also enjoyed talking with the support person who came to school to help Ashley, a senior student with very high needs, eat his lunch. The support person knew that she should redirect Alan to go and play with his peers, but felt bad doing that. 'He loves coming over and chatting'. He said that it was difficult to play with his peers at lunchtime because they usually played rugby and other games on the top field and it was difficult to get up there by himself (the school was in the process of putting in a ramp). Nor could he keep up physically with the games they played.

In class, Alan sat at a desk alongside his peers, although for some of the day he sat at his computer with his back to the class. The teacher aide generally sat beside him, offering support as suggested by the content and progress of the lesson. As a Year 1 teacher in a class with a diverse and behaviourally challenging class, Alan's teacher had no time available to her to adapt lessons to meet Alan's needs, and primarily relied on the teacher aide to support his access to the curriculum 'on the spot'. Alan had 18 hours of teacher aide support each week, which was generally considered to be sufficient to meet his needs well. The teacher aide described her role as 'purely support', because Alan was able to participate in the class programme: 'I just try to keep him on track and explain, simplify things for him'.

Alan's teachers also valued him as a fully participating class member. His class teacher described herself as:

> *… very aware of him being a member of the class. I'm careful about language, like I never say 'we' and 'him'. I'm aware of him having a chance to participate, asking questions, responding to questions, that kind of thing.*

This was very much a situation that could 'cut both ways'. One teacher described reprimanding Alan's class on one occasion, 'and Alan got up and walked off. And I said, 'Where are you going Alan?' And he said, 'It's not about me', and I said, 'Yes it is, you come back here!'

As a 10-year-old Alan had some clear aspirations for his life as an adult: 'I want to be a boat driver on the island. I love the island. I'd like to work on the ferry.'

Alan's parents encouraged him to lead an active life and to have experiences which would support his overall development. He loved fishing and his father often took him out on the boat. His love of music and radio were also recognised as possibly leading to a job in that area, but above all his parents hoped that he would lead an independent and fulfilling life as an adult. They felt that the resourcing he received would continue to support Alan to achieve his goals, and that the school was on the right track in this area, providing his resourcing was not reduced.

Ashley

Ashley was almost 16 and in Year 10 at the time of the study. He lived at home with his parents and five brothers. Life was busy with both parents working. He had cerebral palsy combined with learning disability, and received very high needs resourcing under ORRS ($12,583). He primarily used a wheelchair for mobility and he was pushed around the school, although he could also walk in his walking frame, with assistance, and his daily movement around the school in this was encouraged. He communicated primarily through affective responses, body movements and voice tone. He had had the use of a communication device with Big Mac switches in the past, but this was not currently used because he seemed rarely inclined to use it, particularly when his health was poor. There were plans to reintroduce the buttons in the following term. A communication board was also being considered since Ashley was able to accurately match symbols using both cards and a computer programme. His teacher aide felt that communication was a key issue for Ashley:

> *We need to get him back onto his buttons to learn to push them … surely that gives him some sort of opportunity then. If he can communicate with people properly, everybody can understand what he wants.*

The resourcing available to Ashley was considered to be well-matched to his needs at school, and flexible enough to support his access to the curriculum and his needs for one-on-one physical care. In addition to ORRS resourcing, he received Correspondence School support in maths, and CCS[29] resourcing for support with eating and care at lunchtime. He also has a Ministry of Education-funded computer and communication equipment, and his family received home help. A GSE team provided itinerant support for physiotherapy, occupational therapy, speech-language therapy and mobility. Ashley travelled to and from his rural school on the school bus.

Ashley was a sociable person who was well known to his peers, having attended the same school since he was five. Being involved with his peers at school and being part of his school community were considered important to his development, and there was general agreement that school was the perfect place for Ashley to be. His teacher aide pointed out that other students 'have never questioned [his being in the class with them], because I think he's just always been in this community'. The peer group he moved through school with was in Year 11, and this was the first time he had been placed behind his peer group. It was felt that this placement would prevent any further pressure on Year 11 teachers, who were focusing on NCEA[30] with their students.

Ashley enjoyed the company of his peers, and his timetable was organised to ensure that he was part of the group. His weekly timetable included an interesting and stimulating mix of regular classes in form time: English, technology, maths, social studies and phys-ed. He had some withdrawal to do correspondence work, computer, music and walking, and he travelled once a week to Riding for the Disabled. The physiotherapist described his curriculum as focused on the essential skills:

> *With Ashley we are more focused on the essential skills than on the curriculum areas – communication, understanding and so on, are more important than the actual maths or language.*

His new peer group had adapted well to having him in the class: They held the door open for him to enter the room, greeted him, talked to him, and seemed genuinely pleased if he was placed in their groups. The teacher aide was unsure whether 'it's Ashley they want, or whether they think that because I'm an adult I might know something!'

Ashley's IEP included both learning and physical goals – communication, music, maths (selecting colours, clothes, choosing, correspondence) computer, physical skills (using his walker to walk around the school, and using it backwards to kick a ball or dance), personal care skills (independent eating) and life skills (being with peers, exploring community-based programmes). He was supported full-time by two teacher aides who job-shared over alternate weeks. The teacher aide described her role primarily as 'support rather than teaching him anything', and recognised that anything new he learnt was a real bonus. At lunchtime he sat with a caregiver who helped him to eat his lunch. This activity, followed by toileting, took up the entire lunch hour. During this time he and his caregiver were visited by a

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[29] In 2007, CCS became CCS Disability Action.

[30] National Certificate in Educational Achievement

number of children from the junior school. While his peers shouted occasional greetings to him across the playground, only one or two came over to talk to his caregiver or sit with him for a short time.

Ashley's form teacher (who also taught his English and social studies classes) was very positive about his inclusion in her classes. The welcoming environment created by his peer group had impressed her, something she had not seen in relation to students with special education needs in other schools she worked in. She was interested in Ashley, and wanted to learn more about him, although after one term she had not yet had an opportunity to do that. Increasing her knowledge about Ashley and about his needs and learning goals would, she felt, enable her to plan for his involvement in her classes:

> *I don't think we have come up with a real plan about what I can expect from Ashley and what he should expect from me … I see my role is to make sure he is safe and comfortable at the start of the day and if anything happens in any of the other classes where he is uncomfortable or made to feel uncomfortable, I'll be the person who deals with that …*

She thought a lot about how she might include him in a meaningful way in the class:

> *I don't feel that I do very much and I'm conscious of that. I'm not drawing Ashley enough into what's happening in the classroom. There are times when we break into group work and he participates, but he can't do very much. The students enjoy having him with them, but I'm conscious of that. I'm conscious that he's not enjoying himself and I'm looking for ways to make him enjoy himself as well as deliver my lesson to the rest of the class. I'm always thinking about that. I probably do a lot more group work than is necessary – but this class includes Ashley.*

The planning for Ashley's learning programme was primarily undertaken by his teacher aides:

> *… because we're working with him the closest. It's helped by the people that come to his IEPs, they say where they hope that he may head and then we've got to develop something from that … We take the initiative in that area, we brainstorm a bit together.*

As with Alan, Ashley's therapy needs were primarily met through a consultative model involving therapists, the special education teacher and teacher aides, although the mobility support person also provided direct one-to-one support when she visited fortnightly. This support was valued by the staff at the school, although, like Alan, Ashley's teacher was not actively involved in this area of learning. After a term at school, his main teacher had not met any of the therapists, and she was not aware of the focus or goals they had for him.

Members of the team supporting Ashley shared some concerns about his future when he left school. For example, his teacher aide worried that his curriculum might not support him as well as it could as he moved into adulthood:

> *If only we could train him to do something with his touch screen … like in the photography shop they use the touch screen to restore old photographs, and I thought maybe just if he had had, I mean, OK, maybe he just was born too early, but for someone in his circumstance that's born today might be channelled in that direction and have a future.*

The physiotherapist also described the curriculum as 'problematic' for all the staff in terms of Ashley's future needs:

> *You can take out elements of level 1 as the basis for the programme. It's more about how well we meet his needs. Communication is a key for him, weight bearing so he can help others when they transfer him … He's not doing well in [the communication] area, and that's not a reflection on his SLT [speech-language therapy]. I don't think we do the communication thing particularly well for a lot of*

> *kids. His social needs have changed. He's in a teenage peer group now. Post-school is really hard. There isn't a lot in the area, I don't know actually – that's the fear that parents must have … what else is there?*

The GSE team had discussed transition for Ashley in terms of where he might go and what was available, with a view to contributing to the IEP process.

Focus students: Leah and Laura

Leah and Laura attended small rural schools (Years 1 to 8) in the same geographical region. They received support from a GSE team located in a city approximately 1½ hours drive away.

Leah

Leah, who was eight years old at the time of the study, was a Māori girl attending her local three-teacher, decile 2 school. It was a school with an inclusive philosophy and a very diverse student population. It had a high proportion of students with special education needs, and, according to the principal, a very strong team, which meant the school coped well. It had its own RTLB. The principal described an inclusive philosophy in the school in which students like Leah needed to be able to live as close to 'normal' as possible. He argued that a focus on what she could do was imperative, and suggested that it was 'important to push kids up'. Staff attitude was critical, and he felt that 'our teachers' attitudes are very good – we simply don't have people not wanting them [the children].'

Leah had athetoid cerebral palsy and received resourcing under ORRS for high needs ($10,584). She was unable to sit or walk but she could control her head. She used a wheelchair and Hart walker, and was preparing for a power chair with head control. She was a very social, much-liked child at school with lots of friends, and, according to her teacher, had 'power' to shape and control relationships. Leah said, 'I have really good friends'. Her day began with a bath and breakfast, supported by her home help, and off to school in a taxi at 8 am. After school she went to her home help person's home until her mother finished work. She attended Riding for the Disabled and was about to start Brownies.

Her 'team' included her mother, teacher, principal, two teacher aides, physiotherapist and occupational therapist. She had received a small amount of speech-language therapy, and a Māori advisor had been involved to support the team with some social and cultural issues. The needs assessors were also involved now, according to the occupational therapist, 'to bring them closer to her real life'.

Leah's mother's involvement was primarily related to the IEP process, so she did not know much about what was happening at school, although she acknowledged that because she worked 'it's probably my fault [that I don't know]'. She valued the support of the occupational therapist and physiotherapist and described them as 'really good', although she would like Leah to get more therapy at home and school. She rarely saw the therapist at home, only for wheelchair fittings, although the therapists had advocated on her behalf when a needs assessor reduced the families' support hours at home. Leah's mother also valued the equipment provided for Leah at school. Her main link with people on the team was through the IEP, and she felt that 'they value my opinions. School supports Leah's education really well, better than I thought'. Several members of the team were aware that Leah's mother needed support and advocacy, particularly to access entitlements. For this family, one therapist felt that access to occupational therapy and physiotherapy locally would be particularly valuable because 'it's hard to provide support (from a distance) around things like access at home, although we're working on that'.

The principal saw parents as ‘vital’ in IEPs but acknowledged that for some this could be an overwhelming experience because of the number of professionals attending. He recognised that schools could create barriers to parent participation and that schools needed to work on supporting parental involvement. He placed a high value on good communication between home and school, as did Leah’s teacher. All children in her class had a log book, which moved between home and school to facilitate communication at this level. The principal noted that communication was easier when parents brought their children to school, and harder when they were taxied, like Leah.

At school, Leah participated in the regular curriculum alongside her peers. Her class teacher was also released for the 0.1 FTTE position. The 0.1 FTTE teacher time was used flexibly by organising it into blocks for teacher release once a week. The time was then used to plan with teacher aides, to do other work for children, or to prepare resources. According to the principal, this arrangement allowed teachers to ‘really focus on the ORRS child and develop class programmes that the child can fit into’.

It was the start of the school year and Leah’s teacher had only had Leah in her class for three weeks, but she had a well developed and clearly articulated perspective on Leah’s education which was very consistent with elements of integrated effective practice. She was herself the mother of a child with a disability, and according to Leah this placed her in a very well-informed position to teach her, because ‘she knows what it’s like’. Leah’s teacher was determined that Leah would not be in a ‘disabled carpark’ at the back of the room, and had rearranged the room so that Leah was part of a group, and had good access. The teacher described herself as primarily responsible for planning for and teaching Leah, and she expected that role to be valued by therapists and other professionals. In this regard she saw herself as a key player and part of the ‘first port of call’ when professionals visit.

The teacher integrated her teaching to support Leah’s therapy. Therapy goals were linked into teaching activities and into teaching units and class contracts. She talked about how, in a maths unit on measuring, the children were measuring their bodies, and they had decided that Leah’s measurements could be used to make a cuddle sack for her to sleep in at home because she kicked the sheets off and got cold:

> *When we’re reading a novel to the kids … I’ll make them get her out of her chair and actually lie her on the floor and just quietly stretching her legs out ... she still gets to listen to the novel. … there’s so much happening in the classroom at the moment, I don’t like her getting taken away. I like these exercises to be happening at times when she’s still participating and the kids are really good.*

Leah’s teacher was supported by two teacher aides, one in the morning and one in the afternoon. The school did not like to attach aides to children because this could lead to high levels of dependency. The principal described the teacher aide’s role as ‘in the background’, and available as needed. One of the therapists reinforced this role, suggesting that interactions with the teacher were the primary vehicle for learning. The teacher saw herself as the key person in Leah’s life at school, and this had implications for her role in relation to both therapists and teacher aides. She took responsibility for planning for Leah’s learning, while the teacher aide implemented some one-to-one teaching and provided feedback to the teacher. There was no teacher aide support for part of the lunchtime, so the children gave Leah her lunch.

Her school principal felt that, in terms of resourcing, Leah was well supported, while other students with ORRS high needs in the school received resourcing which was either ‘good or adequate’. The GSE team was felt to provide good support, although teachers occasionally felt overwhelmed by the sheer number of professional people coming through the door. Distance was not a problem, with ready contact available through email, phone or fax. There was a recognition that while the day that therapists’ came into the classroom might be inconvenient and teachers might not have choice, ‘it’s the reality’. It was recognised that travel made their job difficult as well, and that people needed to fit in.

The occupational therapist was Leah’s key worker. In this role she had:

> *… responsibility to know that things are going well for her, and we’ve had meetings with schools at the start of the year … sit down with the principal and talk about the whole school set up, and how it will be.*

The focus of therapy was on Leah’s learning, and on supporting her access to the curriculum. Occupational therapy support was primarily through a focus on her written language:

> *She can speak, but she can’t use her hands … for any functional purpose really … her written language and reading are quite problematic… so I’m thinking about what she will need and introducing it ahead of time. We’ve introduced the computer early because we need to be training people in advance … there’s also the swimming and her desk [with] a work surface and she can be part of a group, and how she can be alongside the other kids.*

The computer had been very important in developing literacy. The walking and mobility support she had received through physiotherapy had benefited her, and it was felt that the introduction of the power chair would help her socially, because, according to one therapist, ‘she’s got such wonderful play skills and such wonderful social skills and I think it will enable her to be closer to her peers’.

Leah’s future appeared bright to many of the team working to support her. Her social nature and high-level awareness were assets, and she was considered to have access to a curriculum that would serve her well as she grew. Her mother in particular had ‘high dreams for her future’.

Laura

At the time of the study Laura was 12 and in Year 8 at her three-teacher school, which she had attended since she was five. The needs of children with disabilities in the school were addressed through the school’s broader concerns for all children. According to the principal, children were constantly being monitored through formal class reviews or informal discussions, and special education needs came up as part of those discussions. The principal described her role as supportive and with open communication:

> *… helping teachers do the best job they can, so I’m always open to people coming and saying to me, ‘I’m not sure about this child or that child, and I need a bit of help or support with this’.*

Access was considered to be an important outcome for students with physical disabilities, although this term did not refer only to physical access, but also to

> *access to as much as they need and just like any other child who may not have a physical disability but may have a learning disability, we need to find ways of adapting to enable them to access.*

Laura had cerebral palsy, which affected all parts of her body, including her sight. She lived at home with her parents and older sister. She was described intellectually as ‘quite up there with her peers’, although she needed some support in the areas of reading and writing. She had ORRS resourcing for high needs ($6,760). Laura was generally considered to be well-supported, although most people on her team agreed that there was insufficient flexible teacher aide time, particularly for support with toileting and personal needs. The principal, who was also the 0.1 FTTE special education teacher, used a lot of specialist programmes to support Laura’s learning and noted that the school had put in a lot of extra teaching time over and above what was allocated through her ORRS resourcing. Teacher aide time was topped up from the school’s operational grant.

Laura had some teacher aide support at school, but only in the mornings. While there was general agreement that there was not enough aide time available, her mother and some other team members acknowledged that there was a fine line between having enough aide time for support and too much aide time so that Laura became dependent. The teacher aide described her role as working with the class teacher to adapt the curriculum, toileting, supporting Laura in her walking frame, and supporting the class teacher. She saw herself as a team member and as having good relationships with the rest of the team. She would have liked to see Laura with teacher aide support in the afternoon because 'she is lost without it'.

Laura sat at the back of her classroom as part of a group where, according to her teacher, 'she can be convenient to her computer and she has easy access and departure if she wants to'. She found handwriting difficult so she did much of her curriculum-related work on the computer, and was learning to use a new laptop. The occupational therapist was working closely with the teacher aide to find the best ways to use the laptop at school. Laura had no reader-writer at school, and her mother said that difficulties in these areas made her feel as though she was achieving at a lower level than her peers. For this reason, her mother emphasised that achievement was an important outcome for Laura, and that 'Laura needs to know that she is achieving'. Along with this came recognition that her physical challenges made her day-to-day life both difficult and frustrating at times:

> *Everything she does is done with physical difficulty and it drives her nuts because … she doesn't enjoy being last, she doesn't think that that's her place in life. She doesn't see why she should always have to be at the bottom of the barrel, and you know, at times, she gets extraordinarily frustrated.*

The class teacher was relieving for term 1. Laura participated in the regular curriculum, and the computer provided her with critical support in the area of reading and writing. Her teacher wrote a special maths programme for her that was implemented by the teacher aide. The teacher's personal philosophy was to 'make her feel that she is part of the class and not different' and to make her feel that she was achieving.

Friendships were, according to Laura's mother, 'a real issue at this age':

> *She's really looking forward to going to college because I think she thinks that, I mean she's no saint and she's been pretty horrible to the kids in her class at times, so they're pretty wary of her at times.*

Laura's teacher agreed, and was very aware of the challenges facing Laura in this area:

> *… it's a bit difficult, say at lunchtimes. Everybody wants to run around and play outside and race around and play a tiggy game, and she has to be on the sideline and she gets really quite – you can see the frustration coming.*

The school principal was also aware of Laura's lack of close friends and kept an eye out for her during unstructured break times in the playground.

Laura's mother described her role as Laura's 'PR person' and as helping Laura with school work, general care and physio. In relation to the IEP, she saw herself as the hub, and the 'co-ordinator and go-between' on the support team, carrying messages from therapists to others. She acknowledged that this could become a full-time job and she had made a decision not to work so she could manage this task and support her family. She emphasised that families were involved 24 hours a day, and that professionals needed to appreciate the ongoing pressure of this. The school principal did have a sense that energy levels could be drained and she hoped that Laura's mother 'wouldn't think, oh, everybody seems to be coming to us for everything'. There were implications in terms of creating support systems that could support families and ease the load imposed by co-ordination.

Laura received occupational therapy and physiotherapy support at school from the itinerant GSE team. She had also had a small amount of speech-language therapy in the past, and some counselling support. Co-ordination of the whole team was around the IEP process and therapists' visits. Visits by different therapists were staggered to try to maintain some sense of ongoing support for the school.

The physiotherapist visited twice a term, consulted with the teacher aide and Laura's mother, and left a written report. Therapists' support was highly valued, with the principal describing them as 'absolutely brilliant'. Despite their geographical distance they were 'just a phone call away'. They had shown particular creativity around reading and writing for Laura through the use of a computer. The part-time teacher aide, however, noted that it was sometimes difficult to find time to integrate therapy goals into class routines without taking Laura away from the curriculum. The class teacher did not always see what happened when therapists came to school, although she was satisfied that the teacher aide knew what Laura needed to be doing physically. The principal, who was also the specialist teacher, was less certain, and wondered if Laura was getting enough physiotherapy, and whether the teacher aide should be 'properly trained' in physiotherapy exercises. Laura's mother was also uncertain about whether Laura has enough physiotherapy at school, and worried that without it she would become less supple. She described a 'loss of therapy' between early childhood education and school.

Laura's transition to high school was being well managed and Laura's mother felt that the school was preparing her well for life as a teenager. In this regard she felt that her personal goals for Laura – to be well prepared to live an independent and fulfilled life, and to reach her full potential – would be realised. Her teacher also felt that school was preparing her for life because 'she's in a real life situation isn't she?'

Summary: Case studies of students attending schools with itinerant therapy

This section discussed the daily lives and experiences of Caitlin, Christopher, Ricky, Rose, Ashley, Alan, Leah, and Laura. Each of these students attended their local schools and received support to a greater or lesser extent from CDS and GSE teams.

Although Rose's progress was observed by the local CDS team, her parents were the ones paying for teacher aide support at school and for out-of-school learning supports. Similarly, Christopher's parents paid for extra tuition for him to keep up with his peers.

Alan, Ashley, Laura, Leah and Caitlin all received ORRS resourcing, but with different levels of support. Caitlin had had no physiotherapy input for over a year because GSE had been unable to fill a vacant position for this to occur. Alan, Ashley, Laura and Leah were visited in their rural schools one to two times per term by itinerant therapists. While stakeholders were generally happy with the support they received, therapists talked about the desirability of having more time to liaise and collaborate, particularly with teacher aides and teachers. In most of these instances, teacher aides were the main point of liaison with GSE, and, in some cases liaison also occurred with the 0.1/0.2 FTTE teacher. In these settings interpretations about what an integrated therapy model looked like in practice varied, and some parents were concerned that their child was not receiving sufficient therapy support.

Christopher's parents had never met the therapists assigned to their son through the moderate contract even though they had set up a meeting, which the therapists did not attend. Christopher's teacher also did not know what the therapists were doing when they withdrew him from her class and did not have time to find out. Ricky was receiving therapy from the local CDS team after ACC funding had stopped, but there seemed few opportunities for these therapists to liaise with his school.

All of the people interviewed for these case studies felt it was entirely appropriate that students should attend their local schools, whatever their needs. However, most settings, particularly those that supported students who were not ORRS-funded, experienced difficulties in respect of resourcing, support, liaison and integrated educational programmes which, while not denting their enthusiasm for the inclusion of students with physical disabilities, could make it difficult to meet their needs.

All of the focus students were relatively well integrated in their schools in a social sense, although several lacked access to friendships and relationships that could have continued outside of the classroom. While this had been recognised as a need in each setting, and a number of strategies had been put in place to support students with respect to friendships, most students had little contact with their peers outside of school hours.

Section 2. 6: Models of Therapy in Schools with Itinerant Therapy

This section describes the approach to therapy provision for focus students attending schools that did not have on-site therapists. Discussion of the models used in these settings centres on the indicators of integrated effective practice described in the scoping study for this research (McDonald et al., 2001).

Itinerant Ministry of Education, Special Education (GSE) and Health-funded CDS teams supported students with physical disabilities and their families in regular school settings**.** The students in these case studies had variable amounts of support, from receiving assistance through ORRS for very high needs, to not receiving any additional resourcing through either ORRS or the moderate contract. Within this context it was difficult to describe what integrated effective practice looked like across all sites. One setting exhibited many of the indicators of integrated effective practice. In others, the level of resourcing and of student need affected the extent to which teams could support students well. Other influential factors included:

- teacher knowledge and experience
- teacher aide roles and responsibilities
- special education needs teachers' roles and responsibilities
- communication between therapy staff and school-based staff
- lack of time available to teachers and therapists to share information and learn from each other
- lack of time for the team as a whole, including parents, to work on a shared understanding about what integrated therapy looks like in schools.

This last point, which was so critical to the focus of the project, deserves particular attention, and the following discussion draws on issues of communication which sometimes compromised teams in their attempts to achieve integrated effective practice.

Organisational matters

Leadership and a shared framework

Professional leadership at various levels in teams and schools, and a shared understanding of the purpose of and approach to team support, were identified by several people as critical ingredients in supporting integrated effective practice for students with physical disabilities.

Good communication among team members was universally described as the foundation stone for achieving a shared understanding. GSE and CDS teams clearly articulated a shared framework for their practice. They based their approach to student and school support on important ideas about inclusion in education and community participation for students with disabilities and their families. Ideas about integrating therapy into functional and natural routines in classroom and school, rather than using a pull-out model, were consistently expressed. Role release (modelling therapeutic approaches and supporting others to use these) and role sharing were also described by therapists from both teams as strategies that support integrated therapy.

Although this framework was shared among members of the therapy teams, schools did not always agree. In this regard the whole team – which included the school staff supporting students with physical disabilities – could not be considered to be working within a shared framework. While schools strongly supported an inclusive approach to education, agreement wavered around the model for therapy provision, with schools and parents not always understanding the rationale for integrated therapy or what it looked like in practice. (This point is addressed in more detail later in this discussion section.) Where schools did not share these perspectives, one therapist suggested that professional development would be needed to establish a shared framework for supporting students with physical disabilities across the whole team:

> *We focus on inclusion and meeting the student's needs within the classroom programme … we've certainly worked on that [as a shared understanding]. That may have slipped a little bit with restructuring, because we haven't yet done teaming kinds of things to let other [new] people know … The GSE team has shared goals, but I'm not sure that this extends to the whole team including the school … we would need time to establish that across the whole team and the best way to do that would be for us all to have an in-service day; a shared planning day would make quite a lot of difference.*

Families were considered central to the processes of planning and teaching, and CDS teams articulated this focus particularly clearly. Families were described as 'the first port of call'. Their involvement with families often began in the child's infancy, and ended with their support for transition to school. This meant that they knew families well and genuinely 'cared' about the families they supported. One CDS team therapist also described a commitment in her team to working with and supporting people with disabilities.

Principals as leaders

In schools, principals can play a key role in establishing the inclusive environment needed to support learning and social relationships for students with physical disabilities. A primary school principal described his staff as 'here for the kids, and the staff know that they're all going in at different levels and have different needs'. The school had a general philosophy that school was a place for everyone, that the school would always do its best to support students with the resources available, and that everyone deserved 'a fair go'. Another principal talked about the school's 'overall vision', rather than a policy of inclusion:

> *Our vision talks about having vibrant, dynamic teams and we really want to develop people as team people. And that means inclusion … I would never turn away anyone at the door – whatever their needs are. If they're in the zone, they're in … the school is so [ethnically] diverse anyway … and they're not all the same, they're all different. In some schools [like this one] when people walk in the door you get the rolling of eyes. I stand up and clap and go 'Ripper!' I think you've got to celebrate who walks in your door. And so the climate of inclusion is there – it's feverish in me, and I believe in everyone we've got in the school.*

A third principal said that what made their school staff work as a team was 'a shared vision of who we are and what we want and what we're trying to do, and ongoing learning … and not giving up'. While not everyone on the staff necessarily shared this view of teachers as learners, 'the longer you're at the school the harder it is to stay here unless you're a learner'. The principal described his own role as being to 'learn as much as I can to create an environment that lets people grow – whoever the people are'. Leadership roles in this school were moving away from hierarchical models, to roles that capitalised on teachers' strengths.

The principal of an area school described a guiding philosophy in the school as being that students with special education needs are:

> *… very much part of the community, very much part of the school, and they're here with just the same status as any other student in the school. Very much so … The general principle is offering students with special needs the same sorts of opportunities or as similar as we can as any other student receives at the school … For all our students we aim for them to leave school well prepared to be able to live adult lives and participate in the community … so the same would be the case for these students with special needs: that when they leave here they've actually had the opportunities to reach their potential, whatever that potential might be.*

Leah's principal agreed that staff attitudes supporting inclusion were critical, but that support for teachers was also necessary for the philosophy to carry through into good classroom practice:

> *Somebody asked Russell Coutts, if [with the Americas Cup] the message has been preparation, preparation, preparation. And he said no, it's been people, people, people. And that sums it up for me. It's an attitude thing. It's that feeling about it, it's worthwhile, it doesn't matter how hard it is, we'll do it. They [teachers] need to be supported though.*

The teachers in his school reflected a much wider set of inclusive community values: 'It's a very inclusive community. No one questions or complains about having students with special needs at the school'.

Leadership structures in schools and therapy teams

In most schools, one person was identified as having responsibility for the organisation of supports and resources for students with special education needs. Usually this was the special education needs co-ordinator or the 0.1/0.2 FTTE teacher in primary schools, and in secondary schools the HoD for special education needs. These teachers had a range of responsibilities, including:

- transition from early childhood education to school
- placement of students in classrooms (through discussion with teachers)
- organising and running Individual Education Programmes (IEPs) and other meetings
- liaison with teachers and families
- gathering student assessment data to identify areas for support and the types of support needed
- selection and allocation of teacher aides.

Some schools maintained communication between professionals and parents by holding regular student-focused meetings. Christopher's school had monthly meetings with the principal, special education needs co-ordinator, teacher and parents to review his progress. The school also held regular child welfare meetings to discuss any issues relating to students with special education needs. These meetings included the principal, Resource Teachers: Learning and Behaviour (RTLB), health nurse and other professionals

The area school had an HoD for special education needs who was a full-time classroom teacher, funded for two hours per week to undertake work in relation to students with special education needs. Her role included making decisions about the allocation and use of resourcing, selecting personnel and matching teacher aides with students, staff appraisals, and providing direct support to teachers. While there had been times when she felt as though she needed more time, generally she did not, because she felt happy to do paperwork at home. There was also support and flexibility in the school to provide extra time:

> *It's not a hassle. I would go to the DP and say, 'Look, I need relief for an hour or two hours … or some time to attend an IEP', or whatever, and that's not a problem.*

Therapists in GSE teams described different structures within teams that supported schools to engage in integrated effective practice. In one team, leadership was considered by an occupational therapist as crucial for good team functioning:

> *Leadership is critical – the team leader has a clear philosophy, which she shares with the team. She gives team members responsibility and models and talks about how we should work and what we shouldn't be doing, and how we should be helping schools.*

In contrast, the members of another team knew that there was probably a 'leader' for their team, but could not name the person, suggesting that the close relationships formed in this team provided a strong foundation for effective teamwork. Regular meetings were also considered important, although one therapist warned that there had to be a balance between meetings and direct support to schools: 'If you went to every meeting it would take up a quarter of your time'. Periods of restructuring in GSE offices could also eat into direct support time, as additional time was taken up in meetings and in enskilling new team leaders and members. A commitment to holding regular team meetings with a regional and student focus had been necessary in one team to ensure that these useful meetings were not overtaken by other work pressures.

One therapist described a 'collective competence' among team members, including team members within schools, which meant that supports were in place to support the implementation of integrated effective practice. Another therapist argued that teams had a better chance of achieving integrated effective practice when three key ingredients were in place:

> *If there is a position of responsibility like a special needs co-ordinator in the school who is switched on and knows what to expect of our service, who we communicate well with and knows what's happening in the school; and schools where the teacher aides know that we are there to assist them to develop a programme that will continue when we're not there … Rather than schools where you go in and you're the physiotherapist and you go in and do your bit and go away; a school where they programme plan, and where there are teachers who acknowledge that the student is part of their room as well, and realise they are the prime mover in that child's education, not the teacher aide, which is the case sometimes. When those three things are in place then you feel you are able to make the most progress.*

Without exception, GSE and CDS teams described ongoing and frequent communication between team members as critical to effective team functioning. This was something most therapists saw as occurring naturally among team members who shared an office, knew each other well, and had mutually supportive relationships. Regular communication was also achieved through formal meetings. CDS teams had weekly case discussions, and ongoing formal and informal peer reviews and supervision. All of these approaches allowed the teams to stay on track in relation to their guiding philosophy and their overall approach. Unlike schools, therapy teams did not always mention formal leadership structures.

Inclusive planning

Caitlin's large, decile 5 primary school had six ORRS-funded students and a large number of students considered by the principal to have special education needs. Approximately 90 students came into this category, and the school initially used IEPs to guide their teaching. However, the large number of students made this task difficult in terms of resourcing. The school staff reviewed this approach and moved to a process of 'inclusive planning', which recognised a general principle that 'we're all special' and that children's learning needs were bound up in the context of the curriculum and the classroom.

While IEPs remained the cornerstone for planning for some children, teachers were encouraged to see that others' needs may be met through teacher ownership and the usual process of teacher planning. The principal explained this approach:

> *We all need to be learning to read, write, have social interactions and be accepted in a community … The teachers saw that a lot of things they were talking about in IEPs would actually move out into the classroom – and so teams started talking about inclusive planning – which then fed in nicely to the next development. There's still a bit of a struggle with being inclusive in terms of ownership. Like when a school trip is being planned and somebody says – oh so-and-so might not be able to come – and you say, well, when you're planning your school trip you plan it so everybody's going on it – so it is not automatic. We've still got that inclusive thinking to get at. But I think we're pretty good.*

In terms of teacher responsibility, the deputy principal felt there had been major advances, and that this had helped establish good working relationships with clear roles and responsibilities established in teams. It was also acknowledged that this was a process that took time:

> *… we're getting better at making the primary relationship the class teacher and the other people supporting in terms of curriculum adaptation. That is our vision. The reality is we are struggling to realise the vision because you've got to upskill people [and encourage] their thinking around that sort of model.*

Flexibility of resourcing

In the case of students receiving ORRS resourcing for high or very high needs, there was a general consensus that resources were sufficient to meet students' curriculum, learning and physical needs. In these cases, resourcing could be used flexibly within schools in ways that supported the student, their teacher and classroom. Where resourcing was restricted, it was not always easy to find ways to meet student's goals. Leah, for example, was funded as an 'under' on the ORRS scheme, and her therapist commented that:

> *Sometimes with students with physical disabilities our hours are not enough. In particular, the hours I spend with Leah are way over what the ORRS scheme brings in, even with the unders and overs.*

Leah's school had supplemented her ORRS money from its operational fund to support the development of adapted learning programmes for her.

One principal argued that resourcing under ORRS meant less flexibility for his school. He was in favour of bulk funding, which he described as making things possible. It provided a 'decent' amount of money, which meant schools could afford to find their own solutions, and provided flexibility so there was no compulsion to employ certain people in certain positions:

> *We were a bulk funded school and we were very much in favour of bulk funding. It made things possible that are not possible now; we achieved flexibility. You didn't get told that you had 20 hours' teacher aide time and two and a half hours teacher. You got $10,000 and when you got $10,000 then you could make decisions about what you'd use it on. And I thought under bulk funding special education was much more effective than it is under central funding.*

Resourcing for teacher aides was also described by some principals as problematic. The $13.57 per hour rate for teacher aides did not cover GST, ACC, or holiday pay. One principal noted that schools had to be creative in their solutions:

> *Some schools have tried to force the [Ministry of Education] into providing either more money or more hours by effectively reducing the number of hours the child receives. I can actually say with some pride that we have never done that. The number of hours we have been allocated, or more, has been provided in every case and the extra money has come from targeted Funding for Education Achievement, the SEG [Special Education Grant] grant, or straight out of the Operations grant. If the agreement is that the child receives 20 hours per week then they should have their 20 hours per week. The [Ministry of Education] of course, should fully fund this, but kids should not suffer simply because there is a shortfall.*

Two principals pointed out that as teacher aides become more experienced, their salaries were expected to rise, but the resourcing allocation did not take this into account. This meant that schools could be forced into replacing experienced staff who knew the children in the school with less experienced, new staff, and this was a situation which did not support their teaching programmes.

0.1/0.2 FTTE ORRS-funded teacher positions

The resourcing allocated to the 0.1/0.2 FTTE positions could be used to support a variety of ways of working. Some principals and teachers filling the 0.1/0.2 FTTE positions had found that the time available to provide good levels of support to students and to school staff was inadequate. This was particularly time-consuming where the 1/0.2 FTTE teacher role involved co-ordination across large and diverse teams. One special education needs teacher had 10 hours to support three ORRS-funded students in an area school – one with high needs and two with very high needs. One student with very high needs attended secondary school, and was involved with six teachers, his teacher aide, and a Riding for the Disabled teacher across the period of one week.

Several 0.1/0.2 FTTE teachers pointed to the large administrative component in their work, which took time away from direct support to children and teachers, and some described working nights and weekends to stay on top of their workload.

Population estimates and unmet need

Under population-based funding, the rural CDS team would be expected to support approximately seven children in its region. In fact it supported 20. In addition, the team had identified many more students requiring support under the contract for provision of therapy services for students with moderate physical disabilities (the moderate contract) than resources were available for. Some of these children and young people had been shifted over to Health funding 'because we know they can see them better under Health'.

Control and local development of services

In schools where students received ORRS resourcing, there were opportunities for schools to control and develop their own services. Leah's class teacher was also the 0.1 FTTE teacher. She used this release time to plan for Leah's learning, adapt lessons and provide support and supervision for the teacher aide. In another school, 0.1/0.2 FTTE positions were combined and used flexibly to provide special education needs teachers with useful blocks of time out of the classroom. These periods could be used for a variety of tasks related to preparation and planning.

Where schools supported students not funded through ORRS, major challenges arose in terms of service development. For children like Ricky, Rose and Christopher, the lack of ORRS or moderate contract funding meant that schools struggled to meet the needs of their students. Ricky and Rose's teachers focused on social inclusion rather than learning outcomes in their students. The CDS teams supporting these families did what they could to help, because they cared about the children and their families. In these situations, however, local service development and integrated effective practice was unachievable. In the case of Rose's parents, they paid for a teacher aide to support their daughter and her class.

A senior member of the urban CDS team felt that changes under Special Education 2000 (SE2000) had resulted in some difficulties for families who now had to make a transition from supportive Health-provided early childhood services to more scarce Education-provided school services:

> *It has made the clarity for families more difficult and I think that really the type of service they get from CDS as preschoolers – they find it really hard to move into the school system and not see anything visible happening.*

Inter-agency and professional collaboration

The Child Development Services team that also held the Education-funded moderate contract for providing therapy services to school students felt very able to provide children and families with a well-co-ordinated and smooth transition from early childhood services and on into the school sector. Although families needed to establish new relationships with school personnel, relationships were already well established with Child Development Services team members, and the body of knowledge built up around a child in the early childhood years could be easily carried over into the school setting.

Inter-agency collaboration around this period was viewed as crucial, and teams worked hard to establish relationships with schools. This was achieved through regular contact with key personnel in each agency. The team had a major focus on transition processes, and worked hard to ensure that transition across the Health–Education interface was smooth for children and families, through joint meetings and the use of intersectoral planning documents. Therapists attended initial school IEPs, visited schools and spent time looking at the school environment, including seating arrangements. The early intervention teacher talked with teachers and discussed any anxieties they might have if this was a first experience of teaching a child with a disability. For the first six weeks at school, support continued with visits to the child at school until 'the child is settled and someone else is ready to take over'. Relieving family stress was an important goal at this time:

> *There's a lot of anxiety around those change periods for families of children with disabilities. It's leaping out into the unknown for them and I guess that's something that we try and actively support as much as we possibly can so that those transitions are less stressful.*

In the case of the rural team, informal networking was also made possible in a small community where everyone knew everyone, although a senior team member also acknowledged the challenges involved in remaining professional and separating out professional contacts from informal ones: ‘You wouldn’t communicate except on a professional basis and through meetings’. Both Ricky and Rose, the two students supported by this service, were involved with a wide range of agencies and professionals. Ricky, in particular, was involved with at least 12 different professionals, and a range of informal community groups, clubs and networks.

Rose’s school principal also felt that it was very important for his school to establish relationships across sectors to support transition to school:

> *We need to be in a position where we can demonstrate what we can deliver and what we’ve got. But also to ensure that anybody who has some sort of intervention support for the child prior to them being enrolled at school has the opportunity to share with us any information that can help with that transition time. In Rose’s case, the early intervention teacher provided us with some good information, her parents gave us good information about the sorts of things we could expect, so I think we were pretty well prepared.*

Team collaboration in rural areas

In smaller rural areas, where therapists did not live in the area and had to travel to the school, often over large distances, a sense of support was achieved in a different way. In the area school, for example, the HoD for special education needs and the 0.1/0.2 FTTE teacher felt very much part of a larger team, which included itinerant therapists. A key element in this relationship was communication and a readiness to be available. Most importantly, therapists were ‘only a phone call away’ and were felt to provide valuable support, even at a distance. The HoD described the relationship in this way:

> *It’s wonderful [support]. I don’t actually do the telephoning , the 0.1/0.2 teacher will normally do that. But I’ll say to her, or she’ll come to me and say ‘We’ve got a problem with something. What do I do?’, and I’ll say, ‘Well, we’ll ring the occupational therapist, or the vision support person and see what’s going on’. I must admit, though, a few years ago we visited [some city schools], and they had these special ed people in and out all the time, and I thought, ‘Why can’t we have that?’. Of course it’s not logistically possible and I’ve got over that now, but they seem to have this help all the time … we live here and we have to make the most of it, and [the therapists] are very good to us.*

The principal of Laura’s rural school agreed. She described therapists as ‘realistic’, and specified that the GSE team provided tangible support through:

- practical ideas
- equipment
- ideas for adaptation
- good communication
- a family orientation.

In another rural area, a Resource Teacher: Learning and Behaviour described a strong and supportive cross-sectoral relationship with the CDS team she liaised with. The small size of the community contributed in part to this, with relationships complemented by a good local knowledge of families and families’ needs.

Rural areas do face some unique problems. Although not strictly issues of communication, some practical issues made it difficult for teams to support their students as well as they would like. It was difficult to find teachers for teacher release time, and the principal in Laura's small school often ended up taking on this role. Replacements for the teacher aide could also be difficult to find. This was most keenly felt in Laura's school when she missed out on attending the school camp because the teacher aide was unable to go.

Team functioning

Families as essential members

Both CDS teams had an explicit family focus in their work. Team members frequently referred to this focus, with one senior team member encapsulating the approach as follows:

> *We very much try and work with the families so it's oriented around talking with families, and building on what they want and where they see themselves going … [In our processes of service provision] nothing has to be cast in concrete, it can be what works for that family and for that child.*

Another CDS team leader described parents as the centre of their team's focus. She acknowledged that while the team might let parents know about the services available and the various advantages of those services, 'at the end of the day it is their decision', although a colleague on another CDS team added that such advice needed to be 'professionally sound'. Where several agencies were involved, the priority of these teams was to get to know the family:

> *Our service is always family/home/client-centred, so the first thing is always discussing with the family and seeing what they want and what their needs are before we go to the school.*

Therapists referred to a 'caring' relationship with families, and a desire to see them and their children well supported. Around transition to school, when some CDS teams ease out of a longstanding relationship with families, therapists talked about regretting withdrawing support, and having a strong need to see the transition process through to a successful conclusion. Close intersectoral relationships were part of this, and one therapist noted that her team 'had been criticised for doing it too well', resulting in the establishment of high expectations for a continuing service under Education. But she emphasised that team members 'really cared' about families, and that transition was the ultimate end point of their service:

> *People only see that little bit of it. They don't see that this is the conclusion of something you've been doing for three years. And you finish off that bit. Because the sort of people that work in this organization are really, really caring – they try to make sure that child's getting the best possible outcomes as they move into Education.*

A GSE team member referred to the importance of trust in a relationship with schools and families:

> *We become friends of the family. We become friends of the school. They trust us – so do the parents – usually. I mean it's very rarely with these children that anybody really gets aggro – because they want the best for their child, and they know that we can usually suggest something*

Schools also valued parents as key members of a team. A primary principal described parents as integral in the processes of planning and teaching. He described this role in the process of transition to school as 'ensuring that the parents have a very clear say as to what it is they see their child's needs as being'. In this school, one of the core values identified by the principal was 'valuing the family of those within the school, and that's something which has existed within the school for a long time'. Within that context he emphasised some key inclusive values:

> *We're certainly keen on making sure that all kids get the best deal possible with what we've got, and that can be pretty interesting at times, but yes, just making sure that everyone gets a fair go.*

Leah's teacher, herself the parent of a child with a disability, said that Leah's mother 'needs to feel that it's not all on her shoulders' in terms of knowing what is happening for Leah at school. While the IEP process 'must involve parents', she believed that IEPs should be followed up with regular assessment and planning meetings with all involved. She was working on a post-IEP 'Leah Newsletter', which recorded the details of the IEP, Leah's social, learning and physical goals, and the implications for teaching and therapy at school. This would, she felt, ensure good communication among all involved on the team, and Leah's mother would know exactly what was going on at school. This level of support was important for this parent, whose own workload made it difficult to stay up to date with her daughter's school experience.

An essential feature of rural teams was that networking was made easier by the small size of the community and relative ease with which people could communicate. Where professionals lived in the area they frequently mixed with families socially, and there were many opportunities to liaise – both formal and informal.

Some families were not always actively included as support team members. One parent of a primary child with surgery-related therapy had had no contact with either the physiotherapist or the occupational therapist:

> *We haven't heard from these people. We don't even know what they're doing. They don't even talk to us. So they did ring – after we told them to ring. And they didn't bother turning up to the blooming meeting.*

This student did not receive any resourcing through the ORRS or moderate contract, and this meant that the infrastructure needed for good communication with the family was not in place.

Initiating services and supports was perceived by some families to be a role left to them. While some, like Ricky's mother, did not mind this task because it meant she knew what was happening for Ricky, others found it draining. As one parent said:

> *I just think a lot of it is there, it's just a matter of managing it better at times. I think that people need to be much more aware of how much pressure is on parents with special needs children at times … I think professionals can forget that. They forget that the parents are 24 hours a day, you know, seven days a week, and the child you see at school is quite different to the child you see at home.*

In noting that parents were indeed the focus of the IEP, one school principal had some understanding of the fine balance between participation and over-commitment:

> *… of course they are probably the most important in this instance, because they do link between all [people]… I hope though that her mother wouldn't think, 'oh, everybody seems to be coming to us for everything'.*

Laura's mother suggested that several families overburdened by the role of co-ordinator could share a key worker, whose role would involve service co-ordination for families. The rural CDS team did not have set case managers, but they did appoint a key person for each family on the basis of that person's knowledge of the family. The relationship between the person and the family was equally important: 'It's what's best for that family or what evolves, or who the person is that that family gets on well with'.

Several therapists described having a role that went beyond the provision of therapy to a much broader role of family support. Relationships with families were based on genuine caring and concern for families' well-being. One team member felt 'quite sad' handing a child over to another therapist to work with, even though she knew the new relationship would prosper:

> *I just found working with the family tremendously fulfilling. Yes – I mean you can't help but get involved in a family and want to do your best … But [the changeover] will be good for him. It's in his best interests and I am still in the background.*

While parents generally felt well-supported by their child's present team, some described extremely difficult interactions with professionals which could be potentially damaging to team functioning. One parent described some early interactions with paediatricians, which were 'just the beginning':

> *I feel like all Ricky's life I have had to fight for him. From the time that he was born … one of the paediatricians told me that I made Ricky the way he was … I had made my bed, now I had to lie in it. And Ricky was this kid who didn't walk, didn't talk – all he did was scream, and I did not make him like that. Another paediatrician said to me once that Ricky was made up of three parts. His chemical makeup, his DNA and his environment. Well that's fine, I'm only a third of his problem!*

It should also be noted that in some of the interviews with therapists, parents were not always mentioned as team members unless prompted by the interviewer. While this did not necessarily imply a lack of family focus, the omission of parents did suggest that the 'team' could be more readily defined as a group of professionals. In practice, some parents also reported not knowing when therapists were to visit their child at school, although it was not always clear at what level the breakdown in communication occurred. One busy mother with early childhood-aged children wanted to know about therapy visits, although being able to attend did depend on her other young children:

> ***Interviewer:*** *When the therapists come to school, do you get to talk to them?*
>
> ***Mother:*** *No, usually I don't even know when they've come.*
>
> ***Interviewer:*** *So you don't know when they're coming, and you don't know when they've been?*
>
> ***Mother:*** *No, not unless [child] tells me. Sometimes it is written in the notebook and sometimes it's not.*
>
> ***Interviewer:*** *Would you like to know?*
>
> ***Mother:*** *Um, I would have done, yes I'd like to catch up with them. But I don't know if I would actually make the effort to go in and see them – I would if I didn't have the other kids. I'd like to know – just a note to let me know they're coming. I used to always make sure I knew, but life is that much busier now … I do know that the occupational therapist comes now during technology.*

Some therapists also worried that heavy workloads compromised their ability to provide support to families, because their time had to be primarily channelled into school support. One GSE therapist described a personal goal to improve relationships with families:

> *I always have 'parent' flashing – because we're good at working with schools … but we don't have enough time or a close enough connection with parents to be able to make the most of that relationship and to support parents enough.*

IEP: The focus of contact and planning

The bi-annual IEP was described by all teams as a key process for assessing student outcomes and planning new goals. It was expected that team members would attend the IEP, and parents were considered critical participants. Parents also described the IEP as an important time because it brought all members of the team together to share information and plan for their child. Parents felt actively involved in the IEP process and described their opinions as 'valued'. Therapists described IEPs as the main focus for co-ordination and therapists' visits. They were considered top priority, although some said that time could be an issue and that it was not always easy or indeed possible to get to all IEP meetings.

Leah's class teacher emphasised that class teachers needed to be seen as central to the IEP process. Initially she felt that this was a position she needed to establish:

> *The therapist had come in and was talking with the teacher aide. And I wasn't there and I hadn't even met her yet. And I just said, 'hang on a minute,' you know, 'I'm the one that's supposed to be writing this IEP' … I'm not too sure who's in charge and I'm going to presume it's me'.*

This teacher planned to write a newsletter following the IEP to co-ordinate and report relevant information from all participants on her team. She felt that the IEP should be seen as the starting point for follow-up meetings by the whole team to encourage well-informed and integrated planning. A therapist from another GSE team agreed with this idea:

> *Not everyone gets to those [IEP meetings], and not even everyone in the school gets to those. What you should do really is have an IEP and follow it up with a planning meeting. That would need more time. We could also use this for role sharing, showing how to do positioning and that sort of thing.*

In some cases, attendance at an IEP could also be a challenge for parents. Leah's principal described parents as 'vital' in IEPs, but acknowledged that for some this could be an overwhelming experience because of the number of professionals attending. It could be difficult for some parents to understand what school was all about, particularly if their own experience meant that the principal's office was associated with punishment. This experience 'created barriers', and he acknowledged that schools needed to work to turn this perception around.

In Caitlin's case, the IEP could not currently be considered as the focus for contact and planning, because the local GSE team had had considerable difficulties attracting physiotherapists and Caitlin currently received no physiotherapy support from this service:

> *There's no physiotherapist goes to these IEPs, no occupational therapists go to the IEPs, you know, she's a physically disabled child, no one from the physical department turns up for her.*

Caitlin's mother described herself as 'the co-ordinator' between Education and Health because she felt that it was important for the school staff to understand Caitlin's physical needs and her needs for rest. Since no physiotherapist was available to convey this information:

> *I want to be there and have input … you know – I don't want them to get lost, those things. Caitlin's IEPs are totally different when physios are at them. Especially Health physios.*

The IEP could also become a vehicle for collaboration across sectors and agencies, resulting in improved sharing of information and co-ordinated support for families. For CDS teams, the IEP was seen as particularly important at the point of transition from early childhood to school, a transition which usually meant a change to services being provided by an Education team rather than a CDS team. One therapist noted that the IEP was a point of contact for both teams in this situation, and forced collaboration between sectors and team members.

The IEP process also resulted in a lasting and working document, which had the potential to support the transition process in terms of relationships, planning, programmes and equipment. A GSE therapist had used the IEP process to involve staff from Leah's needs assessment agency following a reduction in Leah's respite care and personal care hours: 'We used the broken record approach – we've tried to bring them closer to her real life, so we invite them to her IEP'.

One teacher described the IEP as functioning in reverse in that it helped to inform her about the student's learning goals. This Year one teacher had a challenging class, and was unhappy that her involvement in the IEP was so poorly informed:

> ***Interviewer:*** *Do you feel you have a good grip on where he is at with his learning, and his IEP goals?*
>
> ***Teacher:*** *Better now that we've just had his IEP, I feel as though I've got a better look at his overall education … I have a much better idea about what's going on. I sat there and listened really, it was quite good.*
>
> ***Interviewer:*** *So does the IEP help to inform you more about where he's at?*
>
> ***Teacher:*** *Yes, but I hate that. I felt really unhelpful going into the IEP because I thought someone's going to ask me something I don't know.*

Professional development

Professional development was endorsed by all teams as critical to achieving integrated effective practice, and this was a viewed shared by schools and by CDS and GSE teams. When Rose started school, for example, her teacher 'hopped off to a couple of courses, and other staff did as well'. The principal of her school described professional development as needs-based within the school, 'so if there is a need identified, then funds to address that need have always been made available'. Another rural principal described professional development in her school as occurring primarily through chats with the RTLB and therapists, and by having specialist staff coming in.

In schools, principals endorsed professional development as important for all teachers, and supported their teachers and teacher aides to attend any courses relevant to teaching students with disabilities. Staff also searched out opportunities to learn more in this area, although one major concern expressed by teachers, special education needs teachers and teacher aides – almost universally – was the general lack of good-quality and relevant professional development opportunities. The special education needs teacher in the area school pointed out that professional development for teachers supporting students with very high needs was almost impossible to access:

> *I don't get many opportunities to do PD which is relevant [to help us plan for Ashley in the regular classroom]. Courses are few and far between, and often the course doesn't really suit.*

Two principals pointed out that there was an additional cost for schools in supporting professional development for teacher aides. While they were more than willing to find the funds, they saw the training of teacher aides through professional development as important, and as something worthy of Ministry funding.

Some schools supported teacher aides with on-site opportunities to learn. Two principals described 'training' their teacher aides themselves, while some teacher aides learned on the job without a lot of direct supervision, and sought out (generally rare) opportunities to learn more about their role and responsibilities. One of the GSE teams also responded to specific areas of need by providing professional development opportunities directly to the schools they worked in. This service was considered to be an important part of the GSE team's approach to service provision.

CDS teams also valued professional development opportunities. For the rural team this need was met in part through very strong supervision and support networks with staff in a large city hospital, and with therapy and disability experts in tertiary institutions. Distance was not an issue, because 'we can always call up'. The urban team acknowledged that the larger body of physiotherapists and occupational therapists available in Health in their geographical area meant that professional development and supervision were more readily available than in Education. They felt that the 'minimal numbers of staff' in Education meant that it was difficult for those therapists to have good supervision and monitoring of their work.

Roles and responsibilities

Teacher aides

Teacher aides were described in most schools as critical to the inclusion of students with physical disabilities. Their roles were generally well-established in schools, although their roles and responsibilities varied across case study sites. In some schools teacher aides were primarily supported by the special education needs co-ordinator or the HoD for special education needs, with good collaborative relationships involving training and support.

In some cases teacher aides looked to the teacher in the 0.1/0.2 FTTE position for advice about what they should be doing in the classroom, or about particular issues relating to children's learning and their social needs in the playground. The extent to which this relationship produced an effective teacher aide role varied according to the knowledge of the special education teacher. In one school, the special education needs teacher had literally stepped out of the classroom, and had had no training or time to consider her own role, let alone that of the teacher aides.

The extent to which teacher aides' roles were negotiated with teachers varied considerably. Some teacher aides described having, in the words of one, 'pretty much a free hand' in establishing their role in the classroom. In addition, some teacher aides felt they were better informed about the student's learning than the class teacher:

> *The teacher tries to include him as much as she can … I think when it probably comes down to work, I probably have the overall say about what he's doing, because I probably know more than she does about what he's capable of doing. When it comes to behaviour, I think she's probably the one that would have the overall say.*

Alan's teacher aide described the role as 'support rather than teaching' because Alan was able to participate in the class programme. The teacher aide was aware of the need to move back if support was not immediately required: 'I just try to keep him on track and explain, simplify things for him'. His teacher had thought about how she and the teacher aide might negotiate their roles to become more flexible, allowing Alan some time with his teacher, but they had not yet managed to find a time to organise this.

Most GSE therapists communicated primarily with 0.1/0.2 FTTE and teacher aides, perhaps because teacher aides were more readily available than teachers to discuss therapy goals. However, GSE therapists also had clear views on the preferred role of the teacher aide. One therapist pointed out that her role was in part to remove physical barriers for her students, and that in some cases teacher aides could become a physical barrier to a student's independence or to their social relationships. Another therapist in a GSE team extended her role to include advice to schools about the roles and responsibilities of teacher aides. This was particularly important in schools where the aide's role did not support students well, and there was an awareness that this task was not always easy for special education teachers on school sites to take on:

> *Often we are there to say what needs to be said … I can go in and say, do you think the way to do it is – if you leave her to write there and guide there, and leave her for five minutes, she needs that time to*

> *process it and no talking because it's too intrusive … I think we have quite an important role with the teacher aides.*

Leah's teacher was supported by two teacher aides – one in the morning and one in the afternoon. The school had a clearly stated policy of not attaching aides to children because this could lead to high levels of dependency. The principal described the teacher aide's role as 'in the background', and available as needed. The teacher saw herself as the key person in Leah's life at school, and this had implications for her role in relation to the teacher aides. She saw her own role as taking responsibility for planning for Leah's learning, while the teacher aide saw her role as implementing some one-to-one teaching and providing feedback to the teacher.

Teachers

In some of the case studies, teachers indicated that they were not always aware of children's therapy needs. While therapy teams clearly articulated the fundamentals of functional and integrated therapy, the message did not seem to reach class teachers. This may be because much of the information sharing took place between therapists and, in schools, teacher aides and teachers in 0.1/0.2 FTTE positions. This suggests that for itinerant teams a basic framework or structure for integrated effective practice was not always in place.

In one school, however, a classroom teacher did seem well informed, and integrated therapy goals in the classroom. Leah's teacher was also the parent of a child with a disability. She established herself clearly as the key person in relation to Leah's learning and expected visiting therapists and others to respect that by including her in their consultations. This was a position she described as needing to establish herself, and she hoped that she would be able to get good access to information about Leah to support her teaching 'without having to go and look for it myself'.

Other teachers in these settings seemed less certain of their role in relation to their students with physical disabilities. They were not always included in consultations, and several expressed a desire to become better informed, and felt that some release time would provide them with the opportunity to talk with therapists and others, and to plan for their students in an informed way.

Where teachers were not in the loop, students' physical needs in particular seemed to receive little attention. In Rose's class there did not seem to be much attention paid to her physical needs, possibly because her low muscle tone and problems with sensory feedback were not obvious to an untrained eye. Rose's teacher was aware that she had some needs in this area, but had not yet discussed these with the occupational therapist who was supporting Rose, and in fact was not clear about what the occupational therapist's role was. She had not met with the RTLB, although she was aware that the RTLB was available on the end of the telephone if she needed her.

Similarly, Christopher's teacher knew when his joint occupational therapist/physiotherapist therapy was scheduled, but she was not sure what happened in therapy or what the goals of therapy were for Christopher. In the area school, neither Alan nor Ashley's teachers had met the physiotherapist involved in supporting them by the end of the first term, and neither were aware of the goals of their physiotherapy programme.

One primary teacher was very unsure about her student's therapy goals and did not understand the implications for her own role as his teacher:

> ***Interviewer:*** *So what happens when therapists come to work with [student]: do they consult with you or are they there to work with [student]?*

> ***Teacher:*** *They come to work with [student]. The occupational therapist usually works in the technology room, so she's not in my classroom, but she always comes back and has a chat to me. The vision support person usually takes [student] out in the community … I like that because they are working one on one and they are seeing exactly what he is able to do. I'd far rather they were working with him than talking to me about it.*
>
> ***Interviewer:*** *If they were doing things that had implications for what happens in the classroom would they come back and talk to you about that?*
>
> ***Teacher:*** *No.*
>
> ***Interviewer:*** *So you don't really know what they do with him or what their focus is?*
>
> ***Teacher:*** *No. The only reason I know what they are doing physically with him is through the teacher aide. She follows up with what they've been doing because [therapist] is more concerned with the physical side of things and the teacher aide's working a lot with him on that.*

Although Christopher's class teacher saw herself as part of a team, her relationships with other members were on a 'they are there and I can get support whenever I need it' basis. She was unsure about what had happened to the speech-language therapist, who had provided some support last year but had not been around this year. She had met the therapists, and trusted them implicitly as professionals supporting Christopher, but conceded that she did not have time to consult with them or to discuss what they do:

> *If I wanted to I could – if I had the time I could approach [name] and say – look let's have a chat about what's going on in that room. But I don't have the time.*

Overall she felt supported as a teacher, although she wondered if her competency-based view of Christopher was well understood by others on the team:

> *I can see what he can do but some people are more focusing on what he can't do … I'm always saying, 'yes, but – he can do this'. Maybe I'm trying to be too – like gloss over it – but I think he can actually do a lot and I think maybe we need to recognise what he can do.*

A secondary teacher also felt that her role was unclear, and that while she wanted to know more about the learning needs of her high needs student:

> *I haven't been given any information about the school's expectations [of me as his teacher]. I've asked the teacher aide, how much do I give him in six weeks of work, how much should I expect from him … I know very little [about the work he's doing], very little … I need to know what people expect of me as Ashley's teacher. I need to know how much support I need to give Ashley to help him succeed in those classes I teach. That's what I need. I need to know if I'm just there to help him feel safe with his peers and that concerns me as well, because he actually has very little to do with them socially.*

She occasionally chatted with the special education needs teacher at the start of each day about how Ashley was, but 'I haven't really sat down and talked with her about our expectations of each other and I think that needs to happen'. She had given a lot of thought to ways in which he might be more fully involved:

> *At the start of the year when I asked [the teacher aides] what do you expect of me, they just sort of said, 'Oh. Well we just usually sit at the back kind of stuff, and I think they could see I wasn't comfortable with that … I'd like to see him working with the groups more often, and to be able to*

> *contribute. He can draw – it's not going to be hard for him to do some drawings with his group. I have some students in my class who aren't terribly able, so I don't feel he's got anything to hide.*

In contrast, Leah's teacher articulated her role as a key person in Leah's life at school. She was actively engaged in planning and teaching for Leah. She believed that it was important for Leah to remain in the classroom and to access the same learning opportunities as her peers. To this end she had begun integrating therapy goals into the daily class programme and routines. The teacher also felt that to integrate therapy, teachers need to be well informed, and she saw this as the responsibility of therapists. Three weeks into term 1 she regretted that she knew little about therapy goals but felt that 'by term 2 a lot of that will be in place'. At this stage she would like to know more, but preferably 'without me having to go and do it all completely myself'.

Laura's class teacher did not always see what happened when therapists came to school and did not feel well informed about her therapy goals, or about the best way to support these through the class programme. The physiotherapist, for example, had done some assessments in the library away from the class, to give Laura some privacy, and the teacher had received the physiotherapy report. Laura's teacher was satisfied, nonetheless, that the teacher aide knew what Laura needed to be doing physically.

The principal, who was also the specialist teacher, was less certain. When she first came to the school, she asked the teacher aide if Laura had daily physiotherapy and the teacher aide had said 'no': 'and that's where I left it. I've come from a school with a special unit and the children had physiotherapy every day'.

Rather than looking at training the teacher aide to 'do the physiotherapy', the school focused on other areas, like using library time as an opportunity for physiotherapy. She now wondered if training the teacher aide might be beneficial:

> *Maybe we should have the teacher aide properly trained, even if it's in four exercises that she needs to do every morning, and even if it's the first half hour of the day or whatever.*

Two teachers were in their first year of teaching, and found it difficult to find the time to establish a good relationship with their students with physical disabilities when there were so many competing issues to deal with in a busy classroom. Alan's teacher felt too uninvolved in his classroom life:

> *I try to tell the teacher aide before class what we will be doing, but she more or less adapts the task on the spot for Alan. If my class had minimal or no behaviour problems, I would be doing a lot more with Alan than I do now. I feel it's a shame really. I feel like sometimes he's in the wrong class … I feel that sometimes he misses out, but then all the kids miss out, it's not isolated to him, yeah … I would like to be able to do more one-to-one stuff with him … In terms of our relationship, yes, it is the same as for the others, in fact we talk a lot at lunchtime and playtime, so it may be even more time with Alan, but in terms of teaching time I don't have the time to spend with Alan … it would be nice if the teacher aide and I could change places a bit, if I could set a task and spend 10 minutes with Alan while the teacher aide helps the other children, but because of the class we don't get to do that … I mean, he sees me as his teacher, but I don't feel like his teacher, and he knows the teacher aide's role is to assist with his learning, but I would like to have a far more active involvement with the teaching-learning side with Alan than I do.*

These young teachers worried that they did not yet know enough about their students to adequately meet their needs. One teacher described feeling much better after the IEP, because she now had a better idea about the goals for the student at school. These teachers seemed to have little in the way of support to explore the issues they were both seeking help with. One teacher even commented to one of the researchers that she hoped the researcher could 'tell her what to do'.

In particular, these teachers needed time to learn about:

- their role as the student's teacher
- the student's disability, its impact on their learning, and the implications for them as a teacher
- the roles and responsibilities of other staff, including teacher aides, teachers in 0.1/0.2 FTTE positions, and therapists
- therapy goals and how they can be addressed through class and school routines.

Some release time to plan for the inclusion of the student in class lessons would also go some way to alleviating these difficulties:

> ***Interviewer:*** *If you had more time, in order to know more about what he's doing and where he's at and to have a more active role in planning for him, would more time, some release time, help?*
>
> ***Teacher:*** *Definitely. Even half an hour of quality time to sit down with the teacher aide and talk about what [student] has been doing, the input he can have into this class. Like we've been making Antarctica Huts, we could have sat down and really thought about what we can have [student] doing with this, we could have had a really good talk about it, but instead it's always sort of rushed. I said to the teacher aide, set [student] up, that kind of thing. We could use an hour like this [interview] easily. Lunchtimes, she's off, we're doing separate things, it's hard to get that time. But if there was release time it would be wonderful. At the moment it's on the run, walking down to the staffroom, that sort of thing. We do get time to talk in the classroom too, a chat, but that's rare, it's not something that happens every day.*

The ORRS-funded 0.1/0.2 FTTE

Across sites, the role of the ORRS-funded teacher in the 0.1 or 0.2 FTTE position varied widely. In addition to the administrative work associated with these positions, special education needs teachers undertook a range of tasks including:

- consultation with teachers, with very little, if any, hands-on work
- one-to-one work with students through withdrawal or in the classroom
- releasing the classroom teacher to work with ORRS-funded students
- consultation with and co-ordination of teacher aides
- a combination of the above.

Some schools had very clearly carefully defined roles which were responsive to their school's local needs. Caitlin's principal described the 0.1 FTTE special education needs teacher in his large primary school as being there:

> *Clearly to develop inclusive practice and I think we've got a teacher who can actually model that and who's got a pretty clear idea about what that would look like, and with the way we get the teacher aides to work so they are not velcroed [to the child].*

The 0.1/0.2 FTTE teacher described her role as a 'key worker'. The school had six students with ORRS resourcing and the teacher had three and a half days to provide support and undertake administrative tasks. She allocated one-and-a-half hours per child per week for one-to-one support with the child. The remaining time was spent liaising regularly with families; supporting teacher aides with their work and writing their appraisals; and working directly with teachers, therapists and any other involved professionals and services. As 'the base that everyone comes to' she felt that she had 'got to know my job as well as everybody else's to actually see that whole picture'. In her work with the students she maintained a flexible role, sometimes working with the student, sometimes teaching while the student's teacher was released to work with the student. An inclusive philosophy and her experience as a classroom teacher had helped shape her role:

> *I love the inclusiveness, and that's one of my goals – to make it inclusive. I've been in the position where the shoe is on the other foot, where I had a student [with special needs] in my class and I had lots of people coming and going in my class all day – they were all around this student and I couldn't really access that student and half the time it just seemed like this big disturbance in the back of the class. So I said if I was ever in this position again there were certain things I'd do differently and one would be freeing up the teacher… I take the class and the teacher can spend the time with the student – so that they are planning – really planning for that child. Otherwise it just sort of gets left and the teacher aide is there – and just supporting the teacher aide, having rules where they are not actually right beside the student all the time – they back off a bit and give that [opportunity for] independence … I like to see it really, practically work … changing people's views and values.*

In Leah's primary school, the principal felt that allocating half a day per week of teacher time to each ORRS-funded child was not a good use of the time because 'half an hour is such a short time each day you can't really get much done'. In his school, Leah's class teacher held the 0.2 FTTE position, and it would be difficult to find a reliever each day to cover this period. As a solution, the school had combined the 0.2 FTTE time for high needs-funded students into blocks of time that could be used flexibly:

> *So for two and a half hours a week the teacher is released … they might use that time to plan the activities for the week with the teacher aide, and they can sit down together and see how things operate. They can go right outside the classroom and they may work on some of the other work that they have, and not necessarily just one kid because of the additional planning that's required for the special needs child, so you've actually got the flexibility there. In one case we accumulate one hour for five weeks and then that teacher is going to have a day. I actually teach that day and that enables the teacher to really focus on the ORRS child. It will still benefit that child even if it's focused on the other classroom activities, and that's what mainstreaming is. It's not specialty stuff for Leah, it's making a programme into which that child can fit. Most of the teachers have chosen to be released on a Friday … or a Monday … to plan for the following week, so by Monday the new plan is in place.*

In some schools, the role of the 0.1/0.2 FTTE position was less clear. In one school this teacher supported two students with very high needs and one with high needs resourcing under ORRS. Her role included a wide range of responsibilities including: teaching programmes for students with special education needs; monitoring and assessment of student progress through IEPs; managing relevant financial and other resources; co-ordination of special support staff; training teacher aides; teaching one-to-one; organising equipment; and documentation. She had come from the classroom to this position, and learning the ropes had been difficult. She commented on the lack of training and support available to help her do her job well, particularly in the early stages:

> *Initially when I came this was totally brand new, and it was a huge learning curve for me and nobody was there to teach me how to do it so really I learned it by the seat of my pants … I think initially I was quite overwhelmed. I went from being a classroom teacher to this new job … I think yes, I could have done with some help with my role back then.*

This teacher felt that although the students were well supported by their ORRS resourcing, the 10 hours available to meet the requirements of a broad job description were insufficient, and she particularly commented on the difficulty of finding time to consult with and support teachers in both the primary and secondary parts of the school:

> ***SN teacher:*** *I mostly work with the teacher aide. I don't do a lot with [student's] primary teacher. I pop up every now and then when I've got a minute, to see how his other subjects are going. But I don't have much time to do that. I would like more time. I keep thinking how's his writing going. I haven't seen him for so long. I have half an hour in the morning and that's set in concrete … and in that time he's not doing his writing … I do find it hard to keep up with that and that would be true for what all three of the ORRS-funded students are doing … I don't really have any time to talk with their teachers. In the morning they're busy getting their classrooms ready … I could do with more time around that. In the afternoons I'm at another school and by the time I get back after meetings, there isn't much time either. It seems like a very full job but between the two schools it's only 17.5 hours altogether … I do a lot of work at home too.*
>
> ***Interviewer:*** *Is [student's] primary teacher ever in a position where she can think, Well I'm teaching this, how can I adapt this to suit [student]?*
>
> ***SN teacher:*** *No, no, I don't think, well, I don't even know actually, and that's terrible. She might talk to the teacher aide and the aide will adapt. In these respects I feel inadequate because I can't keep my hand on those things that are happening all the time … it's the time again, it's all very well to say they can have 10 hours but boy, you've got to fit a lot into those 10 hours! And I don't always think I use the time as well as I could … sometimes I wonder for [two of the ORRS students] whether that half hour plucked out of the day, whether it achieves much.*

There was no time available to reflect on her role or to establish a role that was flexible and responsive to the needs of students and teachers. In secondary schools, with several teachers involved, the time barrier was magnified:

> *My own role with those teachers – at one stage I felt like I needed a term plan from them because I'd like to think that [student] has the opportunity to learn more about what the class is learning … and I have asked for them … I'd like the time to talk with them more – meeting them in the staffroom or in the hallway, it's about as good as it gets really.*

One class teacher described how these circumstances could ultimately impact on student learning:

> ***Interviewer:*** *Has the special needs teacher been able to give you any support in terms of working out what your role should be with [student]?*
>
> ***Teacher:*** *Oh, no, I wouldn't really talk to her about that. I didn't really know she was someone I could talk to. I sort of saw her role as being his maths teacher, because that's all he goes to her for you see. I'm probably a bit ignorant about that … I would probably talk to the school's Head of Special Needs more about that, yeah.*
>
> ***Interviewer:*** *Have you talked to the Head of Special Needs about that?*
>
> ***Teacher:*** *Yes, but there is, the feeling I get, and this is not particularly from the Head of Special Needs, but just from the whole situation, is that there's not much more we can do about it, because of the class … I do get some feedback from the special needs teacher about [student's] maths but often it's hard to find the time. She will try to talk to me in class and I have to say I can't talk now, I physically can't because something could be happening in the class. I know the level he's working at*

> *and that's from the IEP. If I had an hour a week I could talk with her about his maths. I'd have a better picture of his learning.*

Therapists

Therapists providing itinerant support to local and rural schools used a clearly articulated consultative model of integrated effective practice. Across both GSE and Child Development Services teams, therapists described their role as involving role sharing and role release so that therapy could be integrated into functional routines at school and at home. This involved a process of educating and supporting parents and school staff (primarily teacher aides) to ensure that the children's therapy goals could be met in both settings as required, while maintaining some flexibility to meet individual needs.

Therapists described their role as supporting school teams to see that what the school did itself was as important as the therapists being there. The collaborative consultation model involved therapists working with the student and school staff (primarily teacher aides and the 0.1/0.2 FTTE ORRS-funded teachers), modelling therapeutic approaches, making suggestions, responding to questions, and giving staff the knowledge, information and skills needed to work with their students.

Several therapists referred to the negative impact of heavy workloads, which they felt could compromise their ability to be effective in supporting students' lives at school. This was particularly true for students who received support under the moderate contract, but whose needs were just below those needed to attract ORRS resourcing. In these cases, some therapists adapted their role to respond to the teacher's needs for support in the classroom to meet therapy goals. This happened through on-the-spot problem-solving with school staff, and through consultation with other GSE staff who had the necessary expertise.

Therapists in GSE teams also talked about the importance of sharing roles, and of organising themselves so that visits to schools by one therapist could also be used to follow up on progress in other therapy areas. Weekly team meetings in one GSE office focused on two or three students in one geographical area, and provided therapists with an opportunity to remain up to date in relation to students' therapy goals. While some slippage was noted in terms of their ability to maintain this routine, therapists described this as a useful way to ensure that visits to schools could be productive across therapy areas.

The urban Child Development Services team felt that since SE2000 their team's approach had been dominated by co-ordination of services for families, which made it difficult to achieve their goal of providing a family-oriented service, building on families' aspirations for their children. They tried to ease the impact of this by maintaining good links with Ministry of Education, Special Education and CCS with regular meetings each term, particularly around the transition to school.

Time to be a team

Working and collaborating as a team was seen by everyone involved as important and desirable, and everyone interviewed – parents, teachers, teacher aides, therapists and principals – described feeling that they were a member of a team. However, the interpretation of 'membership' did seem to vary across participants. People talked about a sense of belonging to a wider group focused on supporting a student with a physical disability. There was a general sense of not being alone, and of having some support available if it were needed.

Therapists working together on therapy teams described a depth to their team that was less apparent elsewhere. They emphasised that relationships, shared knowledge and shared values cemented their status as a team, and there was a strong sense of caring and support for each other in jobs that were enriching, but also challenging and exhausting.

It should be emphasised, however, that time was described as a major barrier to achieving good levels of team work in schools where therapy was itinerant. This was further complicated in rural areas, where therapists' travel time encroached on the time available to spend with students and teachers; and in secondary schools, where more teachers were involved in the student's school life. A principal described the issue for him:

> *I think acknowledgement of the time – the time it takes to actually sit down with a group of people and co-ordinate a meeting where you can discuss issues relating to the management of the child at school. Time is money and often you're being asked to put these gatherings together out of school hours or even during school hours, and it costs money. So whether that could be factored into a formula [for resourcing] I don't know.*

Travel to rural areas also encroached on itinerant therapists' time available to provide direct support to schools, children and families. This issue was closely tied up with workloads. An RTLB providing support to rural schools across a wide geographical area had a supportive relationship with the CDS team she liaised with, but her biggest concern was her workload of 30 students across eight schools, and the 500 kilometres she travelled each week:

> *So in terms of professionals working together, I think it works well; in terms of the support that kids get in getting what they need, I don't think it works well. I think there is not enough account made for the fact that we have such a huge geographic area and that we just have to spend so much time travelling and the limitations that that places on everybody's job … Like how much more work can you do?*

Most teachers saw themselves as team members, but some teachers felt that they were not yet able to take on the full responsibility for students with physical disabilities in their classroom, even though they saw this as a top priority. For some, the lack of time to engage in meaningful planning and curriculum adaptation for their student, and to negotiate roles and responsibilities with others on the team, created huge personal tensions. One first-year teacher said:

> *I do feel part of a team, but sometimes I feel I can't participate because I don't feel as though I have a right to as much input because I don't really know what's going on all the time … Even the occupational therapist, she has come in to talk to me about what she's doing and what I need to do and I just don't have time to sit and talk because the class is there. It's the same [issue] – time, being given the time where you could sit and chat … Sometimes I feel like I don't do enough for [student], but a lot of that is to do with my class because it is quite difficult, their behaviour restricts my contact with children one on one … Ideally I would have far more one-to-one teaching time with him, have the time, set the class up and be able to say, OK, now I can have some time with him … I feel like I really don't know quite what he is doing because of everything else, and like I say I'm overwhelmed with everything else that's going on I think, oh, I don't even know what he's been doing today, and that. I would like to know.*

A secondary teacher felt that communication between herself and the rest of the team was not yet well established. This meant that she felt poorly informed about a student with very high needs in her class, particularly in terms of the school's expectations of her as this student's teacher. She had not yet met any of the therapists supporting the student, although she wanted to because 'I think it might help me to plan so I can include him more in the lesson'. Many of her interactions with those best able to inform her (in particular the 0.1/0.2 FTTE teacher and the teacher aides) take place ‘on the run’ when other things were happening in the classroom. These opportunities were inadequate for addressing her need for detailed information to inform her planning and teaching. She valued the teacher aides, who were ‘just as keen as I am to see [student] participate a lot more’. Overall, she did not feel like a team member:

> ***Teacher:*** *I think there is a team working with [student], but I don’t feel like I’m part of that team. I think the teacher aide does a lot to make me feel like I’m important to [student]. She’ll let me know how he is, she’ll explain if he’s late. But other than that I don’t feel part of a team.*
>
> ***Interviewer:*** *Do you think there’s an expectation that you have something to offer [student]?*
>
> ***Teacher:*** *For myself I do.*
>
> ***Interviewer:*** *Yes, you feel that yourself. Do you think the team feels that?*
>
> ***Teacher:*** *No.*

While teachers valued the support of itinerant therapists, some described having no or limited consultation time to discuss the content and focus of therapy, or the implications of therapy for the classroom. This left teachers feeling ambivalent about their ability to contribute to the team’s work.

> ***Teacher:*** *I’m just so busy. Even the time the special needs teacher takes [student], I couldn’t tell you the times he goes out. It sounds terrible I know.*
>
> ***Interviewer:*** *So when the therapist comes to visit it would be quite useful for you to have the time out of class to sit and talk with them?*
>
> ***Teacher:*** *Definitely, definitely, that would be wonderful.*

For this teacher, time was a barrier, and having some release time to talk with therapists and with the special education needs teacher would, she felt, help clarify her role and give her an opportunity to engage in some informed planning.

Interventions

Assessment

To understand approaches to assessment, therapists and teachers were asked the question: How do you know what you are doing works for the students you support? In response, reference was most commonly made to the IEP as a vehicle for assessing progress, and to informal judgements about how students ‘looked’. In relation to IEPs, teachers and therapists described measuring progress against IEP goals, and discussing progress with other colleagues. One therapist described the ‘huge success stories’ related in IEP meetings and the signs of ‘school ownership’ as critical indicators of success:

> *… there is a sense that with the IEPs there are huge success stories – the schools are telling us … we’re right, and that’s how I know I’m doing a good job, because they are owning the child and the child’s learning, and the child’s happy, and so in a way that’s my indicator when I go in [to a school].*

Informal observation of students was also mentioned. One occupational therapist said:

> *I go to the schools and I can see that the student is making progress in an area that was identified as being a problem. That’s how I know the child’s making gains. I don’t know specifically that it’s about me, although I have a sense that what we do as a team works … I can see that I go in and I put in a*

> *piece of equipment, I put in some ideas about fine motor skills and I go back and I can see them in the child's day and that's how I know …*

This therapist had given some thought to functional assessments, but her heavy workload meant that it was difficult to use these thoroughly:

> *I can look at the area of occupational performance and say, has the child gained skill in that area? But I don't have a regular measure that I use for that, although we've often thought that school function assessment would be a useful way of doing that, but with the numbers [caseload] we can't use that sufficiently.*

A physiotherapist felt that assessment was one area where the team might be able to improve, and noted that parents' voices may not always be heard when it came to assessments of their child's progress:

> *I'm not certain that we are particularly good at assessing. I mean some of the other therapists might disagree. I guess how we know is that when we get to the IEP if you've achieved the goals that were set at that IEP you can take them off the list. Or if people tell you that what they've been doing was a waste if time, or if something you were going to set up. But I think that whole sort of sense of satisfaction you get at IEPs is probably the closest we get to the whole thing, apart from doing a particular assessment to see if, say, a person's knee flexion has improved, which may not be a particularly useful measure anyway. I think we might not always hear from parents in that kind of situation, what their real feelings are about improvement, because it's not always the easiest situation for them, is it?*

Attitude and environment change

Most of the schools with itinerant therapy supported the inclusion of students with special education needs in their school, and this was reflected in their written policies on special education needs as well as in an underlying inclusive philosophy referred to by principals and staff. GSE therapists working in schools were clear, nonetheless, that changing attitudes and environments to support students' access to the curriculum was part of their job:

> *We are involved at one school in helping the school to make modifications necessary to the environment so students can access parts of the school which are relevant to their particular programme … we have been involved in working with the school to challenge some preconceived ideas about what people with physical disabilities can do.*

There were times when schools themselves needed to focus on attitudinal and environmental changes which ultimately supported the development of students with special education needs. In one school, the transition of a student with very high needs to the secondary school caused some nervousness among secondary teaching staff. The HoD for special education needs took the initiative in this case:

> ***HoD:*** *It was a real big worry for some of them., until we just got everyone together and explained, 'This is what we'd like you to do and their teacher aides are there to support you'.*
>
> ***Interviewer:*** *So they knew why he was in their classroom?*
>
> ***HoD:*** *I think so.*

Such changes generally occurred smoothly, although staff became polarised in one school when the board of trustees equivocated over the installation of a ramp. Staff supporting students with disabilities, in particular, had found the discussion around this issue very disturbing:

> *The school was really definite they were not going to provide access to that field for people who were in wheelchairs, basically. And at that time I was working with Matthew [another student with very high needs] and to me that was a huge issue, and I was very, very disappointed with that. Very disappointed. And as it turned out, I think the Ministry stepped in and said, it's got to have access.*

Physical access was also an issue for another parent of a senior primary school child. While the school had been 'really good about accessibility':

> *I was mildly horrified when they did the staffroom and the office, and there was no access for her. But I figured that there were other things in life that I needed to talk about more than that … things like that … as a parent you have to work out what you whinge about and what you don't.*

For the student herself, access was a major issue, and perhaps much bigger than adults in the school realised. In response to the interviewer's question, 'What are the things you like here?' she replied:

> *We've got a new library that's accessible … before it was a building that had steps … I can't get into the hall at playtime and lunchtime without people pushing my wheelchair.*

Some areas of the playground were also inaccessible and she had to 'just watch other people on the playground'. In response to the final question, 'What would the best school in the world look like?', she replied, 'Accessible'. This included access to the administration block: ' The office…cos then you can do the same things as the other kids'. When this student won a medal in a sports competition, she had to pull up in her wheelchair next to the staffroom window to share her good news with school staff.

One student with very high needs at secondary level was not using any augmentative communication device. His 'Big Mac' communication devices had been discarded because he either failed to use them, or he was unwell and unable to use them. There were plans to reinstate these, but his class teacher commented that a lack of good communication methods meant that it was not always easy to know what the student was trying to communicate:

> *When I talk to him it's usually the teacher aide who responds. I can tell when he's uncomfortable and I can tell when he's pleased to be doing whatever it is we are doing. He'll smile and he'll touch me. I can tell he's comfortable being in my classroom. I can tell if he's being made to feel uncomfortable. But that's all I can tell … I'd like to know if he's enjoying himself. I'd like to know if he's happy. I want to know if he's feeling sad. I want to know if he's doing what he wants to be doing and I don't get any feedback about that.*

In contrast, where students did have good physical access, there seemed to be positive spin-offs. Leah's playground experiences expanded when she learned to use a power chair, and she was able to make choices about activities, places and peers with whom she would play.

Approaches to teaching and learning

Both CDS and GSE teams placed a very strong emphasis on ecologically based approaches to teaching for students with physical disabilities. At the school level, GSE therapists talked about the importance of a shared understanding of what inclusive education implied for their work, of children's needs, and of the approach used to integrate therapy and educational goals and experiences. In particular, therapists talked about the importance of:

- a consultative model in which school staff were taught how to integrate therapy goals into natural routines
- communication – working in one office provided numerous opportunities to share information and plan as a group for individual students
- role sharing – sharing students and schools meant that team members could use each other to communicate with schools, and share roles. Being able to work across the traditional therapy boundaries meant that students could receive co-ordinated and continuous support.

Both GSE and CDS teams showed a high awareness of the need for teaching and learning to take place in natural contexts. Physiotherapy goals, for example, could be met in the classroom, during movement around the school, during physical education and swimming, and in community settings. Some children with physical disabilities also described seating positions and stretches they could do while engaging in other aspects of the curriculum (e.g. while listening to a story on the mat). Interventions were described as always having a functional purpose, with a move away from the notion of exercise for exercise's sake. A physiotherapist described her team's approach in the following way:

> *I try to get the staff away from the idea of doing an exercise programme in the withdrawal room, and I've encouraged them to, I've tried to say well, when he's moving between classes you can do this with him, encourage him to do this for his balance, when he gets up and down off the floor, encourage this for his strengthening. Identifying the needs like any physiotherapist would do. But putting into more functional settings to practise it. To me the bonus of doing it in education is that you are learning a skill, and you might do that in isolation to start with but if you can't generalise it when you go back into your life it's not much use. So you learn the skill and help the people working with him to see that so many situations during the course of the day can be used to reinforce that skill. That's where I see physiotherapy working in education. You learn it by doing it. So if you are going to improve something, if they see they are going to be able to join in with their mates and kick the ball around, that gives them a much better reason for doing it than if this woman takes me off to kick a ball around for ten minutes. That whole inclusion thing really drives the way I function.*

An occupational therapist took a similar approach to therapy, and based her approach on the social model of disability and current health policy, which emphasises the provision of services in the community:

> *We don't give people programmes they have to do. We try to find things that occur in the child's day and they become the therapy [and the medium for therapy] … and we do that because we think it is less stressful for the child and family and easier to get more repetition in … A lot of people are critical of what we do because it's not hands on, but that makes me want to laugh, so much because it's so old fashioned and I have a sense that what I do is really working and that's what I enjoy.*

However, in reality this integrated approach to therapy was not widely understood in a school community and was therefore not always easy to achieve. Parents and school staff did not always understand what integrated therapy was, nor did they necessarily understand that using this approach would mean students' therapy needs could be well met, or that a one-to-one approach by a therapist was not necessarily the best way to work. It was very common for parents, in particular, to feel that, because the therapist was not working directly with their child, insufficient therapy was being provided at school. One parent reiterated the comments of many others:

> *I'd like to see more physiotherapy – the physiotherapist comes once a term I think, but not necessarily to do hands on. It's to talk to the staff, and makes sure it's going all right. But I'm used to more hands*

> *on than that because [child] was at Conductive Ed. So, if anything, that's an area where I would like to see more happening … I don't know ideally he probably should be having his stretches every day at school, daily physiotherapy, yeah.*

This concern was also echoed by several teacher aides.

For parents it could also be difficult to reconcile the different therapeutic approaches used in the early childhood and school years. One therapist said:

> *In terms of transition, I don't think we are doing enough to help parents understand the difference between the Health-funded physiotherapy their child had as an infant and young child and the focus in the school situation. They are quite different therapy experiences. In the early years they build up a relationship and there are supports there over and above therapy that are very different in the school years. And yet we are working towards the same goals.*

This therapist also appreciated that the shared understanding about integrated therapy held by her GSE team was not always shared by parents, or by team members in schools, and sometimes in order to meet others' expectations she felt obliged to work in more traditional ways:

> *We try to take a collaborative team approach and that means having a group of people with a range of skills, and the team at school, the teachers, teacher aide and family talking about and working out the best way that we can provide a service. Making sure we work well together, and that we all know what each other is doing … Ideally our focus should be the school but the reality is often that the focus is the student … I think we don't explain enough that in order to make the best gains for the students, it's what the school does as well that will make as much of the change as us being there … it's really easy to just slot into what people expect you to do so in reality what I do may be different from what my head says is the best method of service provision. I mean I remember one day Alan just lay down on the floor and said to me, 'Mum said you would be coming today to check my legs, so here you are, do this to me!'*

Some parents and teacher aides interpreted the consultation model as meaning 'the teacher aides and parents get to do [the therapy]', suggesting again that the model of integrated effective practice was not always well understood by all team members. One parent worried that things 'fell over' when it came to the implementation of a therapist's suggestions because of lack of time in the primary school classroom. She felt that in her child's case, learning goals took priority over physical goals, and that the lack of physiotherapy meant her child was less supple. The teacher aide agreed and felt that the physiotherapist had unrealistic expectations about what could be achieved in the classroom. For example, it took about 10 minutes to move the student on to the floor to do stretching during reading time, and by the time they were in position, the reading had finished.

Overall, the teacher aide found it hard keep up with the class programme and fit in therapy without a structured programme. Consequently the teacher aide and parent felt that the student's physical needs were in danger of being left out 'when you're trying to squeeze everything in' to a small amount of available teacher aide time:

> *I think sometimes some people that have come in are a bit kind of, you know, they have the ideal, you know, this is what should happen … they say, 'Oh, we could do this, we could do that', and 'Well, actually, that won't work'. And I don't like having to say that … and they do listen … until the next time when they say, 'Perhaps we could do this'.*

She worried that, in reality, physiotherapy could take time away from the curriculum:

> *The only thing I could say about physical therapy is that's the bit where sometimes, they don't sort of realise that, you know, [we don't have] a huge chunk of time and we need to get her down and exercise her and push on this and you know, 10 minutes down here and 10 minutes doing that. In reality, OK, I can do that, but she'll be losing 20 minutes out of her maths time, you know, or something, or during reading time. But I mean, they read for 10 minutes quietly to themselves – you get [student] out of her chair, down on the ground, get her legs stretched out, and there's your 10 minutes … I still think the physical skills are important, but the stretching out and all the rest of it, you know, that's just, I mean I suppose maybe because I don't understand it very well at all, you know, will 10 minutes once a week stretching out on the carpet make that much difference in the greater scheme of things? I don't know. Whereas missing out on 20 minutes of maths might make a difference.*

A possible solution was to spend some in-service time with parents and staff working on a shared framework in relation to integrated effective practice. One therapist reflected on this as a possibility for her team:

> *The GSE team has shared goals [about the model of therapy provision], but I'm not sure that this extends to the whole team including the school … we would need time to establish that across the whole team and the best way to do that would be for us all to go to the school and have an in-service day, a shared planning day would make quite a lot of difference. And maybe that's something, actually, I hadn't thought of that before, I think we should do that. This would also help the teachers to learn more about what their role could be. I don't know where the money would come from, you would need release time to take the teachers out of the classroom for the day, but that's the thing about teaming with a school. I go to the school and I might see the special needs teacher and I might see each of the boys, maybe one teacher, and I'm only here a couple of hours then you're away. You haven't got time to see everybody … time is the thing actually. Some schools will plan some release time for teachers so they can come out of the classroom so they can talk to you.*

One GSE team had tried this approach by running courses on development and fine motor skills, and by supporting school staff to feel good about implementing therapy-related strategies. As one therapist said:

> *Many areas report schools saying, 'Why don't you fix their hands?' And that does happen [in our area], but not so often. We've run courses [for schools] and it's about sharing knowledge and not holding on to it as something we own professionally. But it's giving our knowledge to other people. In a way, giving people permission to observe kids' development and promote it.*

In a rare example, this therapist described being caught out by Leah's school staff when she suggested a way of supporting Leah at lunchtime. There was no teacher aide support over this period, Leah was a slow eater and had little time left over to play with her friends:

> *I did the occupational therapy thing with her eating once, 'This is how you eat' – you know, thinking of the old days, and then they said, well actually, we thought we'd get some kids to feed her … and I said, well that's great, and so they feed her now.*

The children were, however, beginning to go off this arrangement, and this meant that Leah needed some further support in this area. The school arranged for her to eat lunch earlier, giving her more time to be with her peers, but the occupational therapist pointed out that arrangements could be transient and needed to respond to children's development and over time: 'There's a time when [strategies like this] are naturally appropriate and times when [they're not]'.

Location and provision of service – therapy in or out of the classroom?

One area where teams did not always have a shared perspective on approaches to integrated practice was the issue of withdrawal from the classroom for therapy. Three general opinions were offered.

- Therapy should be provided in the classroom, because this supports a functional approach in which therapy provides access to the curriculum. Classroom-based therapy was less likely to make a student feel different, and would ensure that the student did not miss out on the curriculum and activities of the classroom.
- Therapy should be provided through a withdrawal model in which the student was taken out of the classroom. Withdrawal was considered desirable because it allowed for regular physiotherapy to take place irrespective of classroom activities and constraints. It was private, and students were therefore less likely to feel different.
- Therapy needed to be responsive to the age, needs and preferences of the student and their parents. Some therapy could be readily integrated into classroom routines. Other therapy goals may be met through dedicated therapy time involving withdrawal from the classroom. Privacy was important for some students, and students needed to be able to express an opinion about what was right for them.

Caitlin's situation as an eight-year-old suggested that flexible approaches to the issue were desirable and that the third option above was the preferred one. According to Caitlin's mother:

> *They're saying Caitlin's not supposed to be out of the classroom, but Caitlin doesn't want to lie on the floor and do stretches in front of her friends. You know. So at least they've looked at that and realised there's no way that Caitlin is going to lie on the floor and put her leg in the air in front of 30 other kids … she doesn't want to and she doesn't like them asking [about it] now. She's got to the point where she doesn't want them to see her with AFOs[31] on – she doesn't want to look any different.*

Caitlin's friend Hannah agreed with this point of view. Hannah felt that 'some people are silly and naughty in the classroom and they'd get in the way'.

Caitlin did not mind doing some stretches in the classroom if they were part of the classroom routine, and talked about how her stretches could be done using playground equipment:

> *I do some stretches in the room, like I sit on a box and use my heels [to stretch] … and I do stairs and sometimes I play on the playground and skateboard thingy … you use your arms and push it along … I usually make myself dizzy going around in a circle ... we learn to play hopscotch – I jump.*

The GSE team leader could also see good reasons for some therapy being in class:

> *The child, as they get older they don't want to do those things because they know they're different. 'I don't want to be taken out to do my exercises.' So if you've got a good classroom teacher who can integrate it into the programme it's great.*

Alan was also withdrawn for special music, remedial reading and stretching. While his teacher was happy with this arrangement, she did appreciate some flexibility. She was concerned that:

> *… if he is missing out on something that everyone else is doing I think that's a negative kind of, it's doing something negative to the situation because the kids see him missing out on something exciting and I think he feels different.*

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[31] Ankle-foot orthosis.

Children's perspectives can often throw new light on a subject, and this area of discussion was no exception.

While his teacher felt that Alan was aware that he needed to do these things, Alan did felt a sense of compulsion when it came to therapy outside the classroom or beyond the functional routines of the school day:

> ***Allan:*** *I go somewhere else. I go in the spare room.*
>
> ***Interviewer:*** *Do you mind going out with them to the spare room?*
>
> ***Alan:*** *I have to put up with it*
>
> ***Interviewer:*** *What would you rather do?*
>
> ***Alan:*** *Stay in the classroom.*
>
> ***Interviewer:*** *What about for physiotherapy [stretches with the special needs teacher]?*
>
> ***Alan:*** *I'd rather do that down in the spare room because it's quieter.*

He described having some therapy in the spare room, which was 'Okay, I just have to put up with it. I just have to do it'.

> ***Interviewer:*** *If you were doing something fun in the classroom and you didn't really want to leave, would you say that?*
>
> ***Alan:*** *Yes – but I would just have to do it.*

Another primary student's parents described what happened when their son was asked to forfeit a sports day race for therapy:

> *He's really assertive. On sports day he did the 100 and 200 metres races, he did the races himself, he finished way behind his peers but he finished them, he ran them. And in between the races the therapist came and wanted to do [therapy]. And I thought, well, it's in between [races] that's fine. And he said, 'Mum, I'll tell you what I did. Well, I was going to miss my racing. Sue wanted to go and do therapy – therapy!!! And I just said to her, I'm NOT doing it, and I just walked away'. And I had this vision of him just standing there, and the therapist saying, 'We've got to do therapy', and him saying, 'I'm not going to miss my race!' And I said to him, 'I'm glad you did that, it's important for you to do your race.' It was delightful. He felt confident in himself to make that decision that the race was more important.*

Outcomes

Friendships

Six of the eight students in these regular schools experienced major difficulties with friendships at school. Friends and friendship was identified by all of their parents as an area they worried about. Teachers, on the other hand, were much less likely to initiate comments about friendships, but were quick to respond with concern to this area of the children's lives when the topic was raised.

Undoubtedly children's physical challenges presented the greatest barrier to participation in the games that children and young people play at school with their friends during break times. Rose's parents said:

> *The other kids are into sports, playing soccer, netball, and Rose is not up there. And this I'm finding quite hard. I think she is too … her friend Emma is OK when she comes here to our home, but at*

> *school she's away playing with the other kids, Rose is left there … I'd like to see at school work more in the playground area with an adult, trying to get other children involved with Rose … The other kids they're out there in the playground initiating together, and Rose will be just wandering away kicking the dirt and I'm thinking aaah, what can we do?*

Other parents agreed, but several commented that friendships could not be forced.

In terms of an intervention in this area, school staff did not always know what to do either. A special education needs co-ordinator talked about this in relation to a primary child with ORRS resourcing for high needs:

> *He is quite a loner, and when I'm in my classroom at lunchtime he does come and visit and I say, 'Off you go!'… I don't really know what to do … he'll come in and plonk himself in the chair there and yap, yap, yap, when really he should be out playing with his peers. But his peers are always away playing rugby and cricket … so he'll toddle off to the library … sometimes when I'm on duty he'll say, 'Can I come with you?' and I just let him, and we just wander around and watch what the kids are doing and yap away. I don't know what to do to be quite honest.*

Parents struggled with this area of the children's life and were equally at a loss as to how to improve things for the children. Alan's mother was pleased with his learning opportunities at school, and with his overall progress, but friendships were a concern:

> *I raise it as an issue at nearly every IEP, the lunchtime thing. I ask what can we do as a parent? What can we do? It's hard to explain to the school, they say he's really happy, and the kids are good to him and we know that. It's just that he doesn't have a peer friendship. The kids are wonderful to him, they look out for him . To build that friendship it's a basic thing … we encourage it here by having kids to stay and making sure they have a good time … I think the school does listen, but they don't know what to do about it. They have brought games in and tried to encourage the teacher aide to stand back. But they expect that as kids get older and stop tearing round it will get better.*

Another secondary student with very high needs and a combined learning and physical disability presented equally difficult challenges to the school staff. Although he had been in the school since he was five, teachers could not identify any friends. His regular school education provided him with numerous opportunities to socialise and be with his peers, and some of his peers did greet him in class and respond to his noises. His peers were also observed to call out greetings to him in the playground. Beyond this, however, he seemed to have few opportunities to be part of a social group. A special education needs co-ordinator observed that:

> *None of his peers, I don't think, have anything to do with him out of the classroom … but some of the younger ones [from the primary school] will go and sit with him and talk with him when he's outside … it's a concern, but what can you do about it?*

Twelve-year-old Laura did not have close friends in her rural school. Her teacher aide was unavailable for support during unstructured break times, and the teacher aide was unsure about her role in supporting social relationships. This was something the principal worried about, however, and she described looking out for Laura in the playground at lunchtimes. Laura had emphasised that poor access in the school had sometimes prevented her engagement in social activities, although some recent modifications had made things easier. Her new power chair was also highlighted by several team members as giving her choices about participation in social groups and playground activities. The school had previously used a buddy system for peers to push her chair, but 'the kids got sick of it'. When asked about this, Laura's friend said, 'Sometimes it was like, I'd rather play on my own'. In this regard, the power chair had also allowed more equitable relationships to develop, and removed the association of children's relationships with 'helping'. A therapist also pointed out that the power chair had helped to redefine the team's focus in terms of learning outcomes. Prior to using the power chair, the focus was on teaching social skills, but with the chair 'she's off with the other kids and she's made social gains, she's involved without needing [the children's] help with mobility'.

Two students did have strong and typical friendships. Caitlin's large decile 5 school had gone some way down the track to achieving the kind of playground environment that Rose's mother aspired to, by developing strategies that focus specifically on creating a prosocial environment 'where kids have got choices and everyone feels included'. The 'playground team' comprised teacher aides, trained in support work, including supporting children in the playground. The playground team met weekly, kept minutes and passed the minutes on to the rest of the school staff. They also attended the school's weekly 'behaviour meeting'.

The playground team's role had evolved in response to some early childhood research which suggested that an adult sitting in a comfortable place with spaces for children to join them can promote social interaction among children. The principal felt that this model might work in a busy playground which could be overwhelming for some children:

> *Instead of duty periods [for teachers] and being out looking like a policeman we need a support person so that little kids that maybe just haven't got somebody to play with – or need somebody to talk to – can just call in. Now the impact of that on our special needs kids is well – I know kids – they have social needs – they can sit there and chat away [with the adult] if they want. And they're free – it's a good place to be. It's a safe place anyone can go to. And from there they can be redirected to organise games.*

The special education needs teacher at Caitlin's school also saw her role as supporting this area of Caitlin's life at school, and used games to encourage peers to join in with activities that also supported Caitlin's physiotherapy goals.

Leah was described by her team as very social. She had a wide range of friends, and her class teacher felt that she had the skills needed to be proactive and to make reasonable choices in her social relationships with others. This teacher was observed to model inclusive approaches to teaching in her classroom and to demonstrate equitable relationships with her students. She had a strong sense of ownership and responsibility for Leah as a learner in her class, which translated into an active role in planning and teaching. She made a particular effort to ensure that she was well accommodated in the centre of the classroom, and that she was actively involved in the curriculum alongside her peers. Her teacher also expressed a desire to ensure that she was not withdrawn unnecessarily from class, and that she was given every opportunity to participate in the full class programme.

Class promotion decisions did not always take children's friendships into consideration. Caitlin lost several friends from her class in her third year at school when she was placed in a composite class with another child with a disability. This young boy became her main friend in the class that year, and her mother described her as 'quite unhappy' because she missed her friends. In Year 4, she was placed in a class with her best friend, Hannah, and that, along with a change of teacher, had meant that Caitlin was happy and enjoying school. Christopher also developed a friendship with a classmate, but this relationship fell through the following year when they went into different classes.

Learning gains

Parents valued the emphasis in schools on learning outcomes for their children, and where students received ORRS resourcing, they were considered by parents, teachers and therapists to be accessing the curriculum and to be making progress towards the learning goals specified on their IEPs.

Some schools provided a broader context in which learning outcomes were highly valued for all students. In Leah's school, high expectations were considered to have an important link with the curriculum and with student outcomes. With Leah, there was an assumption she would read, but her principal felt there was a danger with some children that low expectations limits their achievement. For one child attending the school in the past:

> *… a lot of professionals were not prepared to say yes, you should aim at [reading] – they basically said, 'Oh, we'll have to set him goals and take it one step at a time.' Well, yes, but I think it would have been helpful if we'd thought, 'Right, out there, this child is going to read'.*

This context was supported by the school's special education needs and equity policy, which had a strong inclusive focus. The policy emphasised 'the highest standards of achievement through programmes which enable all students to realise their full potential as individuals', and 'equity of opportunity by identifying and removing barriers to achievement'. It was the specified task of the principal and staff to 'analyse barriers to learning [and] the school will provide equality of opportunity by endeavouring to identify and remove barriers to learning'. This policy was observed being put into practice in Leah's classroom, where Leah was encouraged by her teacher to be independent. Primary learning interactions occurred between Leah and her teacher, and her teacher aide supported this by ensuring that she was 'there for Leah, but not there to help her. She's got to help herself'.

Ricky's mother appreciated the emphasis on learning outcomes for her son now that he was at college, and she appreciated that the school did not only focus on behaviour, as some schools had done in their past:

> *All they wanted to work on were his behaviour problems. Not his learning … and he's got special needs. He's a difficult child sometimes. He's also a very caring and very loving child most of the time. But if you're the class clown or if you can't read what's being written up on the board, of course you're going to play up.*

Laura's mother also saw this area of her daughter's school life as critical. In particular, she felt that teachers always needed to show her that she is achieving, and that achievement needs to be understood within the wider context of the challenges imposed by Laura's physical disability. Laura had no reader-writer at school, and her mother said that difficulties in these areas made her feel as though she was achieving at a lower level than her peers. It was important for teachers and other school support staff to understand that 'Laura needs to know that she is achieving'.

Finding the right balance between learning and physical goals was a common problem, and Laura's mother worried that learning goals took priority over physical goals. Laura was a 'priority' student for the physiotherapist, who saw her twice a term. Visits involved consultation with the teacher aide and Leah's mother, and the physiotherapist provided a written report. But Leah's mother worried that Leah was not having enough physiotherapy, and that things just 'fall over again because of lack of time'.

For some teachers and therapists, adapting the curriculum and finding meaningful outcomes for students with very high needs remained a real challenge. A special education needs teacher said:

> *I don't think the curriculum always suits them … it is very hard to adapt the curriculum for Geena [another student with very high needs] and Ashley. We feel we make things up as we go along. The levels don't go low enough, and with Ashley we can have days when he is not responsive for some reason. I don't get many opportunities to do PD [professional development] which is relevant [to help us plan for Ashley in the mainstream classroom], courses are few and far between, and often the course doesn't really suit. I do get concerns about the extent to which their learning needs aren't met.*

Social versus learning outcomes

For some children, the emphasis at school was primarily on social and behavioural needs, and less on academic and curriculum-focused outcomes for students. This was true for Ricky, and for Rose, whose parents were more likely to focus on learning outcomes.

Rose, at the age of six, was considered to be very bright, but learning in the curriculum areas was considered secondary to having her feel comfortable at school and part of the class and school environment. The principal said:

> *I would think that it would be fair to say that there's probably less emphasis on Rose's learning within the classroom at the moment than on developing critical social skills … There are some aspects of her learning where she is well in advance of her peers, but her social skills, or lack of, are going to impact on her learning at a later date, so that's where a lot of the emphasis is going.*

Rose's teacher agreed and said that:

> *I just have this trust that the work her Mum does at home with her is where she's getting that support for her academic development mostly and what I believe is her main purpose in the classroom for herself, her own personal goal, is to develop those social skills. My focus isn't on her absorbing the academic content and marking their learning. For me the focus for her, what I see as her personal goal, is that I see her relating to other children in more appropriate ways.*

Rose had no ORRS or moderate contract resourcing, her teacher had a small amount of support from an RTLB, and Rose's parents paid for a full-time teacher aide. A teacher aide made the same comment about a primary-aged child with high-needs ORRS resourcing: 'I think for [student] a lot of what he'll get out of school is social. I think, I don't really know'.

Ricky, at the age of 11, had a range of needs across learning, social and behavioural domains, but the emphasis in class was on his social skills. His mother placed a priority on learning outcomes, particularly reading as a goal for her son. She also wanted him to be happy. His teacher, on the other hand, identified 'being able to mix socially' as a top priority. With no ORRS or moderate contract resourcing, it was difficult for his teacher to focus on his learning needs, even though these were significant, because until his social challenges were addressed he was considered to be in no position to learn.

Physical outcomes

Several parents and some school-based team members raised questions about the adequacy and amount of therapy provided at school. This question also appeared to be tied up with misunderstandings about what therapy in school looked like. In particular, where therapy team members used an integrated and functional approach to therapy in the classroom and school, school staff and parents did not always appreciate that therapy goals were being catered for. Laura's mother was uncertain about whether Laura had enough physiotherapy at school, and worried that without it she becomes less supple. She wondered if there was an emphasis on learning outcomes to the detriment of physical outcomes, and described a major difference in the amount and type of physiotherapy provided in the early childhood years and that provided at school. She described this as 'a loss of therapy'. A therapist, on the other hand, thought that Laura's mother was instrumental in achieving a balance between curriculum and physical needs: 'Laura's mum is in control of that balance and very much has got her finger on that'.

Therapists, on the other hand, were generally happy with the provision of physiotherapy in situations where resourcing levels were good and where therapists were available. Therapists with heavy workloads did worry that for some students physical goals could be compromised, although some GSE therapists described a capacity in some schools to continue to integrate therapy without much direct therapist contact. Therapists described these schools as characterised by:

- good leadership structures and clearly defined roles and responsibilities
- a key person with responsibility for students with special education needs who understood what therapy teams were trying to achieve in schools
- good levels of communication between itinerant therapy staff and the school
- teachers taking responsibility for students with physical disabilities in terms of planning, teaching and assessment
- clearly established teacher and teacher-aide roles, with the teacher as the key person.

Nonetheless, the case studies suggest that there were several points at which communication between therapists and school staff could break down. For physical outcomes to be prioritised, teachers need to be included. While therapists suggested, for example, that teacher ownership was critical to the achievement of integrated effective practice, the teacher aide and the special education needs teacher were the people most commonly consulted with in schools. Support structures to ensure that teachers were involved were rarely in place, meaning that teachers were not well informed about their students' physical goals and outcomes, or about how these goals could be met in the classroom.

In relation to student outcomes in general, one therapist emphasised that the capacity of the schools to support children had a significant impact on children's outcomes, and could temper the effects of a shortage of therapy support. While her own workload was very high, this therapist felt that because the schools she worked in were inclusive, the children were able to make positive gains:

> *They belong to their school, their school staff own them and they make gains and sometimes I think that's despite my inability to get to them and I feel guilty because there are so many of them that I kind of think, oh, that's one of those neglected ones I haven't got to – or I've seen that child once and I really think they need more but I can't provide it. But … there is a collective consciousness within the team that means – and within the schools that we work – that means that things are in place. There are a lot of competent people around the students.*

This therapist's GSE team saw direct professional development with school teams as part of their role in supporting schools. In contrast, another therapist on a different team felt that while their GSE team worked extremely well together, at the school level the 'team' did not necessarily share this same focus. This suggested a need for professional development, perhaps through an in-service day, where the whole team could work together on developing a shared framework for their work.

Outcomes for students who did not receive ORRS resourcing

Students who did not receive ORRS resourcing – Ricky, Rose and Christopher – were considered by their parents and their teams to be at risk across social, academic and physical areas of learning. Their teachers struggled to find ways to access the curriculum without teacher-aide support in their classroom. Rose might have been less at risk because her parents funded a full-time teacher-aide position, but she received no specialist teacher support and her teacher had only a small amount of RTLB support. There was no certainty that teacher-aide support could continue to be funded in this way. None of these students had good access to therapy despite claims by their parents and professionals that therapy was necessary to support their development. Caitlin also missed out on much-needed physiotherapy because of a chronic shortage of therapists in her area.

Looking to the future

Parents often talked about outcomes in terms of what lay ahead for their children once they left school. Their aspirations for their children included being happy, leading a full and independent life, and having relationships and a good job. Where students received good levels of resourcing and support they felt very satisfied that what was happening at school was preparing their child well for the future. They valued the support of teaching and therapy staff in this regard.

School and therapy staff generally shared this future-oriented perspective in their teaching, particularly as children entered into the secondary school years. Some children, like Alan, had a very clear occupational goal, and teachers acknowledged that this could give them a sound basis for planning. The HoD for special education needs at Alan's school commented:

> *Alan will be OK. I think we can cater for his needs until he leaves school. See, he can say, 'When I leave school I'm going to …' His last suggestion to me was that he was going to have a boat and go between the mainland and the island. So at least he can say, 'This is what I would like to do', so in terms of transition for him we've got a bit of clear goal work to work towards.*

For students with very high needs, questions about the future, post-school, were much more challenging. The curriculum itself posed challenges, with some teaching staff and therapists noting difficulties adapting the curriculum and finding meaningful activities that related to level 1. It was difficult to plan a curriculum that supported the transition to adult life when it was not clear what post-school options were available, and when professional development opportunities were not always relevant:

> *I think we are honestly trying [to plan for transition], but he is just so limited. I actually went to a course recently with our transition/careers person, just to see what was on offer. It was more for the SEG kids, what was available for them. I don't think they went quite as far as [our student].*

Summary: Models of therapy in schools with itinerant therapy

Itinerant GSE and CDS teams supported students with physical disabilities in regular school settings. Students had variable amounts of support, from ORRS high-needs resourcing to no resourcing through ORRS or the moderate contract. While some strains were apparent for students who were funded through ORRS, particularly when access to the curriculum required substantial support from teacher aides, people interviewed felt that Special Education 2000, and ORRS resourcing in particular, met the needs of schools and students relatively well. The schools attended by students who were not funded by ORRS experienced real difficulties in supporting students. In one case, parents paid for teacher aide support, and in another, parents paid for extra tuition for their child.

All of the schools had policies to support the inclusion of students with disabilities, and in each case a number of management and organisational structures were in place to support staff and students. Successful teamwork was described as being reliant on a strong professional leadership (by principals in schools and by team leaders in therapy teams) and on a shared understanding about what constituted integrated effective practice and inclusion in education. The extent to which strong teamwork was achieved in this regard was variable. Structures in schools could support a sense of teamwork across therapy and school staff, and this was facilitated in schools where there was a position of responsibility for liaison, programme planning, and teacher ownership.

Therapy teams used a consultative approach with schools to support an integrated approach to education and therapy which focused on the functional integration of therapy goals into naturally occurring routines across the school day. GSE teams, in particular, had a strong focus on therapy as a vehicle to support students' access to the curriculum. They liaised primarily with teachers in the 0.1/0.2 FTTE positions and teacher aides. In most cases teachers were not particularly actively involved in the consultation process, suggesting that dedicated release time is needed for teachers to become more informed about and involved in the integrated therapy approach their students receive. Time taken by travel and high workloads for therapists meant that approaches to therapy could vary in their absence, suggesting that structures in schools might be needed to ensure that therapy remained consistent with the indicators of integrated effective practice.

Staff in all of these settings saw value in collaboration and integration of services, but time was a constant pressure.

Professional development was a priority in every school, and a number of schools had responded by developing in-house programmes for staff, often led by the teacher in the 0.1/0.2 FTTE position. Other teachers had professional development needs in order to learn more about their student with disabilities and about curriculum and teaching, and in some teams opportunities for whole-team professional development around integrated effective practice could support a consistent approach to integrated therapy. Professional development for therapists was also valued, and therapists commonly used occupational therapy and physiotherapy email lists to share ideas. GSE teams described having good access to current research literature, although there was not always a good supply of relevant professional development opportunities on a national basis.

Most parents of students funded through ORRS were happy with the learning or educational goals set for their children, and in Christopher’s case said his teacher was wonderful. Rose’s parents were also happy with her education, but considered that without the aide they funded, progress would cease. Families were considered central to the processes of planning and teaching, with family involvement usually focused around the IEP process.

Families valued highly the support they received both from schools and from therapists. Therapists often took an advocacy approach in their work with families, and families valued their assistance in the area of seeking resources and information on families’ behalf. Some GSE therapists commented that they would like more time to liaise with and provide direct support to families, particularly in their home environment.

Despite each student being well integrated into their school environment, friendship was an issue for many students. Some schools had found innovative ways to support children’s social lives and friendships by emphasising changes to the school context. However, many students did not have close friendships. School staff were usually aware of this, but in general few schools had prioritised this important area of children’s lives as a focus for change and intervention.

Transition to secondary school and to adult life was a focus for those teams where student transition was imminent. In these cases some planning had taken place to support smooth transitions, although in the case of Ashley, team members were challenged by the lack of suitable post-school options for him.

Section 2.7: Looking Across the Sites: Integrated Effective Practice for Students with Physical Disabilities

This section discusses the ways in which case study sites have implemented the elements leading to integrated effective practice, as defined in the literature. The section is organised according to the key components of integrated effective practice as described in the scoping project for this study:

- organisational matters
- interagency and professional collaboration
- team functioning
- interventions
- outcomes.

Organisational structures

Resourcing: Sufficient and flexible enough to meet individual, programmatic and organisational needs

Of the schools with on-site therapy services, the self-contained school received no transitional funding for occupational and physiotherapists whereas the three schools with attached units did. Virtually all of the students in these settings were funded through ORRS at the high or very high needs levels. Only one of the units was not a specialist service provider, but from reviewing its income in relation to the focus students, it was clear that the 'unders' and 'overs' practice used by the Ministry of Education, Special Education (GSE), meant that its ORRS-related income was substantially similar to the specialist service provider units and school.

Of the focus students in regular class settings, four students were ORRS-funded at the high needs level, one was funded at the very high needs level, and one had services from therapists employed on the contract for provision of therapy services for students with moderate physical disabilities (the moderate contract). Two students did not receive ORRS or moderate contract funding. One of these students had previously received funding from the Accident Compensation Corporation (ACC) as a result of an accident and had some ongoing occupational and physiotherapy support through the local CDS team. The other child participated in a programme funded by her parents. These parents were also paying for teacher aide support in the classroom.

ORRS-resourced students

The self-contained school had approximately 90 students on the roll, many of whom did not have any physical difficulties requiring intervention. The school did not receive any transitional funding for therapists but was able to employ occupational and speech-language therapists and physiotherapists, in addition to teachers, special education assistants, teacher aides and a part-time psychologist. In addition, the principal and deputy principal of this school held non-teaching positions. The only concern raised at this school with respect to resourcing was that once therapists become more senior, their salary costs may be difficult to meet. This school was also the specialist service provider for

ORRS students in a number of other schools and therapists travelled to support these students. The principal felt that therapy workloads at the self-contained school could be a little higher. The deputy principal also pointed out that accessing speech-language therapists with expertise in the area of very high needs was a difficulty in their school, although the resourcing was there to support the service if it was available.

Although a number of schools expressed concerns about ORRS resourcing being attached to students and levels of need, and the uncertainty that this created from year to year as students came and went, ORRS was perceived in all but two cases as sufficient to meet students' needs. However, it was apparent that when students on the rolls of units spent large amounts of time in regular classrooms, or if they were the only student with physical disabilities in a school, it was necessary to be creative with resourcing. This was particularly noticeable in the secondary school, where large numbers of aides were required to support students in a wide range of classes, and in the two rural schools attended by students with high needs. In some instances in junior secondary classes and also at the intermediate school, funding pressure meant that students with disabilities were clustered to enable sufficient aide support.

Two principals with units in their schools raised the issue of equipment and purchases relating specifically to students with physical disabilities in their schools. These people noted that such purchases are not possible from the ORRS or transitional funding they received from the Ministry of Education, and that money allocated to the wider school had to be used in some instances. In two schools, funding for computer software had been sought through grant applications to philanthropic groups, and some parents had also provided funds to purchase these resources. In another school, a decision was made not to build a ramp to a key part of the school campus during a period of school redevelopment. Although the school was later directed by the Ministry of Education to install a ramp, this decision had been a divisive one for staff.

Students who were ORRS-funded and in regular school settings had access to a range of services. By and large these students were supported through GSE using the 'unders' and 'overs' model. One student with visual impairment and cerebral palsy that affected his gait, speed of walking and running, and fine motor skill was funded as an 'over'. This was also the case for a student who used a wheelchair and who, as a result of athetoid cerebral palsy, had very little controlled voluntary movement. Two other ORRS-funded students were funded as 'unders'. The school that the final ORRS-funded student attended received funding just below that allocated through the verification process at the high needs level.

The student funded as an 'over' received 18 hours of teacher aide support per week. The aide provided in-class support, and followed a community-based orientation and mobility programme with the student. His 0.1 FTTE time was taken up with remedial reading instruction and stretches, and part of the specialist teacher time was used to fund a one-on-one music programme.

As was the case with most other ORRS-funded students in regular classes, this student's therapy needs were met by GSE staff who visited the school periodically, using a consultative service model.[32]

One of the students funded as an 'under' had no support from GSE at the time of the case study because the physiotherapist position was unfilled, and had been for more than a year. The school this student attended received approximately half the high needs funding this student was allocated. This money was used for aide support with daily stretching using a programme that, at the time of data collection, was more than one year old and had not been

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[32] In the consultative service model, the therapist works collaboratively with the classroom and specialist teachers; providers of other services; parents; and, where appropriate, the student. The therapist usually models the interventions and coaches the team most directly involved with the student. This team then carries out the programme.

monitored by a therapist in that time. This was an area of concern for both the parent and the school. In addition, the aide helped the student in question, and others, with a programme aimed at increasing the students' sight-reading vocabulary. The 0.1 FTTE position for this student was used for a mixture of one-on-one support for the student in literacy and numeracy, and as support to the classroom teacher, who felt pressured by the demands of the classroom.

Non-ORRS-resourced students

One student with learning difficulties and cerebral palsy that affected his gait, mobility and fine motor skills, and which required regular Botox treatment, received services through the moderate contract. Application had been made for ORRS resourcing for this student but it had been turned down. This student participated in a number of the remedial reading and numeracy programmes running in the school and his parents took him to outside tutoring. Therapy input for him was described by the therapists as inadequate. These therapists saw 20 students and had two days per week to do so. This student, at the time of data collection, was seen every two weeks for one hour. As the student was withdrawn for this intervention and the therapists had to go to another school at the end of the session, these time constraints meant that his teacher did not know what went on in the sessions and consequently there was no carry-over to the classroom. The special education needs teacher in the school, who had several hours per week of release, monitored his programme.

Application had also been made to ORRS on behalf of another student on two occasions. This student had a diagnosis of autism, and in particular she experienced difficulties with sensory integration, very low muscle tone, and problems with motor planning. Out of frustration with early childhood services, this student's parents had been instrumental in bringing an applied behaviour programme to the area in which they lived. Although they had been happy with the results of the programme for their child, they recognised that her physical needs in particular were unmet. In the area where this child lived, there was significant demand for resources through the moderate contract, which was managed by the local CDS team. As a result of pressure on the system, many children were not receiving the supports they were deemed to need, and although the manager of the CDS team visited the school and tried to support the teacher aide and class teacher with ideas to meet her physical needs, all parties felt frustrated that this particular child's needs were not able to be well met. Although the school used Special Education Grant (SEG) money and a small grant from the pool attached to Resource Teachers: Learning and Behaviour (RTLB) services, this student's parents paid for the bulk of the teacher aide support available to the student. In addition to this, the class teacher reported that although the local RTLB teacher had told her that she 'was only at the end of the phone,' this support appeared not to be readily available to her.

Another student in this area had had support from ACC but was now receiving support through the local hospital-based CDS team. This student had social and emotional needs resulting from earlier trauma, and had significant physical and occupational therapy needs resulting from very low muscle tone and from third-degree burns to the top half of his body. It had been deemed a year earlier that this student's needs were related more to impulsivity and learning than as a result of the burns and the trauma surrounding that experience and ACC funding was withdrawn. Although this student was on the roll of the local RTLB service, no in-school support was available to teachers or to the student.

One principal reiterated the view expressed by others that there was a genuine unmet need for funding support, and that this made it difficult for teams to work in ways that were consistent with integrated effective practice:

> *I think there are insufficient children included in ORRS. I think the expectation in people is such that they now feel that the system is obliged to help their children and get resources made available and often it's a question of language. If you've got a nice tidy label to hang on a child you can often attract a lot more funding than if you don't. One of the other things is that some of the most highly resourced children are considerably less disruptive to a mainstream classroom than some of the kids who are not disabled at all … they know they are not succeeding, they're failing, and so they take that*

> *out on the teacher and the other kids, and they're far more difficult to have in the classroom and yet you get no resourcing. I still think there's a huge need to ascertain the need of individual kids and with ORRS it's either in or out, you're either ORRS or you're not, and that means high needs and very high needs. But if you don't cross that threshold to high needs then the level of resourcing you're going to get regardless of needs is much much lower.*

Children not included in the ORRS scheme were felt to be a drain on schools' SEG grants, which were also seen to be too low and inappropriately based on decile. The principal of a decile 2 school said:

> *The SEG grant doesn't take into consideration how many needy children you have in your school, and this is irrespective of deciles … you can go to a decile 8 and 9 school and you know, find that there are more needy children there. The SEG grant should be funded on the number of special needs kids. It doesn't work in the present system and it leaves you with an inadequate SEG grant, and this expectation that you're going to be able to fund the required programmes.*

This principal also felt that funding support for teacher aides was problematic. He felt that the set rate for aides, $13.57, was too low and did not cover GST, ACC levies or holiday pay. He said:

> *Some schools have tried to force the [Ministry of Education] into providing either more money or more hours by effectively reducing the number of hours the child receives. I can actually say with some pride that we have never done that. The number of hours we have been allocated, or more, has been provided in every case and the extra money has come from targeted Funding for Education Achievement, the SEG grant, or straight out of the operations grant. If the agreement is that the child receives 20 hours per week then they should have their 20 hours per week. The [Ministry of Education], of course, should fully fund this. Kids should not suffer simply because there is a shortfall.*

This school had previously been bulk-funded. The principal felt that this had been a good thing and had allowed schools to be flexible and provided opportunities for schools to organise their own solutions to problems of practice:

> *We were a bulk-funded school and we were very much in favour of bulk funding. It made things possible that are not possible now. We achieved flexibility. You didn't get told that you had 20 hours' teacher aide time and two-and-a-half hours teacher. You got $10,000 and when you got $10,000 then you could make decisions about what you'd use it on. And I thought under bulk funding special education was much more effective than it is under central funding.*

Control: Local development and management of services

Given the limitations described earlier, local control and flexibility of service provision were positively viewed features of the Special Education 2000 policy. In some instances, however, a number of concerns were raised relating to the isolation several schools felt in having to deal with difficulties such as what to do with students who constantly challenged the system, or whose needs were not met through any of the resourcing mechanisms. Virtually all of the schools visited supported the inclusion of students with disabilities in their communities. It was apparent that, by and large, principals had communicated a commitment to inclusion to staff, and this set the tone in the school.

Management structures

All schools had established a number of management mechanisms to meet the needs of students and staff with respect to resourcing and support. In all cases, these management systems were viewed as integral to the running of programmes and units. Across the case study sites, management responsibilities had been identified to address the following:

- co-ordination and organisation of therapy and education staff based on the Individual Education Programme (IEP)
- programme development, adaptation and linking students with the national curriculum and evaluation
- liaison with parents and outside agencies
- setting professional standards and implementing the mission that guided service provision and professional development for staff
- allocation and matching of teachers and aides
- student supports
- review of inclusive programmes and IEP co-ordination
- allocation and review of spending in special education.

Local development of an underlying philosophy and guidelines for practice

In addition to the setting of management guidelines and responsibilities, a number of case study sites had identified philosophical positions and developed guidelines for practice. One setting focused on the development of an integrated model of service provision which saw therapists and teachers planning and working together in classrooms to meet students' educational, physical and communication needs. In another setting a similar process had been undertaken, but in this setting students participated in their educational programme in classrooms and then received their therapy inputs, which focused on developing skills in the context of functional activity.

Some areas had also come up with novel ways of using moderate contract funding by focusing on improving the skills of school-based staff to attend to therapy goals in the context of functional activity, or giving students blocks of therapy intervention and then pulling out for a time, and by a combination of the two, revolving students through cycles of therapy and then monitoring the work of aides and so on. Similarly, the GSE teams in the study had spent considerable time on developing consultative models of therapy provision, based on a strong team that provided professional and personal support. In the words of one therapist:

> *We try to take a collaborative team approach, and that means having a group of people with a range of skills, and the team at school, the teachers, teacher aide and family talking about and working out the best way that we can provide a service. Making sure we work well together, and that we all know what each other is doing. We are involved at the school in helping them to make modifications necessary to the environment so students can access parts of the school which are relevant to their particular programme … we have been involved in working with the school to challenge some preconceived ideas about what people with physical disabilities can do … we focus on inclusion and meeting the student's needs within the classroom programme. The team works well because we have an open office, we can chat to each other a lot. We all sit together, we support each other if difficult issues arise, talk things through. There is a real bond and I think that is important. The communication is very open. We try to achieve this in schools by taking the time to sit in the staffroom, talk about the rugby, that sort of thing, not just about what we are doing..*

Another therapist explained her team's position to working in a consultative manner:

> *[Therapeutic activities with the students are] included in their normal classroom programme, sometimes doing parallel learning within that programme, so different maths at maths time.*

> *Sometimes it's about giving permission for kids to be able to do things differently … saying well, look, they've been in the classroom all day, it's all right to take them out for this task, so that they can learn or that they can work in a small group or whatever. So try to work quite closely with the special needs teacher and the teacher aides. There is a rule that we would never work with the child on their own … you're there to enskill other people and to discuss the problems with other people and to come to solutions with other people, not on your own.*

Interagency and professional collaboration

Collaboration to reduce overlap and support communication, continuity and transition

Therapists in on-site settings seemed to do a great deal of liaison with a wide range of other services and, particularly in the case of more severely disabled students, to provide direct support for parents in dealing with those outside agencies. Parents highly valued this level of support in an area of their lives that could be both daunting and time-consuming. Inter-agency collaboration was also a significant part of the work of the CDS team in the rural area. In this instance, however, a great deal of the liaison occurred on an informal basis, because of the small size of the community and the established networks between people. The GSE team, of necessity, had a strong focus on collaboration with families, schools and other agencies.

In all cases where there was or had been involvement with a CDS team, parents spoke highly of therapists' work, liaison with them and support. One mother felt that the only professional involved with her son who was trying to do anything positive for him was the manager of her local CDS team. She said that she really did not have the energy to keep fighting for her son, that everything had been an uphill battle. In the case of another CDS team, however, there was little liaison with schools beyond the period of transition to school, when therapists from school and health services met to hand over a student. As one therapist on a CDS team said:

> *There's a lot of anxiety around those change periods for families of children with disabilities. It's leaping out into the unknown for them, and I guess that's something that we try and actively support as much as we possibly can so that those transitions are less stressful.*

There was a suggestion that people were aware that inter-agency collaboration was an important element of the work but that this had only recently become a priority. One health-based therapist commented that because of pressures on services, it had become increasingly important for therapists to understand the Health–Education interface and ways in which students could be supported, and that this was why people were beginning to address the issue.

Parents, especially the parents of students in regular school settings, felt that they had to do considerable liaison work between schools and outside services. Although some parents resented this extra burden, others said that the reason they took on the responsibility was to ensure that they kept up to date with what was happening to their child. In one case parents had no contact with therapists despite having set up an appointment at which the therapists did not arrive, and in another a mother reported having no idea what therapists were doing. In this case the therapist agreed that liaison with home was an issue she had yet to deal with effectively.

Transition points for children were recognised as critical times for inter-agency liaison. An essential element of this was support for parent, teacher and teacher aide education. This was seen as particularly important as children moved from early childhood services, where there was often significant therapy input, to primary school. A therapist explained it as follows:

> *And in terms of transition, I don't think we are doing enough to help parents understand the difference between the Health-funded physiotherapy their child had as an infant and young child and the focus in the school situation. They are quite different therapy experiences. In the early years they build up a relationship and there are supports there over and above therapy that are very different in the school years. And yet we are working towards the same goals.*

A number of people interviewed shared the view that there were times when, within a function-based model of therapy, parents, teachers and aides seemed to think that the child was not getting the support needed, when in reality needs were potentially met but in the context of everyday activity. Perceptions of what constituted therapy and what did not was clearly an issue for a number of parents, who sometimes moved to centres where they thought their child would get more hands-on or specific kinds of support. In other instances children were transported long distances from home to sites where therapists were based.

With the exception of the self-contained school, inter-agency and professional collaboration was seen as compromised because of a lack of time. Some therapists blamed workload size, and this was clearly an issue for GSE therapists. One service had 280 ORRS students and 30 on the moderate contract for two occupational therapists. One GSE physiotherapist in another area had 47 ORRS-funded students and nine on the moderate contract over a very large geographical area, and another physiotherapist had 100 ORRS students and a further 20 on the moderate contract. This therapist prioritised her workload according to need. Priority students generally saw her once per term. By comparison, unit-based therapists in the study saw between 17 and 20 ORRS-funded students, and in two cases, up to a maximum of 20 other students on the moderate contract. As a result of the high workloads for GSE therapists, they often only saw the special education needs co-ordinator and the aide attached to a particular student when they visited schools, even though they knew that the classroom teacher was the most important person to meet with. At these times therapists used elements of the processes described as ‘role sharing’ and ‘role release’ so that school-based staff were ‘given ownership and responsibility’ to work with the student. This was seen as a big part of the team's work. One therapist reflected the comments of others when she said:

> *I think [sharing knowledge about therapy] is a really big part of the work and that it's about sharing knowledge and not kind of holding it as something we own professionally. But it's giving knowledge to other people – in a way giving people permission to observe kids' development and promote it.*

However, the point was made by one therapist working in this model that although there was a focus on consultation, and on the blurring of boundaries to ensure a co-ordinated service to students, this could not always mitigate the feeling she had that some students received insufficient support from therapists, and that liaison with teachers was not as good as it needed to be. This comment was made on the basis that workloads were high and that it was difficult to schedule time to meet with class teachers, particularly if schools did not provide teacher release time for this purpose.

Classroom teachers often felt distanced from the work of therapists and although many were concerned to integrate elements of the therapy programme into the classroom in order to improve learning outcomes, they lacked the basic knowledge of how to make this happen. Three weeks into term 1 one teacher said:

> *I don't even know yet how many therapists are involved with [student]. And I haven't ever had any of those therapists sit down and say look, this is the IEP from last year and dah dah dah. So, I think that you need to – if you are a therapist working with a child like that, you need to know that the teachers are going to change and each year there's going to be a new teacher … I think when there's all those other adults working with her there should be a bit more – they should be able to tell me a bit more about her without me having to go and do it all completely myself.*

Nonetheless, both GSE teams had worked creatively to try to overcome the challenges imposed by heavy workloads, and to ensure that schools received as much support and follow-up as possible. Both teams undertook an exercise to prioritise their workloads, and therapists on the teams described a process of co-ordinating and staggering their visits to maintain some sense of ongoing support for schools. Visits were scheduled on one sheet sent to the school. The close relationship between therapists on these teams meant that each was well informed about students requiring a range of therapy interventions, and processes of role release were fundamental to this ongoing support to schools. One team worked actively to find ways to provide effective ongoing support to their schools, and maintained a current register on students' therapy and learning goals which was readily accessible to all therapists. This team also held monthly locality meetings to discuss the learning and planning for students in specific regions. This process was particularly useful where some therapists were unable to attend upcoming IEP meetings, although therapists did say that maintaining the meetings could be difficult when conflicting demands arose, and a level of commitment was needed to keep this system of regular meetings working.

Even though on-site therapists had smaller workloads than those of GSE therapists, the requirement for therapists on two sites to see students individually and in small groups meant they had limited time they to liaise with classroom teachers. For one teacher in particular, the effect of this meant that she did not understand the relationship between therapy and education, and she was unable to integrate elements of the therapy programme in support of her students. For another teacher, feeling as if she did not know what to do to support the student with physical disabilities in her class left her feeling very ambivalent about her role on the team.

The two students who were not funded through either ORRS or the moderate contract were on the roll of the local RTLB. The teacher of one of these students had never seen the RTLB or spoken with her regarding that student's needs. Similarly, this child's parent had never spoken to the RTLB regarding support. With respect to the other student, the school was experiencing ongoing difficulties in dealing with the student's behaviour and significant learning needs. This student's classroom teacher said that she felt powerless to do anything to support the student and thought that the RTLB would have some ideas. As with the previous student, however, the RTLB had yet to visit the student in class.

In the absence of opportunities for therapists and teachers to work together, teacher aides were seen as critical to the inclusion of students with physical disabilities. However, a number of the people interviewed (including teacher aides) were concerned that aides had very much a free hand in terms of what they did. One teacher reported that she felt that the aides she worked with saw their relationship with therapists as 'us and them'. She said that the aides made up their own exercises for the student they supported. As a result of this she was trying to work very closely with aides to plan their work and to monitor and mentor them. Further, in order to improve liaison and collaboration among team members, this teacher was co-ordinating a regular newsletter. She said:

> *It's an us and them thing – you know, the teacher aides refer to the therapists as the touchy feelies and it's very much us and them and I don't like that. That's why I hope this newsletter can sort of be a real team thing, you know – everyone works with [student].*

One teacher reported that the responsibility for curriculum adaptation lay with the aide, and that although she knew this was inappropriate and that liaison and shared planning were important, none had yet occurred.

Workload management: Ensuring client- and family-centred services and role clarity

All services described themselves as family-centred and described parents as guiding the goal-setting process at IEP meetings. A number of positive strategies were in place across case study settings to ensure that services were client- and family-centred, and a number of therapists had strong long-term relationships with families. Parents also reported that in a number of instances they were very happy with the work that schools were doing and they felt that they and their children were well supported. Examples of supportive strategies included the following.

- One unit had it as a stated policy that staff would do their utmost to relieve parents of the load of having to co-ordinate, advocate and manage services for their children.
- In the self-contained school, frequent planned and unplanned interactions between parents and school staff ensured that parents' goals and school priorities were one and the same. In this school, parents were encouraged to visit the school and to participate in the regular review meetings held by staff.
- Therapists in the self-contained school made regular home visits, and they attended medical and other health-related appointments with parents if the parents wished.
- One unit had adopted a key worker approach to workload management and, depending on the greatest need of the student, cases were assigned teachers and therapists.
- A GSE team also used a 'key worker' approach whereby one therapist was the key link between the GSE team and the school and family.

In the latter two examples, it was felt that the key worker approach had eased liaison issues with parents and families in that parents knew whom to contact when necessary, individual relationships could be established, and, as a result of a smaller base of responsibility, staff could better respond to parent concerns. One of the therapists at this school also felt that the same approach to liaison, goal setting and planning adopted for parents should be extended to students to allow them a greater voice in their programmes.

Some parents, however, felt that it was sometimes difficult to have their voices heard in schools. In some instances parents were not identified by staff as team members and a small number of therapists and teachers expressed negative opinions of parents' and families' involvement in their child's education. Sentiments expressed included that parents could be too demanding, did not carry goals over to home or follow through with goals, or had failed to come to terms with their child's disability. When talking with these parents, however, it was clear that it was often difficult for them to do what some therapists and teachers expected. Many students had out-of-school activities such as music or swimming lessons and private tuition or therapy to attend. The majority of the focus students in the study had siblings who also participated in after-school activities. Many parents worked and a number of them lived some distance from the schools their child attended. A number of parents also expressed the view that at home they just wanted to be a family and do family things. Finally, in one case, the students' parents said that it was up to their son, as a senior student, to involve them as and when he felt the need.

Team functioning

Families: Essential, well-informed team members

Across settings families were described as key members of the team. Settings with therapy on-site, in particular, seemed to have the infrastructure needed to maintain high levels of contact with families both at school and at home. Families particularly valued a responsive approach by staff in these settings, in which the relationship was negotiated around individual families' particular needs for support.

Families often referred to the need to be the liaison point between services, and some sites had responded effectively by introducing a key worker approach to support for families. Across sites, some therapists had established close bonds with families, undertaking advocacy, seeking information, and exploring inter-agency issues on behalf of families. Families highly valued this level of support in an area that could be both frustrating and exhausting.

The flow of information between home and school varied across settings. One setting addressed this by having an explicit open-door policy in which parental input and participation were actively encouraged at all levels, including planning meetings. Home–school notebooks were a very common feature in schools and were used regularly. Parents valued these as a reliable and two-way approach to information sharing, although filling them in often seemed to be left to teacher aides, who would not normally have access to the sort of information parents wanted and who may have been inappropriate people to receive information from parents.

A number of parents said that they needed to ensure they went to school regularly to see people informally to be kept up with information. In settings with itinerant therapy support, high workloads and travel time meant that therapists sometimes found it difficult to maintain as high a profile with families as they desired. At one site, the school was responsible for ensuring that parents were informed about visits by itinerant therapists, and therapists did not always know if this had happened. One therapist commented specifically on her desire to have more time to visit with families, especially in their own home, and to follow-up on school- and home-based interventions.

One principal noted that keeping parents informed and working with them was much easier when they lived close to the school and when they visited regularly. He noted, however, that it could be hard for some parents to come to school. Meetings could be overwhelming, and some parents remembered their own school experience as negative and associated with punishment. He said these issues created barriers and suggested that ‘maybe it’s our fault’. He described one situation where a parent eventually saw him about her child and a difficult behaviour situation was solved:

> *When she got to me and she found that what we all talked about was how well this little boy was starting to do, she changed, and that was it, that was the key thing.*

One student’s parents were concerned that there were services in the community they could have used, but that because of lack of access to information about such services they remained ignorant. These parents had recently taken the opportunity to move their child into a unit setting. This was done for a number of reasons, not the least of which was better knowledge of, and access to, the services they felt should have been on offer in other settings but which they felt they had previously had to find themselves. Some parents also talked about some of the challenges they faced ‘being heard’ at school, particularly in relation to their preferences for priorities in their children’s lives. Some parents and teachers raised questions about achieving a reasonable balance between academic and learning opportunities on the one hand and functional physical skills on the other. This remained a largely unresolved issue, with some people also raising questions about the place of the students themselves in contributing to decisions in this area.

IEP: The focus of contact and planning

For all students, IEP goals determined the intervention programme. IEP goals included all relevant curriculum areas (in some cases, areas of the curriculum not requiring adaptation were not included in an IEP), communication, social and behavioural skills (or self-management), mobility and vision. Teachers frequently described social and behavioural goals as the most important IEP outcomes. In general, an ecological approach, focusing on the development of skills in naturalistic settings, formed the basis of planning documents.

Parents were always involved, but whereas teachers and therapists did some preparation for an IEP meeting (such as identify future goals), parents were not generally asked to do the same. While this may have been done to try to relieve stress on parents, a number of parents commented that their input at IEPs felt somewhat secondary as others seemed to already have decided on goals. Students were not generally involved in the IEP meetings.

In one regular school, the special education needs co-ordinator and senior management saw it as essential that classroom teachers be the ones who had the primary relationship with the student with a physical disability in their class and with the family of that student. Although the special education needs teacher in this school did some co-ordination work, she saw it as part of her role to free the classroom teacher to do as much of that work as possible. In another school, a teacher said that although she did not know what was happening with the student's therapy programme, as the classroom teacher it was her responsibility to make things happen. This teacher had attempted to ensure that the student's therapy was integrated into the classroom programme, that the student was included in all that happened, and as much as possible it was she (the teacher) who managed the programme and aide support. The teacher said:

> *When we're reading a novel to the kids … I'll make them [the aides] get her out of her chair and actually lie her on the floor and just quietly stretching her legs out ... she still gets to listen to the novel … there's so much happening in the classroom at the moment, I don't like her getting taken away. I like these exercises to be happening at times when she's still participating and the kids are really good.*

Other classroom teachers described difficulties incorporating IEP goals into their programme. Some teachers did not know what a student's IEP goals were, while others did not know how to adapt what they were doing to better meet a student's needs. In one unit setting and in some regular schools, class teachers were not directly involved in the review and writing of IEPs for the students they taught. In these settings teachers expressed a desire to be more actively involved and suggested that dedicated release time to consult with therapists and others, and to engage in relevant professional development, would be of considerable value.

Professional development: Regular and related to understanding physical disability in the educational context

Although professional development was identified as a priority in most settings, available opportunities were limited. The self-contained school was a magnet for therapists and teachers wanting to learn about the integrated therapy and education approach it used, and consequently learning opportunities were frequent. Therapy staff in one of the units were enthusiastic about the professional development opportunities they received, and the principal and unit manager had made it a policy to provide as much support for staff to train and upskill as they could. At this school, therapists:

- had a range of formal and informal mechanisms within their local professional associations for peer support and supervision
- met daily with unit-based teachers to review students' progress and to plan for future intervention
- met weekly to present case studies to their peers and to problem-solve with their peers
- met every two weeks with other therapists in school settings to provide each other with supervision.

Many of the therapists in this school-based unit were very young or new to paediatrics and work in educational settings. Supervision in this instance was somewhat problematic, with a small number of therapists worrying that their work might be compromised by inadequate access to senior therapists to oversee their work.

Therapists working in GSE teams described different opportunities for professional development. Therapists in one team had tried to hold regular meetings focusing on professional development issues, but the budget was limited and little of relevance was on offer. Time off to attend a course meant time away from children needing therapy support.

GSE teams found discussion through a national email list of occupational therapists and physiotherapists particularly helpful in terms of professional development in their own field, although professional development in the area of teaching could be difficult to keep up to date with. One GSE therapist acknowledged that personal professional development through higher degree study had been particularly helpful, and acknowledged the support of her employer to undertake this work.

The need for professional development and support for teachers was significant in a number of respects.

- In some instances the inclusion of a student in regular classes was dependent on the student's ability to meet the demands of the curriculum offered in that classroom. This suggested that some teaching and therapy staff may need access to professional development focusing on the philosophy of inclusive education and the procedures and steps necessary to achieve inclusion for a wider range of students (including knowledge about how to adapt the curriculum).
- Although a great deal of progress towards the development of inclusive school environments had taken place in many case study schools, there was recognition that support was still needed to change some teachers' attitudes about children with disabilities in regular classroom settings.
- A number of therapists provided professional development to teachers of students with more severe disabilities on lifting and positioning. While this was important, many of the teachers interviewed expressed a willingness to take responsibility for students with disabilities in their classrooms but felt that their efforts were insufficient because they did not know how to begin adapting programmes or integrating therapy goals to meet individual educational needs. The majority of the students in this study had difficulties in addition to their physical needs. These needs included learning disability, general learning delays, ADHD, and autism. For many teachers, knowing how to plan for these issues in addition to a student's physical needs meant that they often focused their attention on social skills and on integrating students with their peers;
- Special education needs teachers and/or teachers in 0.1/0.2 FTTE positions expressed concerns that in many respects they did not know what they were doing. A number of these people felt that they needed professional support to establish procedures in schools for supporting students, to work collaboratively with their peers, and on supporting students with a wide range of educational, social and physical needs.

One GSE team did offer teachers professional development courses in areas such as Clicker (a software package) development, fine-motor skills and visual strategies. One of the therapists from this team suggested that an email list for specialist teachers in schools would be a particularly good way of keeping teaching staff up to date with information that supported the implementation of integrated effective practice.

With the exception of in-house support from therapists and some senior teachers, professional development for teacher aides appeared to be as problematic as for teachers. In one school, the unit manager provided twice-weekly supervision and support for the aides employed there. In the self-contained school, aides and assistants appeared to participate in the in-house professional development taking place there. In the regular schools, aides were often the ones who received instruction on programmes and modifications from therapists. A number of these people were also supervised by the special education needs teachers, but in some settings little in the way of supervision or support took place. Very few off-site professional development opportunities were identified by those interviewed as being available for teacher aides.

Interventions

Assessment and treatment: Non-standardised and ecological

Assessment information was mostly ecological in nature, collected informally and in relation to the extent to which IEP goals were met at review times. In all instances, with the possible exception of goals related to post-surgical intervention, therapy goals related to functional skills. In the majority of regular school settings, therapy goals were integrated with educational goals. Therapy staff reported meeting to solve problems relating to goals and to set new priorities or directions based on their assessments. Much of the information gathered about student achievement was anecdotal and resulted from discussions with teachers and parents. Consistent with the indicators of integrated effective practice, observation was used frequently to determine progress or the need for, or success of, programme modifications. Two therapists talked about using formal or standardised assessment tools for some students that assessed functional skills in the context of daily activity.

The educational achievements of more severely disabled students were assessed against IEP goals by their teachers. For those students with significant access to a regular classroom, teachers generally used the same range of assessments they used for any child in their classes (e.g. PAT, running records, various formal and informal curriculum measures).

It was felt by all those interviewed for this study that it was important for staff to develop positive, caring and supportive relationships with students as a way to learn about them and to improve learning outcomes for them. To this end, a number of the therapists in on-site units did playground duties so that they could observe and interact with students in a variety of settings. Other staff members discussed the need for ‘just sitting down and talking to them’ in order to tailor their interventions to meet the needs of their students more appropriately.

Flexibility of intervention

Flexibility of intervention refers to the model, location and provision of service, the balance between physical and educational needs, and the reduction of the negative impact of disability through attitude and environmental change

A range of approaches to intervention was used across case study sites, with a range of opinion expressed on the relative strengths and weaknesses of particular approaches. In the self-contained school, therapy and education were fully integrated for the students on the roll who had very high physical and learning disabilities. All of the staff and parents interviewed in that programme were enthusiastic about the results of this model of intervention. The mother of one focus student in the self-contained school talked about the change in her son’s physical abilities and skills in eating and in day-to-day activities. In one of the units, a similar model of intervention was practised, although it did not extend across the whole of a student’s school day.

GSE teams also practised an approach to intervention that advocated the integration of physical skills across a student’s day, and they used a consultative model to do this in which aides and some special education needs teachers were given the skills and knowledge needed to support therapy goals. In a number of instances, however, GSE staff felt that they should be doing more for students and school staff, but workloads of students on ORRS and the moderate contract did not allow more than one to two visits to a student per term. In the case of some students on the moderate contract, they were able to provide even less support. In one case, and even though this student was a part of the school community which was described as ‘the perfect place’ for him, the special education needs teacher was unsure that they were making a difference because she felt she knew too little about how to integrate the communication and physical skills programme designed to address his complex needs.

Some schools and families were very happy with the progress students were making, but in a small number of settings there was a feeling that there was not yet a good balance between physical and educational goals. In addition, some parents, teachers and therapists seemed uncertain about what comprised a good balance, and how best to achieve this in a student’s life.

A mixture of withdrawal and integrated therapy practices was used across settings. Two focus students favoured hands-on therapy outside of the regular classroom, especially when interventions would make them look different from their peers. A third received a mixture of integrated and functional therapy and withdrawal for stretches. He was reluctant to leave his classroom for this, saying, ‘I just have to put up with it.’ Another spent 15 minutes per day with the aide who did her stretches, but the special education needs teacher at that school was trying to get some support for redeveloping this programme as a series of functional activities so that it could take place in the regular classroom; this student’s mother was unsure as to whether this was appropriate for her daughter. In another case, the teacher of a focus student wanted the student to stay in the room as much as possible and had negotiated with the teacher aide to do stretching in the context of other activity. This teacher was eager to meet with therapists to look at making the intervention more functional but had yet to do this as it was very early in the school year.

Another focus student was withdrawn from class for one hour every two weeks for occupational therapy and physiotherapy. During this time he used a range of equipment designed to address fine-motor issues and impulsivity, and to turn-take and follow instructions. He also went outside and worked with the physiotherapist on his balance by kicking balls and walking on raised edging, and on stamina by running and climbing on playground equipment. Integration of therapy and education goals in this instance did not seem to be a priority. While this student worked separately with the therapists, his class did an aerobics session and circuit of activities.

Most of the people interviewed expressed a desire to work much more closely together in order that therapy goals could be better integrated across a student’s programme and day. In most cases, though, this did not happen, and almost universally the reason given was lack of time to observe, to talk, to plan, to prepare resources, to learn how and to evaluate progress. A commonly expressed concern was that attempts were sometimes made to introduce a new approach, but that the people doing the work were often aides who may or may not know why they were doing things and, as a result, were not necessarily able to identify when and how interventions could appropriately occur.

Naturally occurring activity in natural settings

Despite the recognition that naturally occurring activities were the most appropriate form of intervention, the previously mentioned constraints meant that naturally occurring activities in natural settings were somewhat limited. Staff working with students supported by GSE teams were certainly encouraged to work on functional activities, and some examples of this were observed, but the lack of opportunity for therapists to work with classroom teachers resulted in a feeling that this reduced the potential for carry-over. In some cases classroom teachers also felt frustrated by a lack of time to get through the academic curriculum and expressed a concern that, despite being willing, they did not always know what to do to support their students’ physical development.

For many students, particularly those in units and at the self-contained school, the school day was shorter than usual. Students and teachers talked about transport issues and some students having to leave school early because that was when the taxi came. For other students, just getting through feeding and personal care routines took large amounts of time, especially when students were expected to do much of the work themselves. These examples raise important questions about curriculum priorities, particularly when time is limited. While self-help skills are an important area of a student’s curriculum, the literature in this area advocates a broad curriculum across academic, social, physical, self-help, communication, transition and leisure/recreation domains; a curriculum that is both present- and future-oriented;

and a curriculum that presents students with opportunities to be self-determining within the broader context of the school and community (Christchurch College of Education, 2003; Davern et al., 2003; Giangreco, 1997; Giangreco & Doyle, 2000; Wehmeyer et al., 2002). Teachers and others may need some professional development support in this important area to ensure that a student's curriculum reflects this range. In addition, teachers may need knowledge and support in the area of curriculum access and adaptation so that students can access the essential learning areas and skills of the New Zealand Curriculum (Christchurch College of Education, 2003; Hulston, 2000; Ministry of Education, 1993).

Outcomes

Friendship

Despite the issue raised above, a number of parents expressed satisfaction with the services their children received. However, an unresolved issue identified by many parents was that by and large their children were socially isolated in their schools. Although teachers agreed that this was a concern, and despite the fact that many IEPs focused on social skills and interactions, few mentioned friendship without prompting. A number of students were involved in school activities such as kapa haka or choir, and after-school activities such as swimming or other sports. Although these options had helped a small number of students to develop and maintain relationships with others, most spent a good deal of time alone or with family members or adults. One student did have a number of friends out of school, but this was largely due to his involvement in a community rugby team, and to efforts by his parents to support friendships. At school, poor physical access made it difficult for this student to participate in break-time activities with friends, an issue raised by several other children in the study.

Due to pressures on funding, one school had previously placed two students with one teacher and aide. Based on perceptions of educational need, other schools retained some students at particular year levels. For one student, the effect of being moved away from the peer group that she had been well integrated with, and within which she had a number of friends, had been dramatic. Teaching staff and the student's mother all recognised that that she became lonely, withdrawn and sad. For the current school year, she had been moved back in with her peer group and she and her friend had struck up a relationship in and out of school again. She was reported to be back to her happy self and the two girls were delighting in each other's company.

At this school, staff recognised that there were numbers of students who did not appear to have much interaction with others during break and lunch times. In response they organised an area in the playground where an adult would sit in the middle of a group of chairs. The idea was that the adult would spend time with those children who came for some contact and then she would link groups of children together and facilitate games or activities between them. This became a well-used service, not just by students with disabilities, and it had resulted in a reduction in playground conflicts and an increase in interaction between students of all ages.

At another school, a buddy system of senior students was organised to support a focus student during break times. The Year 6 students involved in this programme had been enthusiastic and helpful in supporting the student during her first term at school. However, staff soon realised that the senior students supporting her were, in effect, keeping her apart from her peer group and they abandoned the programme. This students' parents had also facilitated friendships for her by inviting children to play after school. While this worked well at home, at school the student tended to keep to herself while other students ran around and played the games that she did not have the physical stamina or skill to participate in. The previous points notwithstanding, she did have positive relationships with a small group of students who sought her out at times and who she went to when the class played team games or had to pair up.

Although the inclusion of students with disabilities in regular schools was seen as very positive for all students in those schools, the students with disabilities interviewed for this study all made the point that schools needed to do more to break down the barriers existing around physical disability. A number of students spoke of having been bullied at school, of being repeatedly pushed over and having glasses and mobility aides taken away, and of being abused verbally. In some cases teachers had been aware of this and had taken action to stop these things happening, but in other cases school staff had not known of the actions of some students until parents approached them.

Several of the students interviewed suggested that schools needed to do disability awareness training for other students. Although they did not want other students to be given what they considered private information about their conditions, they felt that information regarding mobility, keeping obstacles away from traffic areas, and basic support skills would be very useful. One student, who was at secondary school, thought that his school should also do something about raising the profile of people with disabilities and promote a positive view of disability. He suggested that appointing a person with a disability as a prefect or head student would be a move in the right direction.

Quality of life: Outcomes promote adaptation and function

For students in regular class settings, and for some unit-based students, the focus of schools and of their IEPs was clearly on students' active participation in the school and wider community. This focus was also stated as being important by staff in the self-contained school and in units. As described earlier, social participation by students with physical disabilities was a concern in most settings. This was a particular area of difficulty in the self-contained school and in some units where students were described as lonely both in and out of school. Across settings some teachers and parents raised questions about educational and other difficulties that, for a range of reasons, had not yet been addressed to their satisfaction. Many of the people interviewed for this study recognised these issues and attributed them to a lack of time to talk and consult; to a lack of knowledge about curriculum, curriculum adaptation, therapy and integrated therapy; and in some cases to a lack of funding support.

Most parents did express satisfaction with what schools were doing for their children but they all had a range of concerns for the future. Transitions to new educational settings were a particular worry for the parents of students in regular class settings, and leaving school, seeking employment or moving into further education was a generic issue. School staff in self-contained settings and units who supported students with more severe disabilities struggled to envisage a sustaining post-school life for their students, and some parents were equally uncertain of the future. IEP goals for these students did not always focus on post-school settings and transition to adult life, and were more likely to relate to teaching students self-help skills or preparing them for 'vocational', low-skill careers. One mother, for example, was at a loss to know what would happen with her severely disabled son when he left school. She thought that he would probably just stay at home with her.

This was not only an area of concern for those teaching in self-contained settings or units. The teachers, therapists and teacher aide of a regular school student also worried about where he might go on leaving his school, which he had attended since he was five. In particular, they aired a concern that his life needed to continue to be as socially stimulating as it was at school and that he must continue to have real choices available to him in a community setting in which he was valued and where others cared about him. Nonetheless, his GSE team was aware of the need to explore post-school options for him and had discussed what might be available for him on leaving school in order to feed into the IEP process.

Although all students had physical needs that had attracted more or less support to them, parents were most concerned with access to friendships and future relationships, and with skills around literacy and numeracy or general educational success. For the student closest to leaving school, the occupational therapist, physiotherapist and his teachers were focused on exploring a range of options with him that would be useful in the future. For another student, teachers and therapists were well focused on her transition to college at the end of the year, and preparations including school visits were planned. In other cases, support for transition – in particular transition to adult life – seemed to receive little attention.

Two school leavers, Rachael and Hillary, were interviewed for this study. Both of them were unemployed. Hillary had done a business studies course at the local polytechnic and had been seeking work for over a year. At the time of the interview she was hopeful of getting an interview with a local organisation in need of a receptionist. Hillary was living independently with her boyfriend, and, although part of a social network, wanted the opportunity to work and to participate in a much wider sense in her local community.

Rachael had stayed at school until she was 20 and now attended a day programme for people with disabilities in her rural area. She had also recently moved from home into a flat, where she and a friend from her school days were supported to live relatively independently. At the day programme, Rachael participated in a number of activities, some of which involved the use of community resources. There did not seem to be any expectation that she could participate in employment at any time in the future.

Although both people had received support from the units attached to their schools, they had spent most of their school years in regular classes. In Rachael's school, a Circle of Friends programme had run for many years and while at school she had been a part of that. Her mother reported that Rachael had had support from a great group of girls while at school, and that they had often phoned her at home and taken her out with them. Although contact had dropped off a little in later years as many of these girls left the area to seek further education or work, a number of them visited Rachael when they were at home and kept some contact by phone. Rachael and her peer group had recently had 21st birthdays, or they were coming up. During her interview she showed pictures and talked about the parties she had been to, including her own, which had been attended by a large number of friends from school and the day centre she now attended.

Change: Measured on the analysis of multiple factors in multiple settings

Beyond discussion and review of IEP goals, or of progress through the curriculum, little in the way of change seemed to be measured in most settings.

Summary: integrated effective practice for students with physical disabilities

This section has reviewed the extent to which services in case study schools conformed to elements of integrated effective practice. In all cases, elements of integrated practices were evident in the supports and services provided to students with physical disabilities and their families. In a number of instances, however, integrated effective practices were compromised by resourcing issues, lack of opportunities for collaboration and shared planning, and lack of a shared philosophy of what such practices should look like in reality. In some contexts it was difficult for teachers and therapists to meet some of the indicators of integrated effective practice; in particular, it could be difficult to access opportunities for functional goals to be incorporated into daily routines in natural settings. These issues are discussed further in section 2.9.

Section 2.8: Discussion: The Effect of Therapy and Service Provision on the Children’s and Families’ Quality of Life

This section considers the third main research question: What is the impact of therapy and service provision on the child’s and family’s quality of life? The scoping report (McDonald et al., 2001) concluded that services provided to children with physical disabilities and their families could be described as effective when they have both focused and delivered on the outcomes listed below.

Inclusion in education

- inclusive school environments
- access to peers and friendships, and differences minimised
- a focus on equalising opportunities for students with and without disabilities.

Teaching and learning, and learning goals

- interventions that focus on quality of life and include multiple measures
- supports for curriculum adaptation
- an emphasis on learning, and on building self-esteem and confidence
- emphasis on quality-of-life outcomes that promote adaptation and function
- meaningful, beneficial, practical and easily maintained goals
- long-term view.

Achievement and assessment

- relevant assessments and monitoring used with a focus on multiple measures.

Extensive family involvement and input

- family involvement
- input from students.

This section looks at the effect of service provision on the quality of life of the students and families in these case studies, in terms of the outcomes listed above. It concludes with a discussion of the effect of resourcing decisions on children and families.

Inclusion in education

Inclusive school environments

The schools in these case studies included a self-contained special school, regular schools with attached units, and regular schools where students with disabilities participated in regular classrooms. Regular schools (including those with attached units) varied widely in terms of their understanding about the place of students with disabilities in the wider school, as reflected in the policies and practices of the schools. Schools with and without attached units worked towards an inclusive model by adopting some or all of the following characteristics.

- Special education needs policies focused on issues of participation, belonging and equity in the school.
- Principals had very clearly articulated positions on inclusion, and leadership qualities, which allowed them to shape staff thinking in this area.
- School structures were put in place to support teachers and other staff to translate the school’s special education needs policy into practice in the classroom.
- Therapists supported school policies and practices through integrated therapy and minimal withdrawal from class.
- Therapists respected students’ preferences and privacy.
- The roles and responsibilities of staff were clearly and carefully defined.
- Schools used student resourcing flexibly to support students, teachers, and classrooms.
- The class teacher took primary responsibility for teaching students with physical disabilities, and for organising other staff involved with the student.
- The regular classroom was considered the primary place for learning.
- Teachers adopted teaching practices which supported both access to the curriculum and children’s friendships and relationships with peers.

Where resourcing levels were considered to be too low, or where resourcing was unavailable, schools were primarily guided by their commitment to teach all children. This meant some schools and parents struggled financially to implement the school’s special education needs policy.

The biggest challenge for most of these schools related to teacher responsibility for students with disabilities. It should be emphasised that the majority of regular classroom teachers did not question the inclusion of students with physical disabilities in their classroom. However, the supports needed for classroom teachers to be fully involved in the school life of the focus student were often not in place. In particular, teachers, therapists and other team members needed time for consultation and time to plan for the inclusion of the student in class lessons.

In the self-contained school, and in some schools with attached units, active participation and a sense of belonging with a diverse peer group and the local community – which are key elements of inclusion – could be difficult to achieve. For example, Isobel only went into the regular classroom for reading, which was an area of real strength for her (she was reading two years in advance of her chronological age). At secondary school, Harry was fully included in the regular classroom setting with an interesting and relevant learning programme, but he sought the social support of peers in the unit at unstructured times of the day. Although the curriculum was meeting his learning needs well, there did not seem to be an emphasis on addressing the social aspects of his life as a 16-year-old at school. In fact, this was the one area that his family was most concerned about.

In the analysis of the data associated with this project, it was clear that context did make a difference to students' experiences, and to the ways in which integrated effective practice was played out on a daily basis. These differences were particularly evident when it came to the effective outcome indicator of *acceptance and inclusion* as described in the scoping study (McDonald et al., 2001).

The present study does raise some questions about how inclusion can be achieved in self-contained settings where students are not part of their local community, and where opportunities for learning from and with a diverse peer group are restricted. Although it is not the intention of the present project to make generalisations from comparisons between settings, the school experiences of some focus students with ORRS resourcing for very high needs reflected some major differences in educational programmes and school experience. This is illustrated by Selena and Simon on the one hand, and Ashley on the other.

Simon and Selena's self-contained school had developed some good systems in the areas of curriculum adaptation, integrated therapy and assessment. Some creative work had been done on adapting the New Zealand Curriculum at level 1, and the school used a wide range of assessment procedures, whereas other schools in the case studies relied on more informal methods of assessment. Their school day was shorter than usual due to transport arrangements, and the school day included long periods dedicated to self-help areas of the curriculum (including toileting and eating). As a result, little time could be dedicated to academic goals and communication that could facilitate greater interaction between focus students and others.

In Ashley's area school, teachers and therapists had been creative in establishing Ashley as a key member of his school community while also addressing his learning and therapeutic needs. His form teacher had given a lot of thought to the ways in which Ashley could be actively involved in classroom groups, with a particular focus on his social and communication goals. As a student with very high needs resourcing under ORRS, he attended a wide range of secondary-level classes in his area school, and his participation was valued and supported by teachers and peers. Like Simon and Selena, though, Ashley did not have a reliable form of assistive communication, despite the fact that his itinerant speech-language therapist had put a lot of effort into trying to establish this. Ashley's form teacher described the opportunities available to Ashley to be part of his peer group, and felt that it was important for the school to include him in the same way that his local community did. She noted, too, the important reciprocal learning opportunities afforded by having Ashley at school:

> *He's exposed to other people his own age, going through changes the same time that they are going through changes. I think it is really positive. I think it is positive for the school as well. I noticed that the students in his class are warm towards him. They're comfortable around him ... I think it's really positive for our school. I think it's part of their education too, you know, that they're growing up knowing that there are disabled people in their society that aren't exactly like them. That's important for us.*

These different school experiences suggest a need for further exploration, particularly in the areas of curriculum priorities, curriculum balance, and curriculum decision-making.

Access to peers and friendships

Friendships and supportive relationships with peers were major areas of concern for almost all students in the case studies, yet these are identified in the literature as critical to children's development and learning (Alton-Lee & Nuthall, 1992; MacArthur, 2002). This suggests that social experiences at school for these students remained a problem area, and one which teachers and other team members needed to focus on. Students in the self-contained school and most of the students in regular primary and intermediate schools, including those with attached units, did not have friends at school. Being in a regular school setting did mean that children with physical disabilities could experience a range of relationships with their non-disabled peers, although the quality of these relationships varied considerably between schools.

Attending school out of one's home district is also recognised in the literature as restricting children's opportunities for friendships and relationships with others, and creates barriers to friendships extending from the school context to students' homes (Heiman, 2000; Meyer, 2001; Watson et al., 2000). Parents of students at the primary schools with attached units raised concerns about their children travelling long distances out of their own community to attend a school with an attached unit. Parents did undertake to ameliorate the effects of being out of the home district. One parent organised out-of-school activities for her child to get to know local children; another commented that it was important to front up once a week to pick up her child from school. This allowed her to maintain contact with the school and with her child's programme, although in practical terms this was difficult because another child in the family attended the local school. Ian, at intermediate school, also made the comment that a lot of the students he had been at school with were now in different places and it was a challenge to get to know children at intermediate. He felt that these difficulties were not overly important, though, because he was the sort of person who liked to observe rather than be involved.

Many parents, and the children themselves, identified friendships as a problem area. Some children did have one relationship. Caitlin had one friend at primary school, and they spent a lot of time together, both in class and in the playground. Ian had one friend who had been at primary school with him and whom he kept in contact with outside of school time, but he did not have friends at his intermediate school. Harry also had a friend he communicated with via email outside of school time, but at school he spent break times with his peers in the special unit. His parents wanted to see him have the social life that his teenage friends experienced.

Two students did feel part of a social group at school, and had friendships which moved between the boundaries of school and home. Leah was described as a very social eight-year-old in her rural school. She had several friends and was described by her teacher as having the 'power' to influence and drive relationships with her peers. Leah's teacher thought about her social development, and this influenced some of her teaching strategies. She also placed Leah in a group in the middle of the classroom, rather than placing her in a 'disabled carpark' at the back. Heather also had several friends in her secondary school, which had an attached unit. At 14 she enjoyed going out and about in her local community at the weekends. Friends would turn up on her doorstep and take her out in her wheelchair, something her mother worried about in terms of safety but nonetheless supported. Her time at school was divided between regular and unit-based classes, and she spent much of her unstructured time in the unit. However, the school had a long-standing peer support programme which encouraged supportive relationships between students with disabilities and their non-disabled peers. Some of these relationships spilled over into Heather's out-of-school time, and at the time of the study Heather was organising what was to be a well-attended sleep-over party for her birthday.

This area of children's lives is complex, and a variety of factors seemed to impact on individual children's experiences. Some details from Alan's story are included here because they epitomise the issues raised by other students and their families in the case studies. Ten-year-old Alan attended his local area school. He was an active member of his community and a member of his local under-11 rugby team. Alan's parents' only major concern at school was friendships. Alan's parents talked about their concerns as follows.

> ***Mother:*** *School's been really good for him. The only thing we feel a bit sad about is his lunchtimes, isn't it? He spends a lot of time in the library. We think he is probably quite lonely a lot of the time, don't we?*

> ***Father:*** *Yeah. He does seem to be a wee bit happier this year.*
>
> *Mother: He can be quite sad sometimes and like, if he's being bullied, he'll ask me to ring that person's mother … you're not there so it's hard to know but I do think he spends a lot of time on his own, but he's got used to it now.*
>
> ***Father:*** *You've got to remember, you can't expect kids to – they're full on, and you've just got to accept it.*
>
> ***Mother:*** *He has accepted it. He's adapted to it. He can go to the library, it's always open, it's warm and safe there are people there to talk to … if he can't play the games he finds something he can do … he goes to kapa haka, and choir, so those are days he has something to do.*
>
> ***Father****: You can't make kids be friends. It's hard.*

While students in his class and in the wider school were generally very friendly and supportive towards Alan, he reported experiencing bullying by some children:

> *Sometimes they give me a hard time … the others sometimes they put me on the floor and then make me get up, and put me on the floor again and make me get up … they bully and stuff, they do heaps of stuff, nasty stuff, they pull me back, and sometimes I fall over. It's kids in my class … people keep on stealing my glasses, they steal them.*

Alan's teacher was aware of this and described tackling similar incidents in class:

> *I don't see Alan as different other than needing some support. And I keep trying to reinforce that idea with the other kids … some of the boys are great in terms of supporting him … But some of the girls, one in particular … she looked cagey, and she stomped her foot down and tripped him … I sent her out and she wouldn't go so I got a senior teacher to come and get her. We had to have a talk about this. A big discussion about it.*

Alan described his lunchtimes as follows.

> ***Alan:*** *At playtime I just sit there and eat .*
>
> ***Interviewer:*** *Do you like that?*
>
> ***Alan:*** *Yep, cos I get really hungry because [the morning] is two hours long! At lunchtime I go to the library. Sometimes I go to see Ashley.*
>
> ***Interviewer:*** *Do you play with your friends?*
>
> ***Alan:*** *Yeah, but they always run away on me.*
>
> ***Interviewer:*** *Do they? Do you find it hard to keep up with them?*
>
> ***Alan:*** *I do, yes. Sometimes I go and visit Nick [another child with a disability]. I don't like going up on the back field … like today I went up on the back field and I didn't know that they [friends] were down on the front field, no one told me where they were … Sometimes I get around with Tom [classmate] but mostly I get around with my cousins [names them all]. But mostly I go to the library … because it's fun. I like reading books and playing on the computer … I like it when my friends go to the library, but they don't usually go.*
>
> ***Interviewer:*** *Are they busy playing outside?*

> ***Alan:*** *Yeah.*
>
> ***Interviewer:*** *Do they like playing fast running-around games?*
>
> ***Alan:*** *Yeah.*
>
> ***Interviewer:*** *And is it a bit hard for you to join in those games?*
>
> ***Alan:*** *It is.*
>
> ***Interviewer:*** *Yeah, I can see it would be hard.*

Alan's friend Max was in his class and occasionally helped him to get around the school safely. They had each stayed overnight at the other's home, and occasionally played together at weekends. Both had motor bikes and enjoyed riding, and both played in the local under-11 rugby team. Although they sometimes played together at lunch time, Max said this was rare, because he usually played up on the back field with his other friends. Alan could make it on to the back field with support from his teacher aide to do fitness and phys-ed, but he rarely joined his peers up there at lunchtimes because 'probably he would fall over on the steps trying to get up there'. There were times when Alan could join in with the games his peers played, but he was not usually able to participate fully, 'because he would fall over and stuff'. According to Max, Alan's day at school was not the same as his:

> ***Max:*** *Because he goes on the computer and plays reader-rabbit, and does story writing [on the computer] and all that.*
>
> ***Interviewer:*** *Does he do other things in the classroom with you guys?*
>
> ***Max:*** *Not really, because we play cards and he doesn't know how to play cards yet … he would probably read with his teacher aide or something like that.*
>
> ***Interviewer:*** *Does he do any things that are the same as you?*
>
> ***Max:*** *I wouldn't say so, no.*

The location of Alan's computer, and his separation from classmates to do some of his work, had the potential to contribute to Alan being seen as different from his peers in the context of the classroom. Max believed that his friend enjoyed playing on his computer most of all, and that the least preferred activity would be 'maths, what he doesn't get to do … well he does do maths, but the teacher aide does some maths for him'. He felt that the teacher aide did most to help Alan at school, although the class teacher also helped him to learn. He did some work using the computer with the teacher aide supporting him. His computer was placed at the back of the room and faced out the window, so his back was turned to the class in these circumstances.

In many respects Alan was observed to be very much a member of his class. He participated in some lessons alongside his peers, closely supported by his teacher aide. He was the subject of some classroom banter, but he was also capable of 'giving as good as he got'. Other children looked out for him, especially some of the boys, and supported him to move around the class and to get access to needed materials. Alan's interactions with his classmates were generally comfortable and relaxed, and suggestive of a real sense of belonging in the class. In one interaction Alan responded to the teacher's request to the class to find a partner:

> *Alan goes over to Max and asks him if he'd like to work with him. He does something to Pete on the way past who responds with disdain, 'Don't, Alan!' Max comes over and joins Alan with the teacher aide. Alan offers some suggestions in relation to the task and asks the teacher aide some relevant questions [writing down what war would be like if you were a soldier]. The teacher reprimands two boys and Alan says, 'Stay on task, Pete'. Pete responds, 'Shut up, Alan'.*

Some students would naturally provide support to Alan without being asked, helping him to his seat and assisting him to access materials:

> *The teacher was handing out tickets for the end-of-week prize draw for good behaviour. Ryan brings over Alan's tickets and asks, 'Alan, have you got any other tickets in your desk?'. Alan replies, 'Don't know'. Ryan goes and has a look in Alan's desk, 'Alan, you don't have any'. Alan replies, 'OK'.*

Adults supporting Alan described some concerns about his social needs at school, and many were aware that he was isolated from his peer group. The difficulty was trying to work out a solution, and, like Alan's parents, most struggled to come up with a solution. What was interesting, however, was the apparent contrast between Alan's school experience and his experience outside school. At rugby practice he was welcomed and included in aspects of the practice which accommodated his physical challenges. His parents supported other children to stay on their farm, and in his home environment he was able to participate alongside his peers. Riding his adapted pushbike and farm bike with his friends and going out fishing with his father were activities he could share and where his disability became irrelevant. At school, however, his biggest challenge was keeping up with his more physically able and active peer group. Finding shared activities in which disability was not an impediment seemed to be more difficult to achieve at school than it was at home or at his community rugby practice.

The bullying experienced by Alan at school was not currently an issue for most of the other focus students. However, secondary students Harry and Heather, and intermediate student Ian, had very fresh memories of being bullied at their previous primary schools. In addition, a sibling of one of the focus students at intermediate wrote that one of the things her sibling disliked at school was 'getting boulide'.

Overall, friendships appeared to prosper in schools where:

- students with and without disabilities were taught together
- there was a school-wide focus on children's relationships, from the principal through to the teacher aide and into the child's family and the wider community
- physical access was a priority in the school
- teachers took social relationships into consideration in their teaching practices (e.g. through careful lesson planning and through the use of approaches that bring children together to learn)
- class teachers saw themselves as having primary responsibility for students with physical disabilities in their classroom
- class teachers had time available to plan for the inclusion of the student in classroom-based lessons and activities
- students were located in the centre of the classroom
- schools implemented a variety of peer support networks, and students were encouraged to support each other in class and in the playground
- teachers and teacher aides set up playground activities which brought children together around a shared activity
- decisions on promotion to a new class took account of friendships
- there was an emphasis on student learning and participation alongside peers.

Equalising opportunities for students with disabilities, building self-esteem and confidence, and minimising difference

Some schools had explicit statements in their policies on special education needs which celebrated diversity and emphasised supports to ensure equity for students. Some schools operationalised these policies by adopting teaching and therapy approaches which ensured that students with disabilities had a sense of belonging in the school. Leah's classroom and school was a good example of this, and Leah suggested that this had been achieved because her teacher had a personal family experience of disability and therefore 'knew what it was like' for her as a student. Therapy provision also supported her sense of belonging in the classroom. Occupational therapy was particularly highly valued because it had given her access to a new computer, which allowed her to 'do things for myself'.

Some schools worked hard to ensure that students were treated with respect and dignity, and emphasised in their teaching relationships with students that the students were valued class members. Building students' self confidence and self-esteem may not have been an explicit goal for all teachers, but some did create environments in which this could be achieved. This aspect of children's and young people's lives is clearly tied up with their friendships and relationships with peers. Some schools supported this area of their student's development through observations and interventions in the playground, and by modelling inclusive teaching approaches in the classroom. Leah's teacher placed her in the centre of the classroom, and encouraged her to be autonomous and independent. Interactions were primarily with her as teacher and not with the aide. Leah was also expected to request assistance from the teacher herself and to feel that she had some power and control in the classroom.

Harry raised the point that in his secondary school, senior students with particular responsibilities in the school were able-bodied. He commented that disabled students should also be represented at this level and that this would send a message to those in the school community that students with disabilities were equally valued and equally able to contribute to the life of the school.

Some schools' physical environments created additional barriers for students with physical disabilities, and several students described difficulties with access. This meant break times were particularly difficult because they were often unable to make choices about where to go and with whom. Isolation for some students at these times was partly a consequence of the student's physical disability. Students described not being able to keep up physically with their friends, and schools responded to this difficulty in different ways. One primary student was unable to access the 'top field' where his peers played rugby, even though he was a member of his local rugby team. While his access to and participation in community-based sporting events was supported, the school environment would not be able to offer this same level of support without a ramp, and although this was now going ahead there had been some school-based resistance to its installation. Laura was also unable to access some of the buildings in her primary school, including the administration building.

In the discussions with students for this research project, issues of access were described as being of paramount concern, and had a huge impact on students' quality of life at school. In particular, poor access prevented students from being with their peers, from making choices about activities and social relationships, and from participating in culturally valued events in the school (e.g. Laura shared her good news with staff through the staffroom window). Laura summed it up when she said the best school in the world would be 'accessible'. In contrast, adults in some schools appeared to be less aware of the importance of poor physical access in children's lives.

Students who did not have access to ORRS resourcing had few and generally inflexible supports for learning or therapy. Their teachers and parents were frustrated by this situation, and the lack of support contributed to a school experience in which it was difficult to minimise difference or attend to equity issues. This point is discussed further in the subsection on funding decisions at the end of this section.

One school described a situation beyond its control which raised questions about dignity for the student and safety for those supporting him. Ashley travelled to and from his rural school on the school bus. As he grew, this had created some challenges for bus and school staff who needed to lift him. His school principal pointed to a national contracting decision which made life difficult for Ashley:

> *Before I started here as principal, I understand the local bus contractor who had the contract for the school run had purchased a special lift so Ashley could be put on the bus easily, and then with the next round of Ministry contracts for the bus run that contractor lost that run … he's got a modified bus … he bought it at quite an expense and the company that now has that run doesn't have that facility … they have to manhandle Ashley on to the bus. The bus driver is very good and the teacher aide at the end of the day they get him on the bus … but that was quite a community issue when that happened … it comes down to dollars.*

It was also difficult for school staff to minimise difference when students were withdrawn frequently from class for therapy and other learning support. This point is discussed in more detail later in this section.

Teaching, learning, and learning goals

Interventions that focus on quality of life and promote adaptation and function

The current project has forced a reconsideration of the question, 'What do students need to learn in order to support a quality life?' In particular, many participants – both adults and children – raised issues about achieving a balance between academic learning and working on therapy goals. One parent described her son with very high needs as having made huge gains in the area of physical development, and attributed this to the teamwork and shared focus of the on-site therapy and teaching team. However, it was very difficult to get a clear picture of physical gains for students across other sites. Even though some therapists were working to integrate therapy into classroom routines, withdrawal for therapy was common in schools and there did not seem to be a good understanding about the effect of this on students' school life and opportunities for learning. Achieving the right balance between therapy and academic learning was an issue raised by several participants, including children.

Withdrawal for therapy?

Ian's experiences and comments exemplified the issues around achieving a balance for students. During observations Ian was withdrawn several times from his regular class for therapy and wheelchair maintenance. The programme was unusual in that it was the start of the school year, but his class teacher worried that he was missing out on important classroom experiences, including some assessments. Ian had come from another school and was struggling to make new friends, a situation that was likely to be exacerbated by his part-time presence in the classroom. When Ian was asked about withdrawal for therapy he said that it did not worry him that much, but he concluded that 'It's better to sit in your wheelchair and know your maths than to walk'.

Withdrawal for some aspects of their school day, usually for therapy-related purposes, was commonplace for most of the students in the project. Isobel had moved from the regular class to the unit because of health needs, and even there her teacher described her as 'away from my care' a lot of the time. Although Isobel was reading two years in advance of her chronological age, it was not clear that academic achievement was a priority for her. Riding for the Disabled was extremely popular and several students in the case studies were withdrawn during school time to participate in this. Although parents and professionals described the benefits of this activity for students with physical disabilities, the possibility of loss of learning resulting from withdrawal from class was not usually addressed. Given the popularity of Riding for the Disabled, some further exploration of the role of this activity within the broader context of students' school programme would be valuable.

Several teachers, parents and teacher aides raised questions about the relative importance of therapy versus academic learning, and about prioritising to support student learning. The students themselves also offered their perspectives, and they each interpreted withdrawal from the classroom in different ways. Harry was happy to be withdrawn from his regular class for physiotherapy twice weekly. As a senior secondary school student, privacy for this activity was important, and the therapy was a necessary part of his post-surgery recovery. At primary school Leah and Laura, on the other hand, did not like being taken out of the classroom for therapy because they felt that they were missing out on what was going on in the classroom. Ian also commented that learning was important for him, and that withdrawal from class meant that he would need to catch up. Laura, at the age of 12, pointed out that there were some discreet exercises she could do in class which fitted into class routines. She made it clear that she did not appreciate having physiotherapy in the library because students would walk in and she felt embarrassed.

Alan gave another insight into withdrawal, showing that student and adult perspectives on this process could be quite different. On the one hand, Alan's teacher felt that he was:

> *… quite happy to go out of the class, and I'm happy with that. The only time he complains about going out is if we're watching a video or something exciting is happening he's reluctant to leave, but the special needs teacher is good, she'll say, well, he doesn't have to come today, or he can come for a shorter time, and he's good like that he understands that he has to do things.*

She pointed out that while withdrawal could support children to meet their physical goals, from a broader learning perspective withdrawal could have a negative impact:

> *… if he is missing out on something that everyone else is doing I think that's a negative kind of, it's doing something negative to the situation because the kids see him missing out on something exciting and I think he feels different.*

Alan's comments about withdrawal showed that he was selective about when it was and was not okay to leave the classroom, and he felt a sense of compulsion when it came to therapy outside the classroom:

> ***Allan:*** *I go somewhere else for [some therapy]. I go in the spare room.*
>
> ***Interviewer:*** *Do you mind going out to the spare room?*
>
> ***Alan:*** *I have to put up with it.*
>
> ***Interviewer:*** *What would you rather do?*
>
> ***Alan:*** *Stay in the classroom.*
>
> ***Interviewer:*** *What about for physio?*
>
> ***Alan:*** *I'd rather do that down in the spare room because it's quieter.*
>
> ***Interviewer:*** *If you were doing something fun in the classroom and you didn't really want to leave, would you say that?*
>
> ***Alan:*** *Yes – but I would just have to do it.*

It should be noted that Alan's therapists did not usually agree with withdrawal for therapy, but at school this did occur at times, and because itinerant therapists were in schools periodically, it could be difficult for them to monitor the day-to-day implementation of strategies focusing on therapy goals.

The comments from children and young people presented here also raise questions about the place of children's voices in decision-making, and their capacity to influence their school experience.

Not enough therapy?

Interestingly, the same theme arose in reverse for some participants. The provision of physiotherapy had been a particularly contentious issue for families following transition to school and to education services in the urban area served by the CDS team. Although Health-funded services for early childhood-aged children were perceived to be supportive of children, the transition to school meant serious reductions in therapy for some students due to a chronic shortage of both occupational therapists and physiotherapists working for GSE in this region.

One primary-age student in the case studies with high-needs ORRS resourcing, for example, had received regular physiotherapy in early childhood under a CDS team, but currently received none at school due to that region's shortage of GSE therapists. This child's mother worried about her daughter's physical development and said:

> *Physiotherapy has always been a problem with GSE. The first year at school we had physio once a fortnight [contracted in through Health because of the shortage of GSE physiotherapists] the therapist did a session with my daughter and altered the physio programmes and that … but since then they got another physio in and, it might have been two since then – but none of them stay … [I've been told] that their caseload is far too great – they can't make a difference so they just leave … and the last physio they had had 60 kids on her books. And so basically she came when … well, my daughter hasn't seen a physio at all this year and we've put it in the notes at her IEP. Actually we put it in the notes for last year. And she's never seen a physio.*

What physiotherapy this student could access at school came through Health and was only provided pre- and post-surgery, despite the student having ORRS resourcing for high health needs. This meant that daily stretches at home and at school (done by the teacher aide) were unsupervised except when the student received Health-funded therapy around periods of surgery. Concerned about the lack of therapy, and about teacher aide hours (which had been reduced from 10 to 5 hours), the parent in this case had pursued the issue with GSE but had been unable to secure either additional teacher aide hours or physiotherapy support:

> *First off she got 10 hours, and then it got cut back to 5. But since she has had the same teacher aide so every year her wages go up – and the hours get cut down. So it's either keep the aide that knows her and knows what she needs, or get a cheaper aide so we can get more hours … I talked to Special Education about it but they said it was not their problem as far as they were concerned, how much wages the school pays. I got told that it wasn't my daughter's money, it was actually money for them to use at their discretion … we use it for unders and overs … and they said to me, and they hammered it home to the school – that my daughter receives teacher time as well as teacher aide time, and they also told me that they only have to come to three IEPs a year.*

In terms of equity, this situation made little sense to the parent:

> *The fact that we had to go through a process to get the [ORRS] money and then we had to go through a process to see how much of that money we were going to get – I was floored that we had to do that*

> *… I mean, it doesn't seem to matter whether she has had plasters on her legs or not, they still haven't fronted up with the 'overs' money for my daughter ever. It's always been the same.*

It was not clear to this parent whether GSE genuinely felt that physiotherapy was not needed, or whether monitoring was considered not to be part of their role, but the parent felt it was important for someone to monitor and respond to the early signs of deterioration in her daughter's legs. To this end, the parent had established a good relationship with Health personnel, and the surgeon involved had invited the parent to phone the hospital if she had concerns. The CDS team had also offered support and advice beyond their funded post-surgery physiotherapy time, and this arrangement was considered to have reciprocal benefits: 'They've had her since she was a baby, and to see what she's got to now, it's just really good for them. So they've been really good for us'.

Some other parents were also uncertain about whether their children received enough therapy at school, with concerns primarily in the area of physiotherapy. One parent worried that without physiotherapy her child became less supple. In a slight turn-around from the argument presented above, she wondered if there was an emphasis on learning outcomes to the detriment of physical outcomes, and described a major difference in the amount and type of physiotherapy provided in the early childhood years and that provided at school. She described this as 'a loss of therapy'. A therapist, on the other hand, thought that this mother was instrumental in achieving a balance between curriculum and physical needs: '[Her mother] is in control of that balance and very much has got her finger on that'.

The various opinions expressed by participants in relation to achieving a balance between therapy and learning suggests that therapists and school staff may need additional time and support to ensure that a shared understanding exists about:

- the overall goal of therapy (to support students' access to the curriculum)
- what is involved in the integration of therapy goals into functional routines at school, and what this looks like in practice.

Supports for curriculum adaptation

Some students valued the co-ordinated support they had from adults working on their team, and the effect of this support on their ability to access the curriculum. Harry had missed a lot of school because of surgery. He described good co-ordination between his school-based teachers and the hospital teacher, with both teachers adapting curriculum materials so that he could pursue his studies as soon as he felt well enough. However, time off school did affect his learning opportunities. His English teacher felt that it would be important to repeat last year's English because he had missed out on so much work. Curriculum adaptation in Year 11 was difficult because of assessment requirements, and this meant establishing himself in a new and younger peer group for this subject. This step might not support Harry in his social life, however, and suggested that teachers might need support to make curriculum decisions that also take into account students' social experiences at school.

Some classroom teachers adapted the curriculum for their students. Leah's current teacher was also the ORRS-funded 0.1/0.2 FTTE, and her block of release time provided her with valuable opportunities to plan for curriculum and lesson adaptation. Laura's principal (who had been her class teacher in the previous year) was also able to use the 0.1/0.2 FTTE time to develop adapted curricula in her small rural school. In both of these cases, a close relationship with the child as their class teacher meant that the process of curriculum adaptation was well informed and linked closely with current classroom events.

In the self-contained school, considerable thought had gone into ways in which the curriculum could be adapted, particularly at level 1, and into ways in which therapy and teaching could be integrated to access the curriculum. This level of thinking was unusual, however, and students with very high needs, in particular, challenged their teachers in the area of curriculum adaptation.

A therapist providing support to a student in a regular school reflected on the challenges in the area of curriculum adaptation, and on the implications for devising a meaningful curriculum for a teenager heading toward adult life:

> *The curriculum for him – it's problematic for us all. You can take out elements of level 1 as the basis for the programme. It's more about how well we meet his needs. Communication is a key for him, weight bearing so he can help others when they transfer him … He's not doing well [in the communication] area, and that's not a reflection on his SLT [speech-language therapist]. I don't think we do the communication thing particularly well for a lot of kids. His social needs have changed. He's in a teenage peer group now. Post-school is really hard. There isn't a lot in the area, I don't know actually – that's the fear that parents must have … what else is there?*

In the secondary school, teachers had little if any time available to adapt lessons to meet the needs of students with physical disabilities. In this and in some other classrooms (primary and secondary) it was not unusual for curriculum adaptation to be done on the spot, often by the teacher aide. Alan's first-year teacher commented on this. She felt 'bad' about not being as actively involved in Alan's learning as she would like, but in a busy and challenging class she felt hamstrung:

> *I try to tell Sarah [the teacher aide] before class what we will be doing, but she more or less adapts the task on the spot. If my class had minimal or no behaviour problems, I would be doing a lot more with Alan than I do now. I feel it's a shame really … I would like to be able to do more 1:1 stuff with him … In terms of our relationship, yes, it is the same as for the others, in fact we talk a lot at lunchtime and playtime, so it may be even more time with Alan, but in terms of teaching time I don't have the time to spend with him … it would be nice if Sarah and I could change places a bit, if I could set a task and spend 10 minutes with Alan while Sarah helps the other children, but because of the class we don't get to do that … I mean, he sees me as his teacher, but I don't feel like his teacher, and he knows Sarah's role is to assist with his learning, but I would like to have a far more active involvement with the teaching-learning side with Alan than I do.*

Other teachers in regular settings made similar comments, and these issues were magnified even further for those teachers working in classrooms where students receive no external funding or resources.

Teacher knowledge of students' goals

Teachers in regular classrooms generally welcomed students with disabilities and worked hard to ensure that they had a central place in the classroom. They attended the student's IEP meetings and actively contributed to this process. In schools with therapy on site, teachers and therapists shared a good working knowledge of students' goals and could integrate learning and therapy goals effectively, supported as they were by a working environment which involved continuous contact and ongoing opportunities for discussion between team members. However, as students moved into regular classrooms, teacher knowledge of students' learning goals became less secure. Teachers in secondary schools felt that they did not always know their students well because of the small amount of time they had together, and they did not have dedicated time available to think about adapting the curriculum or lesson to meet the student's learning goals. The use of the school's intranet for IEP planning was identified as one strategy that would improve the flow of information in the secondary school with an attached unit.

Similarly, Alan’s teacher talked about going to the IEP meeting to learn about his learning goals, and felt embarrassed that she did not know enough to be able to contribute to the IEP process, which was overseen by the 0.1/0.2 ORRS-funded FTTE. The 0.1 FTTE specialist position could be used to provide more direct support to the class teacher, but in this case there were few opportunities for such liaison to take place, and the teacher in the 0.1 FTTE position herself felt a strong need for professional development in the area of effective collaborative and consultative models and approaches.

As discussed in other parts of this section, students who did not receive ORRS or moderate contract resourcing were at risk in this area. Because supports for class teachers were either not available or were inadequate, the teachers found it difficult to get to know the student, or to take an active role in their education. This frustrated teachers, who were otherwise committed to including and teaching students with disabilities. This point is discussed in more detail in the subsection below on funding decisions.

Meaningful, beneficial, practical and easily maintained goals

Parents were, on the whole, actively involved in decision-making around their children’s learning goals. Their participation in the IEP process was the main vehicle for ensuring their voice was heard, and their involvement in this process was expected and supported at all levels. Principals, teachers and therapists alike saw parental involvement in decision-making as critical, and open and explicit lines of communication between school and home facilitated the exchange of information around the IEP process. Parents generally felt that their opinions were valued, although one parent did describe needing to ‘thump the table’ at times, and another mother admitted that she had to ‘pick what I whinge about’. Active parent involvement meant that learning goals selected supported their children at school and at home, and that overall this contributed positively to the family’s quality of life.

A few families considered their children’s learning goals as able to be pursued at home, and therefore felt them to be easy to maintain. However, the extent to which follow-up at home was possible depended on families’ commitments and energy levels. Some parents simply found it too difficult to integrate therapy into their already busy lives, or did not want to, preferring just to ‘be a family’ outside school hours. Home–school notebooks were an asset for a lot of parents and teachers, and allowed a good flow of information between the two settings. For families this communication link was valued, and allowed them to stay up to date with what was happening at school. One parent made the comment that it could sometimes be difficult to continue school routines at home, although she tried to do it because the school asked ‘in such a nice way’.

Long-term view

As described in Section 2.7 of this report, families did waver on the question of the future for their children, and for many parents and therapists alike the future was particularly uncertain for students with very high needs. Where students had high needs, families shared some worries about the future, but on the whole their focus was very much on schools preparing their sons and daughters for a good future as an adult. They talked about the importance of their children being independent, autonomous and happy, and most parents who had children in regular settings felt that school supported their children to develop in these areas. Children themselves talked about their job aspirations, and some also said it was important for schools to allow them to learn academic subjects to help them reach their goals. One of the two school-leavers interviewed for the project felt that school had prepared her well in this regard and she had gone on to live independently and participate in work-related tertiary education, although at the age of 21 she had yet to secure a job.

Ten-year-old Alan's story illustrates some of the concerns raised by the parents in this study. Alan's parents encouraged him to lead an active life and to have experiences that would support his overall development. He loved fishing and his father often took him out on the boat. His love of music and radio were also recognised as possibly leading to a job in that area, but above all his parents hoped that he would lead an independent, fulfilling life as an adult. They felt that the resourcing he received would continue to support Alan to achieve his goals, and that the school was on the right track in this area, although his mother worried about what might happen if the funding were reduced:

> ***Mother:*** *He loves radio. He wants to work in radio, he's going to work on a ferry to the island, or on the Cook Strait ferry because it's bigger. Maybe the radio would be more practical! … I think school will listen to him and support him to do what he wants to do when he leaves school … I'd like to see him be independent, go to University. I can genuinely see him working in radio. I don't know about the Cook Strait ferry.*
>
> ***Father:*** *I'd like to see him live a fulfilling life. We try to do that here: give him a lot of experiences, do interesting things, like skiing, fishing, we ride our bikes, he can go on a ski biscuit by himself.*
>
> ***Mother:*** *At camp he went on the flying fox, and the other kids were terrified … He was carabeenaed [secured] into it and he did it. He was confident to do it. We get him to do as many things as other kids do, don't we?*
>
> ***Interviewer:*** *Any worries about the future?*
>
> ***Father:*** *If he becomes too reliant on us, that wouldn't be too good.*
>
> ***Mother:*** *I hope he'll be independent and safe. He is confident and that's good.*
>
> ***Father:*** *Have a relationship*
>
> ***Mother:*** *Yeah, we hope he'll get married and that sort of stuff , yeah.*
>
> *Interviewer: Do you think the support he's getting at the moment is helping him to head down the track towards those dreams you have for him?*
>
> ***Mother:*** *Yes, I think so. He's going to get independent from being educated and that's the whole basis of it. If he weren't getting the funding, the teacher aide in class and so on, that would make a big difference. He needs to keep progressing and he's only doing that because he has so much input. He is an 'over' and if he lost that it would be a concern. The funding gives us confidence but if there were changes to that we would be worried … he wouldn't get his education and we or the school would have to meet that.*

School staff, like parents, had a range of perspectives on the future for their students. Some staff felt it was important for student goals to be those that made things easier for parents and families. Valued outcomes included learning to sit quietly, transferring one's own weight independently, and eating independently. Another principal felt that student learning needed to focus on the student's overall development with a long-term view to a quality life both as a child and as an adult. He felt that goals needed to be carefully selected to support student learning with adult life in mind, and that academic goals were therefore a priority, along with physical goals. These divergent views on what constitutes best practice in the area of curriculum for students with high and very high needs suggest that this topic could be an area of priority for professional development in schools that support students with physical disabilities.

Achievement and assessment

Relevant assessments and monitoring used with a focus on multiple measures

The self-contained school in this project and the primary school with an attached unit used a wide range of assessment tools to focus on multiple outcomes. These included ecological and standardised assessments, as well as those related to the particular philosophy of the school. In other schools, assessments were primarily described as informal, and included progress towards IEP goals, observations in classrooms, and general impressions about how the student looked. Where students attended regular classrooms, curriculum-related assessments were usually undertaken.

Across all schools, parental input was considered vital in assessing student achievement, particularly in relation to IEP goals, and their opinions were most frequently sought through the IEP process. Some therapists suggested that the parent voice was or should be one of the multiple measures to be included in the assessment process. However, providing parents with suitable contexts in which they can feel free and comfortable to address their child's progress can be difficult. One therapist conceded:

> *I think we might not always hear from parents in that kind of situation what their real feelings are about improvement, because it's not always the easiest situation for them is it?*

In schools where therapy was itinerant, it was not clear if part of the teacher aide's role was to monitor physical progress or deterioration. Therapists committed to integrated therapy in these schools consulted with school staff (primarily teacher aides and the 0.1/0.2 FTTEs) and described and modelled procedures for integrating therapy into class routines using elements of role release. However, heavy workloads meant that visits to schools typically took place only once or twice each term. In one case, no therapy was provided. In one school, the teacher aide described 'making up the exercises', raising questions about safety for the student. One therapist suggested that the new Health Practitioners' Competence Assurance Bill (before Parliament at the time of the interview) would provide new challenges to therapists, and might have an effect in situations where role release to teacher aides was integral to therapy provision in school.

Extensive family involvement and input

Family involvement

All schools had a strong family focus, and this was clearly reflected in families' comments that they felt involved and valued in their children's schools. As described above, parents were generally happy with the amount of input they had in their child's education, and felt that in the IEP process, in particular, their perspectives were listened to and valued. The deliberate building of supportive relationships between schools, therapists and families meant that families across all schools described school and therapy staff as highly supportive of their child, of themselves as parents, and of the family as a whole. Therapists often described working outside their usual boundaries to ensure that families had information and support. The self-contained school had clearly expressed statements about family involvement in its documentation, and particular care was taken in this school to be supportive and responsive to families, and to provide education and support in ways that were responsive to and respectful of their cultures.

The role of co-ordinator did seem to fall to many parents, who described being worn out by this role. Laura's mother, for example, described her role as Laura's 'PR person' and as helping Laura with school work, general care and physiotherapy. In relation to the IEP, she saw herself as the hub, but also acknowledged that this could take its toll on her time and energy. On the team that supported Laura, she saw herself as 'co-ordinator and go-between', carrying messages from therapists to others. When Laura had Botox treatment, she also became the co-ordinator between Health and GSE physiotherapists, but she emphasised that this was not a problem with the people involved. There were 'gaps in the system', which meant that information did not flow smoothly across sectors. Laura's mother suggested that to relieve this pressure, a small group of families would be well supported if they had one person to co-ordinate their needs for them:

> *I just think a lot of it is there, it's just a matter of managing it better at times. I think that people need to be much more aware of how much pressure is on parents with special needs children at times … I think professionals can forget that. They forget that the parents are 24 hours a day, you know, seven days a week, and the child you see at school is quite different to the child you see at home.*

Some sites in the project had adopted a key worker approach, in which one team member became the main point of contact for the family and school staff. Parents valued this approach highly and commented that it relieved them of considerable stress, particularly in the areas of seeking out information and resources, and in co-ordination. In noting that parents were indeed the focus of the IEP, a school principal had some understanding of the fine balance between participation and over-commitment:

> *… of course they are probably the most important in this instance, because they do link between all [people]… I hope though that [student's] mother wouldn't think, 'Oh, everybody seems to be coming to us for everything'.*

Another principal valued close relationships with parents and described their role in the IEP process as 'vital'. At the same time he recognised that close involvement with schools could be difficult for some parents, and that schools had to be responsive to parents' understanding about schools and work carefully to overcome their fears. It was particularly hard, he felt, for those parents who did not know what schools did, and whose own experience of going to the principal's office as a child was for punishment.

Feeling well supported at school was also thought to be about more than just relationships between teachers and parents. Both parents and professionals interviewed described a wider supportive community as a foundation for school inclusion. This was felt particularly strongly in the rural communities, where families and teachers lived in the same area and knew each other well, both at school and socially. As one principal said: 'Other parents are very positive about having kids with special needs in the school. It is a very inclusive community. No one questions or complains'.

The extent to which family input should shape a child's experience at school arose as an issue in this study. In some cases parents' views were accepted as definitive, with one teacher suggesting that where there was a divergence of opinion, 'the parents are always right'. One therapist gave a more measured account of her team's approach by suggesting that parents' perspectives, while needed and valued, should be balanced with sound professional judgements.

Access to supports and entitlements

On the whole, parents reported they found it difficult to find out about and access entitlements. Parents who had spent a lot of time searching these out as their child grew had become advocates for other parents, ensuring that they, at least, had good access to information and entitlements. Therapists also talked about parents needing support and advocacy to access services and entitlements, and many had built advocacy into their role. Three families in the case studies had encountered difficulties with the needs assessment process, and had required support to access resources needed for home modifications and carer support. In Harry's case, for example, it was impossible for him to learn to cook at home because kitchen modifications would not be made while non-disabled people lived in the house (his parents).

Although families on low incomes were likely to be most at risk, other families also faced difficulties. One parent, for example, described being expected to pay for supports themselves because they had ‘a nice house’. One therapist summed up the situation that therapists often found themselves in: ‘I feel sorry for those families that are shopping around … we kind of have a broader responsibility to make things smoother [for families]’.

Therapists talked about ‘caring’ for families and several described active and responsive support with families which sometimes went beyond their role. Therapists on teams, in particular, used a variety of approaches to ensure that parents received the entitlements and support services they were due, including the following.

- Therapists described actively advocating on behalf of families who required that level of help.
- Therapists followed up with families to ensure they had accessed promised services and supports.
- Teams make links with other sectors and agencies a high priority in their work in order to support the smooth provision of services for families.
- CDS teams worked very closely with families and schools to support the transition of children from early childhood to school.
- A GSE team invited Health sector professionals to moderate contract meetings so that decisions could be made ‘there and then’.

However, therapists also recognised that being responsive to families’ needs in this way was not always easy to achieve when carrying a heavy workload. Primary relationships were with schools and school staff, and contact with parents tended to become a secondary consideration. Some therapists wanted more time to work closely with families in their own homes, and one described a ‘personal goal’ to improve relationships with families:

> *I always have ‘parent’ flashing – because we’re good at working with schools … but we don’t have enough time or a close enough connection with parents to be able to make the most of that relationship and to support parents enough.*

A parent whose son received support from a CDS team expressed some concerns about barriers in the process of applying for supports through Health, a process she was relying on because her son received no ORRS or moderate contract resourcing despite having a wide range of complex needs. In particular, seeking supports through the paediatrician had been frustrating:

> *He doesn’t really see the big picture. I said something to him once about my son not being able to read and he said, ‘Well, Jonah Lomu can’t read’. Who cares, kind of thing. And this is the attitude of the system. Now if I could change my paediatrician I would, but he’s the only one who comes here, so what can you do?*

Input from students and siblings

Teams supporting students and their families tended to focus primarily on adult ‘family’ input, although one school with an attached unit said that they involved the students themselves in decisions about how their funding should be used for support at school. Schools could be very student-focused in their planning and teaching, but in the observations associated with this project, not many examples of students with disabilities being asked for their opinions or perspectives. One good example was the secondary school with an attached unit. Students were generally not involved in their IEPs, and while this may be by choice, it was not clear that their voice had been taken into account in determining learning goals, or in the assessment process.

In terms of students' futures, teachers – and sometimes parents – were not always sure about students' personal aspirations. This suggests that in planning for the student, a future-oriented curriculum would be difficult to achieve. One therapist did reflect on this aspect of one focus student's life, and on the implications for the team supporting him:

> *I think how well he does will depend on the team, and on how well we prepare for that transition to adult life, because there is a tendency to leave planning for that a little bit late. Things can take a while to learn and starting at 15, 16 is leaving it too late, you miss out on the time to ensure he is well prepared. And it can be hard for parents to think about those things so early … but also we don't ask children with disabilities what they want to be when they grow up. Finding out what they are interested in might be a really important part of that whole preparation for adulthood and not just slipping them into something because it is the only thing around.*

During the data collection for the project, siblings of students also became known to the researchers, and in some cases offered their own perspectives on their brother's or sister's life. The presence of these children and young adults was a reminder that family support involved more than parents or caregivers. It was rare for team members associated with students with disabilities to mention siblings during observations and interviews, yet it was clear that siblings had their own perspectives to offer and their own set of issues to deal with. In Heather's family, for example, her 18-year-old brother had to assist with lifting for toileting, and, like his mother, was very aware of the inappropriateness of providing personal care for his sister. He also supported her positioning in her chair and felt responsible for ensuring that she was learning things at home that would support her to be independent when he left the family home. He hoped that at school she was also being provided with opportunities to weight bear so that his mother would not be faced with lifting her when he was no longer around to help.

Other siblings variously annoyed and were annoyed by their brother or sister with a disability. While this is not an unusual family experience, aspects of the sibling's disability were sometimes at the centre of these battles. One sibling felt that his sister with a physical disability was jealous of him because he did not have cerebral palsy. Another wrote about his sister: 'When she had a seager [seizure] I was cryin' and scared, so even if she is anoyin' I still love her'.

The effect of resourcing decisions on children and families

Resourcing decisions have the capacity to either support or place barriers in the way of teams' attempts to work in ways that are consistent with the indicators of integrated effective practice. The effect of under-resourcing was felt primarily in regular schools where applications for ORRS resourcing for the focus students in the study had been unsuccessful. The material on the effect of resourcing decisions is presented separately for two reasons. Firstly, for focus students who did not receive ORRS resourcing, the lack of resources and supports was constantly referred to by participants as the major contributing factor to stress in schools and in families. Schools talked about the frustrations of wanting to meet children's learning and physical needs without the services and infrastructure they require. Several principals and parents made reference to a perceived inconsistency between the Ministry of Education's pro-inclusion rhetoric and the reality of teaching children with inadequate resources. Secondly, the impact of poor resourcing was felt widely in terms of the outcomes relating to integrated effective practices in schools. The issues described below cut across the areas already discussed above, including inclusion, assessment, curriculum adaptation, learning and social outcomes, friendships, team collaboration, and school–family relationships.

In some cases a perceived shortfall of funding could compromise the relationships between schools and families. One principal of a primary school with a strong inclusive focus (both in terms of its written policies and in the observed structures and teaching practices in the school) was concerned that the Ministry of Education could mislead parents into expecting support which schools could not provide because of poor funding levels. This put schools in the difficult position of wanting to offer support to families and children, but being unable to come up with the resourcing considered necessary to support the child:

> *The [Ministry of Education] sends out documentation to parents that says your school is funded to take care of your special needs child, ask your principal. And they come and ask me, and that's fair enough, because that's what the [Ministry] said, and I say, 'Yes, we did have some money, we got a SEG grant of $9,000, it's now July, we've spent $18,000', and I'm not joking, that's the sort of level – I'm sorry, there's no money left. Now those parents and children have a right to that money and it's gone– it's totally inadequate and it was very misleading of the Ministry to say that sort of thing. It wasn't fair in fact, and I'm not talking about me, I can tell parents I'm sorry there's no money and they can choose to go somewhere else. It's unfair on the kids because there was an expectation that something would happen and really, in many cases it didn't.*

When students were turned down for ORRS resourcing, in particular, families experienced high levels of anxiety about their children's future development, and schools often struggled to provide the support that was needed for the student to access the curriculum. This was the case for three of the focus students in the case studies: Ricky, Rose and Christopher. Students who did have ORRS resourcing were perceived, on the whole, to be well supported at school (although, as pointed out in the case studies with itinerant therapy, there was not always a shared understanding about the amount and quality of therapy provision). For students who did not have ORRS resourcing, there was a cost involved in terms of quality of life outcomes for students and families.

Costs in terms of workload and energy

Some families were tired from the advocacy they saw as necessary to access scarce resources for their children. One father of a child in a regular primary school commented:

> *We've been told that we're very proactive and we're interested in what we're doing. Our child is lucky because we are actually trying to get things done. But hell, I can see why people stop doing it. Because you might as well hit against a brick wall. I can see why people get disillusioned.*

Parents were quick to point out the benefits of a regular class education for their child, but they were puzzled by the apparent inconsistencies between education policy that supported inclusion, and levels of support which they felt compromised their child's access to the curriculum. One parent sympathised with his daughter's class teacher who had a large and diverse junior class with 1½ hours of teacher aide support weekly:

> *Her teacher said that the actual hands-on time a teacher can spend with our daughter in a week is minimal … at home we are constantly reminding her [about seated positioning]… at school that doesn't happen so she's probably not getting through the amount of work she probably could do if there was more assistance there for her … I think schools should not have to beg to have someone there to help children – and it shouldn't be part-time … I think they should perhaps have teachers who are specialised for special needs, paid for by the government, and they are at that school every day to help those kids … coming through the classroom every day … because we know how much we can get through with our daughter one on one.*

The principal of this school, in reflecting on the challenges of teaching in such a classroom, wondered whether workload could therefore be a concern for that teacher: 'How much is [the teacher] doing off her own bat that we don't know about?… I'd like to know if she is – if it is a real struggle and if it is really tough for her'.

The workload of the special education needs co-ordinator was also an issue for this principal, who felt that the part-time teacher position currently allocated to this job was inadequate and that in the end the student's education would be compromised. To meet the needs of children he perceived to be falling through the gaps, the principal suggested that the special education needs co-ordinator needed more organisational time available to her.

> *The job is huge. The teacher's teaching four days a week, and has one day out to – she's got six ESOL [English for speakers of other languages] staff who are teaching second language children and slower children … it's about developing a system that can try and pick them up as well. You need someone to organise it and run it and be part of it … we can't afford teachers to work with them, so you've got to organise parents – they need to be trained [as teacher aides]. It's a big job. It's a really big job.*

As a Year 1 teacher, six-year-old Rose's teacher agreed that teacher aide support was needed for Rose to access the curriculum. Rose has sensory integration, motor planning and major social challenges, and had been turned down twice for ORRS resourcing. In Year 2 at school, and in a class of 26 children, her parents agreed to pay $3,500 per term for a full-time teacher aide. The teacher had recently experienced what it might be like not to have this level of support:

> *Rose's teacher aide had to leave for the afternoon. That was my first afternoon with Rose unsupported and I was shocked. I was shocked at how difficult it was. I could not be with her all of the time, and just had to let so much behaviour go just because I was stretched in so many other directions … The teacher aide and I are developing a good routine of stepping back and stepping back … but for my peace of mind, just knowing she's there to keep an eye on her when she runs out the door … to be with her on the mat … just not having her there drew so much of my energy and attention away from the rest of the room that it made it really clear to me how much I rely on her in the classroom with me.*

One team leader said:

> *It's very hard when you put in an ORRS application and it gets turned down … one of my colleagues has a boy on her caseload who is 13 who still cannot toilet himself etc, etc – and he gets turned down. I mean, what opportunity has that kid got? … Kids fall through the cracks and that's where they remain, sadly – they don't get the opportunity and I feel for their parents.*

She endorsed the comments of several principals in this study by describing the key area for change as:

> *More funding. No two ways about it. More funding for those children who we give the bare necessity to – more funding for those children who are mainstreamed. I think that is our biggest issue … there's too many children missing the bus.*

Financial cost to families

Poor access to resources can also compromise families financially. Several families described offering to pay – or actually paying – for teacher aide support in their child's class. Rose's parents felt that she would be unable to cope at school without teacher aide support. She had received comprehensive support in early childhood from her local CDS team, but her parents now felt abandoned. According to Rose's mother, Rose was a bright student but without teacher aide support her disability would interfere with her capacity to learn:

> *Rose can do it academically, but I thought there's no way she's going to cope there. She hasn't got the social skills. She has trouble comprehending and decoding information and all that sort of thing. So at the IEP I said to the principal well, look, he was trying to rack his brains of how we could get enough*

> *aide in there for him … he was starting with nothing. And it would have to come from the school, and the school could no way take that out of their SEG grant to cope with our daughter. So we said well don't look at that, she needs the aide so we'll look at the money side, we'll get the money. It was like, it all comes down to money. She only needs the aide because it's a money thing. We said no, don't look at it that way, if she needs the aide we can get it, she needs it all the time until we can work out the parts of the day she can get through without an aide. So that's what we've done. We've funded this term which has just been over $3,500, and we're probably looking at most of next term, as well, and we're hoping in term 3 we can get some funding through the RTLB [Resource Teachers: Learning and Behaviour] for next term which will cut our expenses back.*

This family had sold their business to enable them to pay the teacher aide's salary. Rose's parents described the school as 'very supportive' of the family:

> *They can all see that Rose has needed that teacher aide support, and they've been fine … we're not going to scrape around [for the money]. If she needs it then she has it … and she's probably always going to need some sort of aided help … our goal is for her to be able to function to her potential within the school, and at this stage, that requires aide input to get her there, and it's working.*

Her school principal felt frustrated at the gap created between an inclusive school philosophy and a lack of funding to support Rose:

> *I think everybody is here for the kids and they all know that they're going to be at different levels and different needs. Catering for those needs can be a bit challenging at times, but everybody's here for the right reasons … the Board is alongside, but they feel pretty hamstrung about the resourcing issue … we certainly could not afford to be providing an additional 25 hours like Rose is getting at the moment.*

The school principal did not consider going through an appeal for ORRS resourcing because of the 'long haul' it required. The school had received some RTLB support and could supplement this with some transitional funding for speech-language therapy, but in comparison with ORRS resourcing, the principal felt that this approach created considerable uncertainty and affected the school's ability to teach Rose adequately and to successfully undertake long-term planning for her education as decisions had to be made term by term.

Costs in terms of good assessments and access to the curriculum

Teachers in classrooms with little support also felt compromised. Ricky, at age 11 and with both physical and emotional challenges, received no teacher aide support in the classroom, and his teacher felt that even attempting to support him to access the curriculum was a big ask:

> *I'm not sure how much I can do, because I am so much in demand with others as well within the class, and I know they'll respond, whereas Ricky won't respond always … he's very difficult, he hasn't got the social skills.*

In contrast, his mother wanted the school to focus on his academic learning and wanted Ricky to be happy. She also understood that he needed to be happy to learn.

The principal of Rose's school was concerned that under SE2000, the application process for ORRS resourcing had become impersonal and that children's needs for support were not adequately understood or assessed:

> *The thing I find really concerning at the moment is that you don't have any guarantees beyond what for us is the end of term. We have to look to cope as best we can with what we've got. So that's where I get a bit grizzly about the situation we're in. I used to quite enjoy knowing that if we had kids with high needs or even moderate needs that a trained professional was in a position to assess needs and then make a recommendation on her funding. And that was needs based … But to arbitrarily say she doesn't fit [the ORRS criteria]. See, as far as I'm aware, no one from that ORRS team has made a formal assessment of Rose's situation other than what they've seen on paper.*

While the Special Education Grant (SEG) fund gave principals the autonomy to manage this money, the principal felt that he was not in a good position to make judgement calls about the needs of individual children like Rose. In this regard, the professional status of the person assessing children was felt to be critical to understanding and meeting that child's needs:

> *Those people who were making the assessments [prior to SE2000] had a pretty good knowledge, and for most of the children, an historical knowledge as well, of what was happening for those kids. And just to know you have a visiting professional coming into the school on a regular basis and reassessing each kid's circumstances and then be able to go back and say, 'Little Johnny in school A really does need six hours of support a day as opposed to someone else'.*

He commented that the gap between support at early childhood level and school was felt to be considerable, with good early intervention support and transition to school processes, followed by 'cold turkey'. This was a situation that generated considerable stress in families and in schools:

> *I think there does need to be some sort of ongoing monitoring and support from [GSE]… cold turkey is not good enough. I think there needs to be a co-ordinated approach towards some sort of continuous support monitoring than what's going on at the moment. And looking longer term. Early childhood supports look out to age five, if we're talking about seamless education, age shouldn't be a determining factor in when the funding stops … we used to have an educational psychologist from Special Ed who would be in touch and say, look, you've got little Johnny coming, this is what's happening for him now, these are the things you need to consider, this is the level of support we can provide you with … and you could plan for it, you could organise your staffing around it. The way it is at the moment I can make no guarantees to Rose's teacher aide*

Some principals experienced a level of frustration at what was perceived as policy rhetoric which did not truly support schools to be inclusive for children with disabilities. One principal said:

> *The policy makers are talking about inclusive education, inclusive programmes and including kids in mainstream classes and those sorts of things and I agree wholeheartedly, that should be where we are heading. I'd hate to see kids like Rose being denied access to what we have here, but in order for that to happen successfully the funding for kids like Rose needs to be increased substantially. And kids with learning needs such as hers need to be recognised. You just cannot address it by saying she doesn't meet the criteria.*

Another principal believed that, overall, the level of support available for students with special education needs in his school was 'just below adequate':

> *I think there is a gap between ORRS and the rest. And I think ORRS is becoming increasingly difficult to get and that gap – there is a noticeable gap there that isn't really being met by the RTLBs or that*

> *because these children do still need special help … the Ministry will fund ORRS and then just below that they've got RTLBs to pick up whatever else, and there's a gap.*

In relation to seven-year-old Christopher, who had cerebral palsy and did not have ORRS resourcing, the school principal felt that while his needs for physical support were well met through the moderate contract, his learning needs were not well met:

> *… in terms of his academic requirements – he's just another number – another child that the teacher's dealing with who's below their academic ability. Now he's down there because of his physical abilities – it's meant that he's slow to develop in academic areas.*

Perceived areas of waste

Some parents found it difficult to keep up with the personnel and sources of services and supports. One parent struggled to remember where the funding for his son's occupational therapy and physiotherapy originated, and at the same time voiced his frustration at what he perceived to be poor use of funding:

> *I get slightly frustrated with the different departments and the different people and you sit down at a meeting and you've got all these people and you think – you've got a guy sitting there who organises – but gives you no input – and you think, well, why are we all here? It's very bureaucratic. I sort of think to myself, we're spending all this money, on all these people … and the school gets something like $3,000 for the whole year for special needs [in the SEG grant]. That's only $10 per child.*

Personal costs to families

Advocating for their children to receive adequate resources was an exhausting experience for some families, and it was recognised by some parents and professionals in the project that not all families had the money or the energy to advocate on behalf of their children. A parent who had struggled for years to get support for her son simply said, 'It's been an uphill battle to get the services and to get the things that he needs'. Others failed to understand the logic behind assessments for ORRS, and felt concern for other parents they had met who were in the same boat as them:

> *GSE have always said that about funding – that she's not bad enough – and I don't know how they worked that out. They say there's a lot of kids worse off than our daughter, and getting less than she is. But does that make it right? Is that supposed to make it better? You know what I mean? We feel really sorry for these people too and we are constantly getting calls from other parents that are not getting this help still. It's sad.*

Following unsuccessful applications for ORRS resourcing, one alternative was to apply for support under the moderate contract. However, even this process could be stressful for families, and one therapist pointed out that parents needed to be warned not to get their hopes up. Therapists' approaches to identifying and supporting these children were very family focused and it had become part of some therapists' roles to source other services for students who were not accepted on to the moderate contract. In these situations, good links with other agencies (e.g. therapists in hospitals or in private practice) were vital. One therapist said:

> *The students often need a lot from us in terms of level of disability … often they might not be diagnosed and often they don't have any services and the families are fairly anxious about what is going to happen for their child – quite rightly – and so that involves a lot of work … We don't fill out the form and then [tell the parents to] expect there will be a service delivered. We try [to find services*

> *for them], because the problem is that people can't find services [on their own], or if they can find services they can't find teams around kids.*

Summary: The impact of therapy and service provision on children's and families' quality of life

Section 2.8 has described the impact of therapy and service provision on the quality of life of focus students and their families. In relation to inclusion and education, the majority of schools, including those with attached units, described themselves as working towards an inclusive model of education which emphasised a celebration of diversity, student belonging, and participation, although schools varied widely in their approach to inclusion. Most regular schools, including those with attached units, were committed to inclusion and had adopted a range of inclusive policies and practices. In the self-contained school and in some schools with attached units, teaching practices did not always fit with ideas about inclusion and student diversity as described in the scoping study for this project.

Access to supportive peer relationships was a major area of concern for most students, and was particularly difficult to address where students were not in regular classes.

In relation to teaching, learning, learning goals, achievement and assessment, some students were well supported with meaningful, relevant and future-oriented goals, with integrated teaching practices. Parents were usually happy with the choices made for their sons and daughters at school in relation to learning and therapy, but some felt overburdened by co-ordination and the requirement that therapy goals be pursued at home.

In some classrooms there was an over-emphasis on social skills rather than learning or physical goals. In schools where there was a desire by the team to integrate physical and learning goals, structures were not always in place for teachers and therapists to consult. While some teachers felt well supported in the classroom, others lacked support. For Year 1 teachers this lack of support meant that they struggled to know and teach the focus student.

The project raises questions about how to achieve a good balance between learning and therapy goals, and suggests that the area of best practice in curriculum for students with high and very high needs is an important one for professional development. Students were often withdrawn for therapy and missed classroom-based learning opportunities. This practice is inconsistent with the goal of integrated therapy whereby therapy supports student access to the curriculum.

In some places a range of ecological and functional assessment approaches were used, but typically assessments were informal and tied into the acquisition of IEP goals.

All schools articulated a strong family focus and saw parents as critical in the IEP process in particular. Some schools worked particularly hard to include parents and make them feel comfortable at school. In others, parents described not always having their voice heard. Therapists working on an itinerant basis worked hard to provide good levels of support to schools and families, but some felt that they needed more time to visit with and support families well.

Students' needs were considered to be well met in schools where funding and resourcing levels matched the schools needs for support. Staff in these schools felt that this level of support had a positive impact on their ability to meet the indicators of integrated effective practice. Where funding decisions did not support schools well, this created some stress for families, as well as schools, and children's learning and physical goals were considered to be compromised.

Section 2.9: Conclusions: Working Towards Integrated Effective Practice in Schools for Students with Physical Disabilities

The case studies provided the research team with a snapshot of focus students' lives at school and at home. Several models of therapy in schools have been described. Themes emerging from the research project emphasise that context affects the way in which education and therapy are provided, and on the way in which integrated effective practice is implemented. Key differences were highlighted between schools where therapy was available on-site and those where therapy was provided through an itinerant service. This report has described the features of these models and identified areas where the models represented (or failed to represent) the features of integrated effective practice, and has considered the effect of these models on the quality of life of students with physical disabilities and their families.

This section discusses some of the key findings within the context of the literature on integrated effective service provision for students with physical disabilities in relation to the three main research questions:

- *Research Question 1:* What do models of therapy and other service provision for students with physical disabilities in the compulsory school sector look like across a spectrum of services, settings and locations?
- *Research Question 2:* To what extent do these models reflect the components and principles of effective integrated practice?
- *Research Question 3:* What is the impact of therapy and service provision through the support team on the life and quality of life of the student with physical disabilities and their family?

This section also highlights some of the issues arising out of the case studies which seemed to challenge teams in their attempts to remain true to the various indicators of integrated effective practice. These issues are raised here because, as the basis for reflection and professional development, they have the potential to move teams supporting students closer to the principles of integrated effective practice in their own work.

The discussion in this section is predicated on the right of children with disabilities to receive their education in their local or any other state school, which is legally mandated in New Zealand's Education Act (1989). This right is also supported in the stated philosophy of the New Zealand Curriculum (Ministry of Education, 1993), in special education policy (Ministry of Education, 2000), and in the *New Zealand Disability Strategy* (2001). In launching *Making A World of Difference, Whakanui Oranga: the New Zealand Disability Strategy Discussion Document* (Minister for Disability Issues, 2000), the Minister also discussed the need for New Zealanders to work towards 'a fully inclusive society, where our capacity to contribute and participate in every aspect of life is continually being extended and enhanced' (p.4).

Research Question 1: Models of therapy

Research question 1 asked: What do models of therapy and other service provision for students with physical disabilities in the compulsory school sector look like across a spectrum of services, settings and locations?

Models of therapy and education in settings providing on-site therapy

A specific integrated approach

The self-contained school and the primary school with an attached unit had strong philosophical foundations, resulting in unique approaches to therapy and service provision in which educational and therapy goals were highly integrated. Most students in these settings had significant disabilities and were funded at the high or very high needs level under Ongoing and Reviewable Resourcing Schemes (ORRS). One of these settings also received transitional therapy funding in addition to ORRS resourcing. Such funding allowed for a degree of flexibility and, by comparison with other settings, relatively high ratios of staff to students. There was a strong focus in the self-contained school on functional skills, particularly in relation to self-care and mobility. There was a similar focus in the primary school with the attached unit, but there was also an overriding emphasis on academic and social development.

Collaboration among on-site staff was able to take place at high levels, and the diversity of staff on-site meant that inter-agency links seemed less salient than in other settings. Workloads were generally considered to be comfortable, and this meant that staff had good access to time for meetings and planning, and for deliberate and close collaboration with families through both formal and informal processes. In addition, there was an emphasis on providing services and supports to students and their families in ways that were highly responsive to families' ethnicity and culture.

There was a strong focus on ecological assessment and intervention, and it was clear in both settings (the self-contained school and the primary school with an attached unit) that the Individual Education Programme (IEP) was the basis for teaching and therapy interactions. Professional development was highly valued, ongoing and responsive to the day-to-day issues of teaching and therapy.

Traditional model

Two other schools – an intermediate and a secondary school – had attached units. Most of the students in these settings were also funded at high or very high levels through ORRS and had significant physical and sometimes multiple disabilities. As was the case with the other two sites with on-site therapy, this level of funding, in addition to the transitional therapy funding both units received, enabled relatively high ratios of staff to students. However, the more traditional withdrawal model of therapy provision followed in these two schools meant that the resources available to some students were not seen as meeting their needs as well as some therapists interviewed would have liked. All of the staff in these settings emphasised the need for collaboration between therapy and teaching staff, and while management made such time available on a regular basis, a number of those interviewed would have liked greater opportunities to observe each other's work and to plan collectively. Such limitations on interaction also made it difficult to be as flexible in terms of intervention as participants would have liked.

Inter-agency collaboration was a greater focus for staff working in these traditional therapy provision models than in the other settings with therapy on-site, and to this end therapists in particular spent a good deal of time liaising for ongoing services and in support of transitions from one school or setting to another.

Families were seen as essential to the functioning of both services, and the intermediate in particular encourage the involvement of families in relation to goal setting and review. In both schools, the IEP was the focus of goal setting and assessment, with ecological and anecdotal assessments being common.

Professional development was highly valued in both schools. In the secondary school, one therapist felt that the professionally isolated nature of her work meant that ongoing supervision was critical, but this could be difficult to access. At the intermediate, in particular, professional development was actively encouraged. Therapists had time to meet with therapy colleagues regularly, at which time they studied individual students and supervised each other's work. At this school, therapists appraised, and provided professional development to, their education colleagues, and teacher aides met regularly with unit management for professional development.

Models of therapy in sites with itinerant therapy support

Students in sites with itinerant therapy support had a range of funding provision. Students with ORRS resourcing were generally well served in relation to their learning and therapy needs. Funding was used flexibly by teams, with an emphasis placed on meeting students' individual needs. In one region, the unavailability of therapists and the local use of 'overs and unders' approaches to the distribution of funding meant that one child received no therapy at school. Where students did not receive ORRS resourcing, levels of service provision were described by all as inadequate, with families reporting the need to struggle or pay for resources and supports themselves. In these cases therapists were strong advocates for families and often went out of their way to explore ways to access therapy and other forms of support.

Teams supporting students on an itinerant basis generally had high workloads, making it necessary for teams to prioritise. Teams of therapists used role-sharing across the therapies to ensure that schools had a sense of ongoing support. Open and frequent communication in therapy teams was further supported by structures in therapy teams that ensured all therapists remained up to date with children's progress in terms of their learning and physical needs and goals.

Intervention in schools was based on an ecological approach and the functional integration of therapy goals into daily routines, with assessments primarily based on informal approaches and on observation in context. Therapists used a consultative model of service provision based on principles of role-sharing and role-release. The main points of contact for therapists in schools were the 0.1/0.2 ORRS-funded FTTEs and the teacher aides. Interventions were consistently based on principles of inclusive education and emphasised the active participation of students in their classroom, school and community. This philosophical foundation was generally shared by all members of the team – therapists and school staff.

Families were considered integral to the team's function, with a range of approaches used to support family participation. Some teams had high levels of direct contact with families at school and at home, while others advised families about upcoming school visits through the school, leaving the decision to attend up to the family. For the majority of families, involvement was primarily focused on the IEP process.

Research Question 2: Reflecting effective integrated practice

Research question 2 asked: To what extent do these models reflect the components and principles of effective integrated practice?

Organisational matters

There was a strong relationship between level of funding and the capacity of teams to provide integrated effective practice. ORRS-funded students were, by and large, well served, particularly those students with on-site therapy provision, as this model created the potential for good levels of staff and family collaboration and consultation.

All case study sites had developed management structures and approaches to service provision which sought to meet the needs of students, although each worked under a number of constraints that sometimes affected the provision of services. Local structures that worked well had a strong philosophical foundation that was well understood by all team members.

Interagency and professional collaboration

All service providers recognised the need for collaboration and consultation, both within their own teams and between services to agencies. High levels of collaboration were achieved in the self-contained school due to the presence of all staff on-site, and because of providing programmes that were consistent and well understood by teachers and therapists. Such close collaboration was more difficult to achieve in sites with itinerant therapy, due primarily to time constraints and distance. Nonetheless, CDS teams and GSE teams worked hard to overcome these barriers and to provide a service based on the key principles of consultation, collaboration, role release and role sharing.

Team functioning

All sites adopted family- and client-centred approaches to services, and roles and responsibilities were clearly defined in this regard. The self-contained school had very manageable workloads, which provided staff with numerous opportunities to plan for formal parental involvement at all levels, including planning meetings. It also actively encouraged informal family involvement. In sites with itinerant therapy, workloads were considerably higher, and while teams had adopted strategies for managing these, several therapists commented that they would prefer a higher level of direct involvement with families.

All sites valued family involvement highly, and families were always integral members of the team involved in planning through the IEP. The IEP meeting was described by all participants as the one key place in which all team members could meet, although staff in some itinerant sites occasionally found it difficult to attend these meetings. Context did make a difference to parental involvement, with the self-contained school focusing strongly on providing formal and informal opportunities for parental involvement. In other sites parental involvement varied. Some parents who lived out of the school district found it difficult to be actively involved because of the distances that need to be travelled. On the whole, however, schools actively supported parents to feel welcome at school, and to be active and contributing team members at a level that suited their personal circumstances.

Families felt well supported by itinerant teams and generally knew how to access support when needed. They valued highly therapists' willingness to advocate and seek information on their behalf. Families' involvement was primarily around the IEP process, and, as described above, some therapists commented that more time to support families, including in the home environment, was desirable.

Professional development was highly valued in all sites as the key to ensuring that team members worked within a shared framework, and that practice was effective and evidence-based. The self-contained school had become a magnet for professional development in its area because of its strong emphasis on an integrated approach to learning and therapy goals. In many settings, participants' comments suggested that a whole-team approach to professional development would be valuable, with a particular focus on local and salient issues for the team and their students.

Interventions

Most settings tried to be flexible in terms of the interventions they provided, but a number of limitations were imposed by funding, opportunities for collaboration and follow-up, and the location of services. Teams agreed that there needed to be a focus on the functional integration of therapy goals through naturally occurring activity in natural settings, and that therapy and education needed to be grounded in key ideas about inclusive education. Therapists and school staff worked together to achieve this in practice, with the usual point of contact being the specialist teacher in schools, and teacher aides. Teacher aides generally felt well supported by therapists, but some therapists found it difficult to ensure that a consistent message and focus for integrated therapy was conveyed to all parties. For itinerant therapists, the gaps between visits could present opportunities for slippage away from original intervention plans. In this regard, specific structures for continuing on-site support in schools might be useful to ensure that functional, integrated and inclusive approaches are maintained.

The limitations described above could compromise the extent to which therapy was able to be fully consistent with the indicators of integrated effective practice. Achieving a good balance in practice between attending to students' physical and educational needs was a significant issue in several settings. These points are discussed in more detail later in this section.

Issues of discrimination were widely recognised as being present in children's lives, but opportunities to deal with such issues were limited. Children's social lives at home and school generally reflected current themes in the literature of isolation: lack of friends, and in some cases, bullying (MacArthur, 2002; Llewellyn, 2001).

Issues and challenges arising from Research Question 2

While the various sites described in this project had worked hard to establish their own approaches to providing services using an integrated approach, many participants did raise questions and issues which, in their experience, could constitute barriers to their attempts to achieve some of the indicators of integrated effective practice. These issues are explored further in this section because they provide a focus for reflection and professional development in the area of integrated effective practice.

Teamwork and a shared understanding of integrated effective practice

> *The GSE team has shared goals, but I'm not sure that this extends to the whole team, including the school. (Therapist)*

A particular difficulty faced by schools with itinerant therapy was attempting to achieve a good general understanding of what integrated effective practice looked like. One case study site with itinerant therapy had released the class teacher for the 0.1/0.2 FTTE specialist teacher position. This position provided her with an opportunity to focus very closely on the student's learning, and on lesson planning and curriculum adaptation. She took a lead role as the child's teacher and saw herself as the key person in the student's life at school, and she expected therapists and other itinerant staff to approach her first. The teacher aide's role was clearly established as 'in the background', and the primary teaching–learning relationship was described as being between the teacher and the child. These roles were reinforced by therapists who provided itinerant support to the school. Itinerant therapy was aimed closely at accessing the curriculum, and therapy goals were integrated into the classroom routines. This teacher was also the parent of a child with a disability, and the student acknowledged that she 'knew what it was like'. In other sites such high levels of teacher ownership were rare, and this may have been related to the common practice of itinerant teams liaising primarily with teacher aides and 0.1/0.2 FTTE teachers who were not classroom teachers.

Although teams worked hard at establishing and working within a shared framework, it was not always easy to achieve this in practice, particularly when the model of therapy provision was itinerant and consultative. Misunderstandings could arise within teams about whether or not therapy was 'being done', and in some cases parents and professionals did not always share an understanding about what integrated effective practice looks like, or about its rationale. Some participants understood therapy to involve physical manipulation in separate places around the school, while others saw therapy as using opportunities that occurred in the natural flow of the school day to integrate therapy goals, so that students could access the curriculum. Some students were withdrawn for apparently unsupervised stretching in schools where therapists were trying to encourage the integration of therapy into class routines.

A poor understanding of what therapists were trying to do in the school context meant that parents also worried that their children were receiving insufficient therapy. Because itinerant therapists were in schools only once or twice a term in most cases, it was difficult for them to follow up on consultations and to monitor the ongoing provision of 'integrated' therapy between visits, although teams tried to share roles across therapies to maintain ongoing support to schools. In one case, Caitlin's 'therapy' was not monitored at all, and in another, Christopher was asked to do some things he could already do in the classroom and other things that would have happened in the classroom had he not been withdrawn. These experiences suggest that team-based professional development could focus on the establishment at the outset of the school year of a shared framework for integrated effective practice (Giangreco, 1997). In addition, structures in schools could be arranged to ensure that all staff remained focused on providing services that were consistent with the indicators of integrated effective practice.

Roles and responsibilities in schools to support integrated effective practice

The self-contained school in this project had tried some innovative approaches to curriculum adaptation, and had also used a range of assessment practices. Its integrated approach to therapy and education was largely achieved through the close relationships between teachers and on-site therapists, which were possible as a result of multiple opportunities during the day for collaboration and shared planning. However, it was also difficult for self-contained settings to meet some of the indicators and outcomes associated with integrated effective practice because their students lived at some distance from the school which meant a consequent lack of opportunity to learn in the social context of a diverse peer group and to integrate functional skills in natural settings. Empirical research has shown the developmental, social and educational benefits of learning in ordinary school settings (Ballard, 1998; Evans & Meyer, 2001; Laws et al., 2000; Fisher & Meyer, 2002; Meyer, 2001).

In contrast, regular schools, while able to meet the indicators of inclusion and social relationships, experienced greater difficulties in achieving a shared understanding of integrated effective practice. This situation was no doubt complicated by the fact that therapy staff were not as readily available. Therapy teams did talk about the importance of sharing an office, and of the opportunities afforded to share perspectives and philosophies on their practice. However, communicating these perspectives to schools that may only be visited twice a term by each therapist, and where opportunities for scheduled team and other meetings were few, was difficult. Even in sites where an attached unit supported classes in regular schools, there were areas of breakdown because teaching staff did not usually have dedicated time available for consultation. On the whole, roles and responsibilities were poorly established for teachers, teacher aides and the 0.1/0.2 FTTE teachers, suggesting again that whole-team professional development may be needed to clarify roles and responsibilities to support students' learning and social experiences.

Classroom teachers

Classroom teachers were frequently the least well informed about students with physical disabilities in their classrooms. They wanted to know more about learning goals and about how to adapt their lessons to include students in meaningful ways, but they did not have the time in busy classrooms to do this. As discussed earlier, therapists did not always have the time needed to collaborate closely with teachers, and teacher aides were often identified as the main point of contact. This situation was further exacerbated in classrooms where students were not ORRS funded. Year 1 teachers had their own set of unique needs (Lang, 1999), and support should take these additional needs into consideration.

This lack of engagement and ownership by teachers, and a concomitant over-reliance on teacher aides to adapt lessons, suggests that students could be at risk in the area of academic learning (Giangreco et al., 2001). Quality teaching is responsive to student learning processes, and teachers need opportunities to learn about their students and to develop responsive teaching approaches (Alton-Lee, 2003). Teachers may be encouraged to be fully participating team members when dedicated release time is provided to consult fully with therapists, teacher aides and others, and where professional development opportunities focus on real issues relating to teaching their students with physical disabilities.

Teacher aides

Teacher aides were commonly observed to be taking responsibility for adapting curricula and lessons for students with physical disabilities, and often this took place on the spot. The research literature identifies a series of inadvertent detrimental effects associated with the use of teacher aides as teachers. These include separation from classmates, interference with peer interactions, dependence on adults, loss of personal control, reduced teacher–student interactions, limited access to quality instruction, and a lack of teacher ownership of the student (Giangreco et al., 2001). These authors argue that it is essential for educational teams to consider whether the role of teacher aides and existing models of service provision in the classroom contribute to, hinder or replace teacher engagement.

Similarly, the legitimate concerns of teachers who are challenged to work with students with disabilities need to be listened to and acted upon to ensure that they have appropriate supports and working conditions to teach the student in their classroom. Opportunities for training and professional development for teacher aides alongside classroom teachers could assist in this area, particularly where the focus is on the mutual establishment of clear roles and responsibilities to support integrated effective practice.

ORRS-funded 0.1/0.2 FTTE teachers

This position worked well in schools where the 0.1/0.2 FTTE knew the student with physical disabilities. In one case the class teacher held this position and was able to effectively use the release time to plan on the basis of a good knowledge of her student. In some schools, the position was part-time, and in the area school the role was complicated by the involvement of a large number of teachers across the primary and secondary parts of the school. These positions were held by teachers who had not necessarily received training, and for whom relevant professional development was scarce. These teachers felt that to be effective they needed professional development opportunities and some guidance in the most effective ways to support students and teachers within a framework of key ideas about integrated effective practice and inclusive education.

Time to be a team

Teachers in primary and secondary schools, including those with attached units, consistently asked for dedicated time to work as a team. This was requested particularly where support went to students in regular classrooms. There are several examples in the recent literature of teamwork in practice (see, for example, Appl et al., 2001; Hunt et al., 2001; O'Connor, 1997; Rainforth, 1998). Hunt et al. (2001) describe the effective implementation of a collaborative teaching model to support students in regular classrooms. The model involves the classroom teacher, specialist teacher and teacher aide meeting regularly to develop educational supports for mutually defined goals, the establishment of clear roles and responsibilities, and a willingness to be flexible with role boundaries. Monthly meetings were also held to revise the plans for individual student supports, making it possible to focus efforts on individual students and to support the classroom teacher to implement student support plans. The authors suggest that one of the reasons for the programme working as well as it did was having:

> *… the time to reflect together on an ongoing basis. The need for compensated time for regularly scheduled team meetings appears to be an essential component of the collaborative teaming process. (p. 254)*

Given that time to collaborate and plan was frequently raised by teachers in the current project, this model may have some potential for supporting clear roles and responsibilities, teacher ownership and student learning.

The role of the IEP

The IEP process was widely referred to by parents and professionals as the key to achieving teamwork and supportive relationships between home and school. For some parents this was the cement for the team – one of the few opportunities they had to meet with 'the whole team', although some therapists also said that it was not always possible to get to all IEP meetings. Others described the IEP as the vehicle through which home–school communication was achieved. However, this should not be the main function of the IEP, which needs to be understood as a process rather than a meeting (Giangreco, 1995). For some students, the IEP seemed to function as a working document. For other students the relationship between the IEP and the class programme was not always clear, suggesting that the IEP could function more as a management or organisational document rather than a working document focusing on learning and classroom practice. Some class teachers' experience of the IEP was as an opportunity to learn about their student with a physical disability rather than an opportunity to contribute to the plan. Other teachers did not have the opportunity to go to IEP meetings. For students who did not receive ORRS or moderate contract resourcing, the IEP either did not exist, or simply could not function because of a lack of support infrastructure.

Several therapists talked about the need to develop relationships between school and home that went beyond the IEP process or brief meetings fitted into a busy schedule. More sustained relationships would support the integration of therapy goals into the child's daily life rather than just their school day, and would provide opportunities for therapists to support families in other areas such as home modifications. A closer relationship with families would also provide the foundation needed for families to understand integrated effective practice, and for therapists to understand the realities of families' lives, particularly as they affect families' capacity to support therapy goals at home.

Principals supporting inclusion and schools supporting teachers

The case studies provided further support for the idea that leadership and a shared vision about inclusion are critical elements in achieving an inclusive school where teachers feel supported, and where diversity in the school population is valued (Booth, 2003, Corbett, 1999; Slee, 1997). Teachers in regular schools were likely to express ownership of and responsibility for students with disabilities in schools where:

- the school principal expressed a personal commitment to the values of equity and justice and a respect for diversity (including students with disabilities)
- this commitment was translated into a clearly articulated school-wide vision about inclusion as 'a shared vision of who we are and what we want and what we're trying to do, and ongoing learning … and not giving up' (principal), and where there was an emphasis on:
    - school as a place for all students where 'everyone deserves a fair go' (principal)
    - a sense of ownership and responsibility by teachers – teachers were 'here for the kids and the staff know that they're all going in at different levels and have different needs' (principal)

  - establishing a sense of belonging in the school for all students
  - high expectations for all students
  - professional development and continuing opportunities for learning, in which there was a culture of ongoing learning in the school: 'My role is to learn as much as I can to create an environment that lets people grow – whoever the people are' (principal)
- staff worked together as a team
- there were flexible structures to support teachers to take an active role in planning for and teaching the student with a disability, and where teacher capability can be supported by:
  - allocating the 0.1/0.2 FTTE specialist teacher position to the student's class teacher, or by rotating this position in the school
  - having flexible arrangements between teachers on the one hand and teacher aides, principals and 0.1/0.2 FTTE specialist teachers on the other, to release the class teacher for professional development, for one-to-one or small group work with the student with disabilities, for planning and preparation, or for release time to meet with visiting therapists and other support staff. (In some schools the class teacher had release time to plan alongside the 0.1/0.2 FTTE specialist teacher.)

It should be emphasised, however, that working on a shared school vision of inclusion and creating structures in schools that support the building of capability in school staff also relies on adequate funding, resources and support for teachers (McDonald et al., 2001; Wills & Cain, 2003). Some principals were frustrated in their attempts to be innovative and to carry through the school's philosophy into good classroom practice by a lack of funding and resources. In schools where students did not receive ORRS or moderate contract funding, it was difficult – if not impossible – to explore alternative ways of working. One principal articulated this challenge when he said that while attitudes supporting inclusion were critical, support for teachers was a necessary part of the equation: 'It's that feeling about it, it's worthwhile, it doesn't matter how hard it is, we'll do it. They [teachers] need to be supported though'.

Achieving integrated effective practice – some recommendations for teams

On the basis of the discussion in above, we suggest that some consideration of the following points could support teams to achieve a working model of integrated effective practice.

- Working as a team is critical, and resourcing needs to support teachers to be part of that team. This project suggests that teachers in particular need release time to:
  - consult with therapists and with 0.1/0.2 FTTEs and heads of department (special education needs) in secondary schools
  - collaborate with other professionals and parents
  - establish their role in relation to others
  - work collaboratively with teacher aides to define the roles and responsibilities in the classroom.
  - review pedagogical practices and planning for curriculum adaptation and teaching.
- There is a need to establish clear roles and responsibilities, which are consistent with the current literature on effective teaching and practice, and to allow adequate release time to support these people to work as a team. This applies to:

  - teachers
  - teacher aides
  - therapists
  - 0.1/0.2 FTTE teachers.
  - These roles could be established through dedicated professional development days, and/or through opportunities to observe others known to be working effectively in these roles (perhaps in other schools).

- Principals, teachers, teacher aides, therapists, 0.1/0.2 FTTE specialist teachers, parents and others need professional development to meet a range of needs relating to integrated effective practice. Such professional development could include scrutiny of different theoretical positions which support teachers and others to address the key issues of diversity, oppression and exclusion in schools described by some participants in this project, and reiterated in the research literature (Ballard, 1999; Barton, 1997, Slee, 2000). Professional development should also focus on practical issues relating to teaching students with physical disabilities, including:
  - professional development days in schools at the start of each school year (the focus of these days would be on integrated effective practice – what it is, what it looks like and why it is important)
  - team-based professional development to address real and salient issues relating to assessment, the curriculum, teaching and learning for students with physical disabilities in schools
  - release time for teachers, teacher aides and teachers in the 0.1/0.2 FTTE positions to establish roles and responsibilities that are consistent with effective practice
  - courses for teachers on curriculum adaptation, development of effective pedagogy, and enhancing friendships and relationships in school contexts
  - courses for therapists on the New Zealand curriculum and its implications for student support, and on evidence-based therapy in schools
  - courses for teachers, therapists and relevant others on working effectively and collaboratively as teams
  - courses for principals and senior personnel in schools on management and support for teachers who have children with disabilities in their classes, for other relevant support staff in the school, and on making changes in the school to support inclusive education.

- There is a strong need for reduced workloads for itinerant therapists to allow them to support schools to provide safe therapy, to liaise more closely with and support families, and to monitor and support integrated therapy in practice.

Funding

> *There is a huge need to ascertain the need of individual kids and with ORRS. It's either in or out, you're either ORRS or you're not – if you don't cross that threshold to high needs then the level of resourcing you're going to get, regardless of needs, is much, much lower. (Principal)*

As has been discussed previously, students receiving ORRS resourcing were seen as being relatively well served. However, the setting and service model made a significant difference to the extent to which ORRS resourcing met actual student need. Access to funding and support for students not included in ORRS was highly problematic and, by-and-large, the less funding available, the less likely it was that integrated effective practice could be achieved.

In respect of integrated effective practice, the literature suggests that if the work of therapists and teachers is to lead to positive outcomes for students there is a need for:

- opportunities for individual staff members to clarify their own roles and relationships to other team members (Llewellyn, 1994) including parents (Hunt & Goetz, 1997)
- the integration of therapeutic goals with educational goals (Kasser et al., 1997) leading to educational achievement and social acceptance, interaction and friendship in inclusive settings (Hunt & Goetz, 1997)
- opportunities for collective decision-making (Muhlenhaupt, 1998), sharing of knowledge (Mackey & McQueen, 1998) leading to the development of collective knowledge (Rainforth & York-Barr, 1997) and efficient and effective communication (Kasser et al., 1997)
- adaptations of the curriculum as essential components (Hunt & Goetz, 1997)
- multiple measures of success, multiple perspectives from all stakeholders (O'Connor, 1995; Giangreco, 1995) and multiple-component interventions to address multiple needs (Hunt & Goetz, 1997).

Funding through the transitional allocations for therapists, where available, and from significant numbers of ORRS-funded students and operations and Special Education Grants (SEGs) meant that the self-contained school in particular felt well-resourced to support their students' educational and therapy needs. The closer students moved towards the regular classroom setting, however, the greater the challenges faced by teams to provide integrated effective practice. This seemed to happen for several reasons, as follows.

1. Individual students moving into regular classes from units were often seen to need teacher aide support. This resulted in the need to employ large numbers of aides to support students in single classes. Inevitably this compromised the extent to which therapy could be funded outside of schools and units that were designated for students with physical disabilities where no transitional funding existed for therapists. In these instances, funding for therapists competed with funding for aides, and as a result opportunities for shared planning, teaming, liaison with parents and families and collaboration were compromised.
2. The greater the number of teachers for therapists outside of units or in regular schools to liaise with, the greater the strain there was on time for this to happen. This resulted in situations where teachers did not know some of the therapists, were sometimes not included in consultations when therapists visited the school and, on occasions, did not have the opportunity to attend IEP or other planning meetings.
3. The more that students attended their local schools, the greater the stress on therapists and other specialists in terms of workload, time for travel, shared planning and collaboration. This resulted in a general perception that it was less attractive for therapists to work in Education than in Health, with the net result that a number of Education-funded therapy positions remained vacant and children unserved. In other cases, this resulted in Education-funded therapists having workloads of more than 100 students.
4. The lower the level of funding support, the less likely it is that students will have educational, therapeutic, or integrated programmes to meet their needs. The research team's observations (as experienced teachers, therapists and researchers in this field) confirmed what teachers, principals and parents were saying about the level of need and the associated need for support. That is, that help is genuinely needed in schools for teachers, principals and parents to feel comfortable that children are getting a fair deal in terms of curriculum, learning and assessment, despite therapists being very creative in trying to meet student needs.

Further strains were also reported arising from the perception of arbitrary allocation of resources through both ORRS and the contract for provision of therapy services for students with moderate physical disabilities (the moderate contract). In a number of instances, the 1% threshold for ORRS and the allocation of resources through the moderate contract based on the perception that there would be 400 students nationally were seen as creating problems for schools and services that were already strained. It was argued by a number of principals that the allocation of resources based on national population predictions (e.g. ORRS criteria or population distribution as for the moderate contract) was in effect applying a standard for inclusion or exclusion to resources. In relation to ORRS criterion 7, relating to high-level needs for students with 'personal care and/or mobility, positioning, transfers', the Ministry of Education (2000, pp.14–15) notes:

> *These students will require a high level of continuing intervention and monitoring from specialists such as physiotherapists, occupational therapists, conductors and speech-language therapists. Daily care and supervision will be part of their intervention programme. These students will rely on considerable personal support (and usually specialised equipment) for mobility, changing direction in their wheelchair or walker …*

With respect to the use of measurement tools, the literature states that emphasis must be placed on ecological assessments that analyse the factors that could lead to quality-of-life outcomes for students (Borkowski and Wessman, 1994; 1994; Graves P, 1995; Graves K, 1999; O'Grady et al., 1997; Snell, 1997), rather than a student's ability to fit within a relatively tight set of criteria.

Ironically, even though ORRS and moderate contract funding was very tight and seen as necessary for many more students than were receiving funding, anomalies in the allocation of resources were noted in this research when looking at Caitlin, Christopher and Alan, whom it seemed to us all have almost identical physical and learning needs but were not all receiving ORRS support. Alan had received ORRS resourcing for high needs as an 'over' from his first day at school as a five-year-old. Caitlin was initially turned down for ORRS high needs funding, but following advocacy by her mother (through direct approaches to a duty verifier) began to receive ORRS resourcing for medical high needs as an 'under'. Christopher had been turned down for ORRS high needs resourcing and was recently accepted under the moderate contract. In these three cases the services they received, and the opportunities for learning, were directly linked to the resourcing they received. Alan's level of resourcing provided therapy and learning support (18 hours of teacher aide time) and there was general agreement that his needs were well met at school. Caitlin also received a small amount of teacher aide support (five hours), but no therapy due to a shortage of physiotherapists. Christopher received 40 minutes of teacher aide support weekly for one-to-one reading, and one hour fortnightly for combined occupational therapy/physiotherapy. Further contrasts between these students' funding and support can be seen in the summary table in Appendix H.

Curriculum and assessment in integrated effective practice

A common theme arose in the areas of curriculum and assessment, suggesting that these areas could become the focus for professional development. Various opinions, concerns and uncertainties were expressed by families, therapists, and teachers about achieving a balance between educational and physical goals.

Learning or physical development as a focus for teaching?

A critical issue arising out of this research relates to curriculum. In particular, two questions continued to arise as transcripts were read and the data were analysed :

- What should we actually be teaching students with physical disabilities?
- How can a balance between learning and physical outcomes be achieved?

These questions are at the heart of integrated effective practice, which aims to support children to overcome barriers to learning imposed by their disability. They are also at the heart of ideas about inclusive education, which hinge on an understanding of commonality of human need rather than 'special' need (Wills & Cain, 2003) and on an understanding that change is needed at policy level and in schools to support education for all children and young people in a school's local community (Booth, 2002, 2003; Corbett, 1999; Slee, 2000).

Central to this discussion, also, is the notion of independence, defined by Oliver (1989, p.14) as:

> *… the ability to be in control of and make decisions about one's life rather than doing things alone and without help. Hence it is a mind process, not contingent on a normal body.*

There were conflicts for some students in respect of the amount of time spent engaged in activities outside the classroom and away from academic and social activities and interactions. Quality teaching provides students with sufficient and effective opportunity to learn (Alton-Lee, 2003). It is important for students to have access to opportunities to learn the skills needed to make informed and reasoned decisions, and to exercise choice in relation to the ways they want to live their lives. In addition to this, withdrawal has the potential to interfere with teachers' attempts to establish a supportive learning community in their classroom, and can contribute to the negative stereotyping of students with disabilities (Kugelmass, 2001).

The future for a significant number of students in this project will be determined by their abilities to make good decisions and to have positive relationships, so their school experiences needed to focus as much as possible on opportunities for academic learning and social development (Hunt & Goetz, 1997), to allow them to participate maximally in their lives and worlds (Rothstein, 1994). Therapy in this context would aim to overcome barriers and support students' access to the curriculum in relation to functional skills and participation (Coles & Zsargo, 1998; Stile & Mitchell, 1995; Wylie, 2000). Students with physical disabilities have indicated in the literature that their preferences with respect to functional skills relate to opportunities to interact and make friends with others, and to choice-making and community links (Mitchell & Sloper, 2002).

The literature on the curriculum for students with disabilities can also offer some guidance in this area. Educators are encouraged to explore and offer wide subject choices to students with high and very high needs, in order to expand their future learning and career opportunities and to reflect valued life outcomes (Educable, 2000; Giangreco & Doyle, 2000). Ford et al. (1982) identify cognitive skills, personal development and preparation for citizenship and future roles as being key outcomes of education which are not always addressed in the lives of students with disabilities.

Teachers are warned not to assume the limitations of any student's ability, and to focus on the use of natural peer networks and assistive technology to connect curriculum areas and increase student communication and participation (Fisher & Frey, 2001; Giangreco & Doyle, 2000). A 'watering up' rather than a 'watering down' of the curriculum is advocated in order that all students have access to knowledge and higher-order thinking (Ellis, 1997; Queensland Department of Education, 2001). In practice, schools can actively support access to curriculum areas that require mobility, and ease the way for student participation in schools' extracurricular activities. This latter area is frequently missing in the lives of students with disabilities, yet these contexts also have the capacity to enhance students' social lives. A wide variety of approaches to curriculum provision is described in the literature to promote students' active engagement and participation in the curriculum within the context of a diverse peer group. Examples include multi-level learning approaches, partial participation, goal adjustment and integrated curriculum (Field & Hoffman, 2002; Giangreco & Doyle, 2000; Thorburn, 1997).

Students with physical disabilities may benefit from a school experience that has been carefully considered and justified by adults on the team supporting them, and in which they too have a voice. In recognition of Peters and Heron's (1993) guide to determining effective practices in terms of whether they have a sound theoretical and methodological basis and the potential for desirable and consistent therapeutic and social outcomes, the following questions could be also considered:

- Does therapy withdrawal need to occur during school hours?
- Is there sufficient justification for the value of disabled-only activities such as Riding for the Disabled for it to take place during the school day ?
- Does/can the type of therapy students experience really help them to access the curriculum or meet their needs, as they define them?
- Is there an evidence base for the types of therapy provision available to many students (i.e. in terms of therapy leading to specific desired outcomes)?

These questions arose primarily in response to observations in the case studies, the first of which showed that withdrawal from the regular classroom for ‘stretching’ was reasonably common, despite evidence that other than substantial periods of stretching are unlikely to be of any significant benefit (Tardieu et al., 1988). As noted earlier, therapists did not condone this practice.

For some students there was a significant focus on social goals in the classroom rather than on academic learning. This was especially true in classrooms where students did not receive ORRS resourcing and teachers struggled to meet the sometimes challenging and wide-ranging needs of their students. In some cases the student with a disability was expected to be the one who changed in order to fit into the classroom, by learning acceptable social skills and by meeting the same curriculum expectations of others in the class as a pre-requisite to entry. This approach is inconsistent with current thinking about inclusion in education, which emphasises the responsibility of schools to respond to diversity by exploring cultural changes in schools which reflect a valuing of difference and diversity (Corbett, 1999; Slee, 2000). Change is a critical element of inclusion, and Booth (2002) refers to this as an unending *process* of increasing the learning and participation of all students.

A further point which should be raised relates to students who miss a lot of school because of periods of hospitalisation. This was the experience of two students in the project. For Harry, at secondary school, some good links had been established between his hospital teacher and his school to ensure that work continued to be provided. It had been suggested that he would need to drop back a year in his English class, however, due to missed work in the previous year. The curriculum and learning needs of students like Harry are not well understood. Some research suggests that these students may adapt well to the dual demands of hospitalisation and school, but there is a risk that they become ‘solitary copers’, and that this in itself may be understood as a subtle form of exclusion at school (Bailey & Barton, 1999). Those providing support at school and itinerant support need to be alert and responsive to the unique experiences of these students.

While some students with disabilities may need to learn skills that support their relationships with others, teachers also need to make careful decisions about priorities for change in the student’s repertoire. The focus should be on teaching skills that will make a difference in social interactions, and that are valued by the child’s family and cultural context. The peer group itself may also benefit from adult information and support to interact in positive ways with students who have disabilities (Meyer, 2001), as was suggested by both Harry and Ian. Davis and Watson (2001) also argue that rather than pathologising behaviour as essential and innate (blaming the child), teachers need to question their own interpretation of students’ behaviour and offer the child the opportunity to state their own views. This approach assumes competency in children and provides a structure that enables them to confront disabling practices themselves.

If quality of life is achieved by maximising function and social integration (Dabney et al., 1997), then education and therapy may best occur in settings where access to social interactions is fostered and encouraged, and where opportunities for learning in natural settings are readily available (Bell, 1987; Slee, 1997). It should also be noted that if integrating therapy with educational goals is something that is valued, teachers, therapists and support people must have opportunities to work together for those practices to become part of an adapted classroom experience (Hunt & Goetz, 1997; McEwan & Sheldon, 1995).

Vygotsky's work in the area of disability and development offers a useful theoretical position from which to understand the contribution of regular education environments (Higgins, 2001; Rieber & Carton, 1993). These authors suggest that it is often not the impairment itself that is the primary problem, but the social implications of the impairment: where an impairment affects interactions with people, opportunities for interaction and development are restricted. The task of teachers is to minimise the restrictions by adapting teaching and the curriculum to provide children with opportunities to learn and develop through social interactions with others. From a socio-cultural perspective, then, development and learning will be encouraged in environments that provide rich contexts for the growth and development of every child (MacArthur et al., 2003).

Models of therapy may also need to be scrutinised in terms of their impact on children and young people's self-esteem and identity. Research evidence suggests that 'many of the potential problems of disabled childhood are not caused by impairment, but are outcomes of social relations, cultural representations and the behaviour of adults' (Shakespeare & Watson, 1998, p. 22). Like the students in Davis and Watson's (2001, 2002) British research, several students in the project resisted some of the stereotypes about disability imposed by adults. In particular, they said that they did not like being withdrawn from class for therapy or other specialist interventions, particularly if it meant missing out on events in the classroom. Eleven-year-old Ian indicated that given the choice he would rank academic learning above therapy. Laura disliked having physiotherapy in the library because she felt embarrassed when others walked in, and some adults in the study also raised questions about therapy compromising learning time and students' dignity.

The findings of this study suggest that the approaches used for therapy and education need to reflect children's preferences. In a critical analysis of the relationship between disabled people and health and welfare professionals, French and Swain (2001) draw on evidence from research and from the writings of disabled people to suggest that 'professional–disabled people's relationships are varied but can be experienced as dehumanising and abusive by disabled people' (p.739). The literature shows that:

> *… the self-image of many disabled people has been damaged by constant involvement with professionals, particularly during childhood when play, enjoyment and discovery were replaced by stress, medical examinations, and developmental programs. (p.739)*

The intention here is not to suggest in any way that students in this project were subjected to dehumanising experiences. These retrospective accounts by disabled adults are simply a reminder that professionals do have the power to define the identity of children with disabilities. In this context it is important for therapists and teachers to listen to children's perspectives and to make careful and informed judgments about the reasons, approaches, time and place for therapy and other interventions.

Teacher expectations

The case studies revealed that the expectations held by schools in relation to the curriculum and student achievement were varied. In some schools, high expectations drove decisions in relation to the children's curriculum and learning opportunities. High expectations for children's learning are identified as a key element for effective teaching in classrooms with diverse groups of students (Alton-Lee, 2003), yet the literature suggests that students with disabilities can have very limited subject choices due to low teacher expectations (Educable, 2000). Students with very high needs were generally expected to be working on the essential skills, and to be working at level 1. Some students with high needs had similar experiences, with few expectations of exceeding level 1. This is a concern because inappropriate expectations can undermine students or create barriers to effective teaching.

This is particularly important when considered alongside evidence that teacher expectations have been found to vary by student ethnicity, dis/ability, gender, and other student characteristics unrelated to a student's actual capability (Alton-Lee, 2003). Alton-Lee describes problems around teacher expectations as persisting in New Zealand, and cites a study by Good (1987), which suggests that these problems need to be addressed by training teachers to expect to be able to teach students effectively regardless of their current performance. It should be emphasised that high expectations are in themselves insufficient, and must be supported by effective and appropriate pedagogical practices.

ORRS resourcing was also considered to contribute to low expectations. Several teachers, principals, parents, and therapists alluded to the fact that if students were thought to be succeeding (for example, by achieving above level 1), they were in danger of losing their funding.

Assessment

Assessment of student learning and development in the case studies was primarily subjective and informal, and was generally focused on progress towards IEP goals. While this is one area of assessment, the scoping report for this project suggested that assessment approaches should be wide-ranging, and focus on the active role of the client and family (Gallegos & Medina, 1995) in the problem-solving process, and on the use of non-standardised observation and interview, assessment and treatment, and curriculum-based assessments (Borkowski and Wessman 1994; Davies & William, 1994; Graves P, 1995; Graves K, 1999; Hunt & Goetz, 1997; Kientz & Miller, 1999; O'Grady et al., 1997; Snell, 1997; Watling, 1999; Westcott et al., 1998; Wishart et al., 2000) in natural settings (Bundy, 1995). Some therapists recognised that this could be one area where expertise was lacking, suggesting that this is an area to be emphasised in future professional development for teachers and therapists. One student in the case studies illustrated the importance of sound, ecologically based assessment by showing that in his later years at primary school reading was a realistic goal once he had glasses.

Research Question 3: Effect on quality of life

Research Question 3 asked: What is the impact of therapy and service provision through the support team on the life and quality of life of the student with physical disabilities and their family?

How well does therapy support children's development?

The case studies involved a week-long 'snapshot' of students' lives at school, and so it is not possible to draw any conclusions about the relationship between therapy provision and physical development for students. To evaluate the effectiveness of interventions on children's learning and development, more detailed and longitudinal research would be required. At best it is possible to draw some tentative inferences from the observations and from interviews with people who have had a long-term view of students' development.

In several instances, adult participants described clear gains occurring for students. All of the participants supporting Simon and Selena, for example, reported good gains in physical skills because of the particular intervention approach used in their school. Simon was described by his mother as moving from being a floppy young child to being a young man able to move around the house independently and who was starting to participate in some basic food preparation activities. She was in no doubt that the change had occurred because of what the school had done. Similarly, Harry and Heather had well defined and relevant learning goals determined in consultation with the students themselves and their families. In both cases their personal desires for independent mobility and transport were translated directly into goals that supported both short- and long-term development in these areas. Therapists showed a particular sensitivity to their needs and wishes in this regard, and actively supported them through the IEP process.

For these and other students, the provision of equipment had a significant impact on their ability to access the curriculum and clearly supported their learning and development. Equipment provided by the occupational therapist for Alan, for example, had made a big difference to his capacity to participate fully and be independent in food technology classes. Similarly, Laura's and Leah's computers provided them with critical support and independence, particularly in the area of literacy. Leah was also preparing for a new power chair, which was widely considered to be a real bonus for her in terms of independence and choice.

Ashley and Alan's learning and physical goals were generally well supported at their area school. Ashley as a young man with very high needs was encouraged to be physically active, and to be independently mobile using his walker. Alan also showed good physical gains, with both his teacher and teacher aide using naturalistic opportunities throughout the school day to support therapy goals. Therapeutic interventions were considered by school and therapy staff to be leading to functional gains.

Some students were receiving post-surgery-related therapy and goals related primarily to stamina (Ian) and recovery (Harry). In both cases there were strong links between health and education settings and therapists, with a good flow of information across sectors. This area was described by several therapists as important, and while some therapists said that these relationships had been poor in the past, positive changes were occurring.

Some students received regular medical intervention in the form of Botox treatment to relax muscles and avoid contractions. In these cases CDS teams provided pre- and post-surgery physiotherapy. Outside of these times Caitlin was stretched daily by her teacher aide and mother, although this work was unsupervised and there was no monitoring of Caitlin's physical needs by a physiotherapist. Christopher had physiotherapy under the moderate contract approximately once every two weeks for 30 minutes. These withdrawal sessions focused on stamina and balance. On the day of observation his class were doing similar things in an aerobics class.

For some students, poor levels of resourcing meant that approaches to therapy were compromised, and there appeared to be little appreciable impact on their development and ability to access the curriculum. For example, although Rose would have benefited from a sensory intervention programme, a lack of resources meant the CDS team therapist could have only minimal contact with Rose's teacher and teacher aide. There was, in the view of the research team, good reason for looking at ORRS (reviewable) resourcing for Rose to support these areas of need, and to relieve her parents of the financial burden of paying for a full-time teacher aide. Ricky had significant learning needs and also needed both physiotherapy and occupational therapy to build stamina, increase tone, and develop his fine and gross motor skills. His needs were not addressed, and his teacher could not see beyond supporting his social needs at school, despite his mother emphasising that his learning needs were of paramount importance. Caitlin had the unique experience of receiving no physiotherapy because of a shortage of therapists in her area, despite having ORRS resourcing for high needs. GSE retained money for therapy she was not receiving. Her mother commented several times that this lack of access to therapy had been extremely detrimental for her daughter.

In many cases it was difficult to conclude that evidence of change affected subsequent interventions. When therapists were asked to describe how they knew their students had changed, assessments were generally described as anecdotal and based on observations or discussions at IEP meetings. While observation is an important part of assessment, the indicators of effective integrated practice described in the scoping study for this project emphasise the use of a range of ecologically valid approaches to assessment. Some therapists interviewed for this project did describe keeping up to date with the research literature in their field, and undertook professional development, where it was relevant and available, to support their use of an evidence-based approach. Others made no reference to an evidence base for their work, although most provided thoughtful rationales for their work with students. Some alluded to the limited availability of good-quality, relevant professional development in their various fields, and to the limited availability of release time to undertake professional development.

Sahagian Whalen (2003), in her literature review on the effectiveness of occupational therapy in the school environment, highlights the need for therapists to respond to the demand of articulating evidence-based practice. Swinth and Hanft (2002) recommend that all therapists who work in schools should:

> *… examine their practice and consider how to embrace the varied contexts of the educational system and focus on improving each student's performance throughout all school environments and activities. (p. 20)*

Given the current thrust towards evidence-based practice in the health and education fields, this is one area where further research and an emphasis on relevant professional development would be very likely to benefit students with physical disabilities and their families (Buysse et al., 2003; Meyer, 2003).

Friendships and relationships

> *I have really good friends. (Leah)*
>
> *Mostly I go to the library at lunchtime – I like it when my friends go to the library, but they don't usually go. (Alan)*

The children and young people interviewed for this project experienced life – both at school and at home – in very different ways from their non-disabled peers. Their physical disability undoubtedly contributed to many of the challenges they faced, and this was most noticeable in the area of friendships and relationships. At primary school they found it hard to keep up with their non-disabled peer group, and the games they played were largely inaccessible. Some schools did seek out creative ways to help students overcome these barriers in the playground, and to thereby support friendship development. Other schools created further barriers, the most obvious being physical barriers which prevented children from participating in culturally valued things together. However, practices in classrooms and some approaches to therapy could also create barriers to friendship formation and development.

There are a number of ways that schools can support friendships (see, for example, MacArthur, 2002). Rossetti and Tashie (2001) argue that schools need to strive more generally for a celebration of diversity, and not simply tolerance of differences, so that friendships can develop:

> *Reject the not-so-subtle message to students that 'you are welcome only if you act, sound, think, talk like us,' and send the message to all students that 'you are welcome exactly as you are'. (p.22)*

Schools can also create an inclusive school culture in which diversity is valued, and unequal power relations are rejected (Baker & Donelly, 2001; Corbett, 1999). Schools are required by the *Health and Physical Education Curriculum* (Ministry of Education, 1999) to develop in children a 'sensitivity to and respect for, other people' and to encourage them to 'use interpersonal skills effectively to enhance relationships'. The curriculum document (which is based on a curriculum framework in which the rhetoric is pro-inclusion) has a strong emphasis on social well-being and relationships with other people, and could serve as the basis from which to explore ideas about disability, diversity, and difference with students, and as the basis for effective classroom teaching.

What teachers do in their classroom also matters. Teachers are powerful models of attitudes and behavioural intentions. Certain aspects of the classroom environment may, for example, reinforce the negative perceptions of some students: The structure of the classroom, where and with whom the child with a disability sits, and teachers' expectations of and interactions with children who have disabilities can all have an impact on how peers view their classmates with disabilities (Baker & Donelly, 2001; Meyer, 2001; Davis & Watson, 2000, 2001).

Watson et al. (2000) suggest that a teacher can transform a child with disabilities by identifying them as different in a regular school or by segregating them from their peers. In the present study, the common practice of seating students with physical disabilities at the back of the room, establishing primary teaching interactions with teacher aides instead of teachers, withdrawing students from the classroom, and having low expectations in relation to curriculum and learning all have the potential to contribute to interpretations of disability as difference. In forming these associations, schools can reinforce notions of 'the other' which undermine the development of friendships and relationships (MacArthur & Gaffney, 2001; MacArthur, 2002). It is for these reasons that school staff and therapists need to think carefully about the models and approaches to integrated therapy used in schools.

In a slight twist to the usual themes in this area, Ian commented that after being the only student in his primary school with a disability, he liked having other children with disabilities at his intermediate school because it made him feel less like a 'man from the moon' with his walking aides. Being able to share common experiences and interests is the foundation for many children's friendships, and being able to share the experience of disability is something which some children with disabilities have described as important in their lives. In a North American study of children's friendships, Turnbull et al. (2000) described cross-age friendships and friendships between two students with a disability where the age difference and presence of disability were of no relevance. Their point was not that segregation is the answer; rather they suggested that teachers and researchers interested in friendships need to be not only open, but also eager, to explore a broader range of friendship possibilities. Within a New Zealand context, MacArthur (2002) has suggested that:

> *In our drive to see children with disabilities taught in the mainstream, and to make friends with other students, we may have also overlooked the need of some students to explore relationships with others where disability is a common experience. For [some students] there may be some comfort in spending time with others who share their view of the world, where explanations about their disability are not necessary.*

Schools that include several students with disabilities may be able to support these links where the students themselves show some interest. In the present study, students' relationships took different shapes. Leah and Heather, for example, had a number of friends who did not have disabilities and they were active in initiating and sustaining friendships with others. Harry and Ian, on the other hand, attended regular classes but went to the unit at break times. While they may have chosen to spend time with others who have disabilities, it was not clear that their class programme supported their social lives well. Both students were described as very able, academically, and Harry as friendly and gregarious. Neither had close friends at school or outside of school. These young people's experiences challenge teachers to see this as a critical area of their development and of their lives, and to adjust their teaching approaches to include social relationships as a meaningful goal.

Parental involvement

> *Professionals forget that parents are 24 hours a day, seven days a week. (Parent)*
>
> *I feel sorry for parents who are shopping around – we have a responsibility to make things smoother. (Therapist)*

Parents in this project were generally happy with the level of their involvement in their child's life at school. No parents were alike in this regard, and it is important to emphasise that there is no 'one-size-fits-all' model for parent involvement and participation. Some parents were happy to be in the background and receive information, while others requested active involvement. Some chose not to work in order to maintain this latter role; others worked fulltime and relied on the school to do the right thing for their child in their absence. These parents sometimes found it difficult to stay in touch with what was happening at school, and others found it hard to carry over into the home what the school was emphasising during the school day.

All parents found the active support and advocacy frequently provided by therapists to be of particular value. Seeking out information for these families could be a stressful, exhausting and time-consuming process, and the presence of caring and supportive people makes a considerable difference to families' lives (Darrah et al., 2002).

The '24-7' reality of caring for a child with a disability along with other family responsibilities was demanding for most parents. On top of that, several parents took on the exhausting task of service co-ordinator, suggesting that service and agency co-ordination do not always work well. Within this context it is not surprising that some parents did not have a good understanding of integrated effective practice, and often felt that therapy was lacking. Several parents supported the idea of having a service co-ordinator for families or groups of families to ease the strain of undertaking this role themselves. Therapists also talked about wanting to provide more and better support for families, but excessive workloads for itinerant therapists precluded this. Many therapists did work outside their hours and roles to ensure that families had access to supports and entitlements. The need for available time for therapists to work with families and in the home setting was clearly indicated by the research.

These findings are consistent with recent comments by Action for Children and Youth in Aotearoa (ACYA, 2003) on the limited implementation of the United Nations Convention on the rights of disabled children and youth in New Zealand. They reported segmented service provision and a lack of co-ordination between agencies, with adequate service provision for families often being dependent on parental advocacy. Other research projects have raised similar issues (e.g. Darrah et al., 2002; Mitchell & Sloper, 2002). Darrah et al. (2002) reported that families of adolescents with cerebral palsy described having problems in education with respect to service provision, and perceived barriers to inclusion for their sons and daughters at school. They experienced difficulties obtaining information and frustrations because of poor links and structures between services, and a preoccupation with medical model thinking. Like the families in the present study, they were forced into co-ordinating roles they did not really want and suggested that services needed to work *with* them rather than *for* them.

A number of protocols have been developed to facilitate interaction and information-gathering with families, and central to these protocols is an awareness and appreciation of the multiple factors that may influence the values and perspectives of individual families and children (Graves P, 1995; Piggott, 2000; Wolfendale, 1996). The factors recognised as critical to professional sensitivity (particularly in cross-cultural situations) are an awareness of the impact of the following on families:

- discrimination and acculturation
- poverty

- family composition
- work practices
- living arrangements
- experience of disability.

Several parents in the present study suggested that a key worker to assist with service co-ordination would make their lives much easier. Mukherjee et al. (1999) have analysed and evaluated key worker services for families with disabled children and provide and in-depth analysis of the processes needed for this approach to work well.

Other researchers have undertaken to work with children and families to explore their experiences of service provision and to identify key markers of effective practice in this area (see, for example, Beresford et al., 1996; Boyd & Dunst, 1995; Mitchell & Sloper, 2002). Mitchell and Sloper (2002) explored the concept of quality in services, as defined by disabled children and their families, and found that parents focused on broad organisational and whole-family issues, including staff training and ability to listen, accessible information, services that meet their child's and the whole family's needs, and agencies working together. Parents identified quality indicators as follows:

- *staff approach and training* – staff respect and listen to parents' views and act on their wishes. Parents value staff whose training equips them with the skills to work competently and confidently with families
- *information* – should be accessible and jargon free, and ideally available through a key worker
- *service organisation* – needs to be flexible and work with rather than against families' lifestyles and routines. Multi-agency collaboration is important to ensure the effective co-ordination and provision of services.

In this study families and children emphasised different quality criteria, stressing the need for service providers to listen to children's voices.

Children's assessments of service quality were grounded in their community-based experiences and included:

- *staff attitudes and approach* – children value staff that make them feel welcome
- *meeting and making friends* – friends play an important part in children's lives and quality services need to respect this and nurture friendships
- *choice making* – real opportunities to make choices are acted on and valued
- *community links* – services providing age-appropriate and community-based activities were highlighted.

Information provision is most likely to support families if it is three-dimensional and personally interactive (Joseph Rowntree Foundation, 2000). Information should be :

- presented in clearly written, in-depth, informative booklets
- accompanied by shorter, more succinct directories/newsletters of local services
- supported by personal contact with a locally based key worker or facilitator who can guide families through the information.

These core indicators provide a set of standards which could be the foundation for any family-focused support service, including teams working in schools to support students with physical disabilities.

Children's voices and children's rights

> *The best school in the world would be accessible. (Laura)*

The Ministry of Education's Advisory Group on Students with Physical Disabilities, which commissioned this case study work, wisely suggested that the research should have a child and family focus. Focus students in the project provided the research team with many opportunities to observe the world of school through their eyes. This report has tried to bring their voices to the forefront, particularly when their perspectives have contrasted with those of adults. In doing this, it is emphasised that there is a variety of children's voices in this study, and that these need to be understood within the context of the structures (the cultures of parents, teachers, therapists and others) that influence and are influenced by what children do and say (Davis, 1998; Davis & Watson, 2001, 2002). Children's experiences at school differ, and so does their understanding, and these differences need to be explored and valued by adults supporting children and young people with disabilities at school.

Like their British counterparts, the students in this study did not talk about themselves or the challenges they faced at school in terms of their physical disability. They were much more likely to describe their difficulties as having more to do with discrimination, disabling environments or lack of acceptance by others (Allan, 1996; Davis & Watson, 2001, 2002; Priestly, 1999; Priestley et al., 1999). This was particularly clear in three areas: physical access (it's really important), withdrawal (we don't like it when we are young and when the classroom is fun), and relationships with others (we are lonely at school and we are bullied). Some students in the project experienced lack of access as a barrier to their inclusion in school. The failure of some adults to appreciate the impact of physical access on students' lives in this project is mirrored in the educational research, which rarely debates physical access arrangements in schools:

> *Yet the literal, physical barriers to access to ordinary social settings are part of a whole set of disabling and excluding barriers in terms of educational structures, school cultures, discourses, curricula, and pedagogy reflecting and reproducing discrimination and exclusions in wider society. (Barton & Armstrong, 2001, p.703)*

Physical barriers can define social relations in schools and produce and reproduce values and meanings about disability which maintain difference. The students in this project indicated that poor access at school meant that they could not always participate in culturally valued experiences, and they drew links between the presence of physical barriers and their experience of isolation at break times. Some children drew attention to other structures that prevented their participation, including withdrawal from class and whole-school experiences.

In contrast, some students also highlighted those relationships with adults which they perceived as supporting them and their families. Harry made a point of emphasising that the support of teacher aides at secondary schools was critical to his survival, and suggested that in the wider scheme of things they were undervalued. Several students described warm relationships with their class teachers, and conveyed a real sense of belonging in the classroom, even when some of these teachers questioned their own capacity to support the student well. Most students described positive relationships with therapists and genuinely valued the support of people who they described (often by first name) as 'nice' and as 'there to help me'. There was a common interpretation by children and young people with disabilities that adults genuinely 'cared' about them at school.

Other schools also conveyed this sense of caring and empathy for their students and were very perceptive about the structures in schools that could make life difficult for students with disabilities. Caitlin's teachers had recognised her need for friends at school, and had set up a system to support this area of her life. An adult sitting under a tree with Caitlin and other children became an effective strategy for engaging children in activities which ultimately formed the foundations for friendships. Similarly, Leah described her teacher as particularly sensitive to her needs, and appreciated the efforts she went to establish her place as a student who truly belongs in the classroom.

The few siblings interviewed for the project repeated their disabled brother's or sister's assessments, often using the same language to describe the relationship between their sibling and adults who support them at school. Siblings also described aspects of their own lives which serve as a reminder that support for families should also include an awareness of the strengths and needs of siblings (Burke & Montgomery, 2000; Gallagher et al., 2000), and of their sometimes active role in providing care and support for their sibling at home. Living with a sibling with a significant physical disability can impact in a variety of ways. One younger sibling described a very typical sibling relationship in which the presence of disability could both support and challenge their relationship. One described being fearful when their sibling has seizures, while another older sibling who undertook physical care at home focused on supporting his teenage sister's independence so that when he left home his mother would be able to cope in his absence. His support was active, and included assisting his sister to transfer from her chair, to sit correctly in her chair, and to be independently mobile on the floor. While siblings' experiences are now well articulated in the disability literature, support for siblings is not always well understood in practice (Gallagher et al., 2000).

Teachers may find it difficult to understand how students with disabilities experience the world, and how that experience affects the formation of friendships, yet this understanding can be used skilfully by teachers to inform their teaching. The children's voices in this project have the capacity to inform teaching and therapy, and to make schools places that are truly child-centred. Learning about disability involves listening to the previously 'unfamiliar voices' of students with disabilities and their parents as they share their perspectives and experiences, and giving validity to those voices when decisions are made about curriculum, teaching and relationships at school (Corbett, 1999).

Recognising children's capabilities to think, contribute, and participate at school is consistent with the aims of the United Nations Convention on the Rights of the Child, which urges those who work with children to listen to their views (Bray & Gates, 2000; Hammarberg, 1995). New Zealand is a signatory to the Convention, and the expressed views of the children and young people in this project provide an opportunity for teachers, therapists, and others to review their values and practices in light of children's rights under the Convention. This suggests that teachers and others need to adopt flexible roles as listeners and learners, and build a relationship of trust and co-operation between adult and child (Corbett, 1999; Davis & Watson, 2000). However, being responsive to the things these students have said requires a commitment to make the necessary changes to teaching and therapy approaches, to school environments, to school systems, to support systems, and to the wider policies that determine and support all of these. In working towards integrated effective practice, and in solving the challenges raised by this research project, the connections now need to be drawn between what we know through research and what we do in practice (Buysse et al., 2003; Meyer, 2003).

Summary – Working towards integrated effective practice in schools for students with disabilities

This section described several models of therapy in schools. Themes from the research emphasise that context affects the way in which education and therapy are provided, and the way in which integrated effective practice is implemented. While participants on all sites worked hard to implement the indicators of integrated effective practice, key differences were highlighted between schools where therapy was available on-site and those where therapy was provided through an itinerant service. These differences highlight key areas in which teams may need to be supported to achieve integrated effective practice.

Funding affected the capacity of teams to provide integrated effective practice. ORRS-funded students were generally well served, but it was difficult for teams to meet the indicators of integrated effective practice where students received ‘unders’ funding or no ORRS or moderate contract resourcing.

Collaboration and consultation were highly valued by all participants. Collaboration was easy to achieve in the self-contained school, but as students moved closer to the regular classroom, limitations on time for consultation meant that there were more challenges involved in meeting students’ needs. Team-work was also highly valued by those interviewed. In those sites with itinerant therapy, therapy teams themselves maintained several structures to support their work.

Maintaining a shared framework for integrated effective practice across school sites was considered important, but some barriers were described in relation to achieving this. Teams also raised other issues and challenges which affected their capacity to meet the indicators of integrated effective practice, including:

- establishing clear roles and responsibilities in schools to support integrated effective practice
- maintaining clear links between the IEP and the class programme
- ensuring that policy and funding supported all students
- ensuring that policy and funding supported leadership structures in schools and therapy teams
- the ready availability of relevant professional development to support the implementation of integrated effective practice at all levels.

Finding the right balance between students’ educational and therapy goals was a significant issue across sites, with a range of opinions expressed about the relative importance of each. Questions raised in this area suggest that this is an important area for professional development in general. It was also clear that students themselves did not always have the opportunity to contribute their voice to this critical area of their lives.

In the area of assessment, the study suggests that schools supporting students with physical disabilities may need support to ensure that a wide range of ecologically valid assessment tools are used to support student learning and development.

Consistent with the research literature, the social lives of students with physical disabilities were frequently described as atypical, with loneliness and isolation experienced by several students. Some schools had worked hard to create environments in which friendships were more likely to be supported, but on the whole this was not an area of students’ lives which received a lot of attention despite a recognition that problems exist.

Parents in the project were generally happy with the level of their involvement in their child’s life at school. Some parents’ experiences suggest that schools may need to focus on developing structures that support both informal and formal parent involvement. Many parents still talked about the demands they faced accessing and co-ordinating services and support. The role played by therapists in this area was highly valued, and some schools had worked hard to ensure that their environment was open and welcoming for parents. The need for available time for therapists to work with families in the home setting was clearly indicated by the research.

There was a variety of children’s voices in this study. Children’s experiences at school differed, as did their understanding about their learning and their therapy. The research showed that children’s voices did not always have a place in the decisions made about them at school, and that those children who did have a voice in this regard highly valued the opportunity to actively participate in decisions that affected their lives. Children described their difficulties as having more to do with discrimination and disabling environments than with their disability. This was particularly clear in the area of physical access, withdrawal for therapy and relationships with others. Students highlighted, in particular, those relationships with adults which they perceived as supporting them and their families.

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Appendices

Appendices to Part 1

Appendix A: Ministry of Education operational protocols with the Health Funding Authority and ACC

Appendix B: 2001 Household Disability Survey questionnaires

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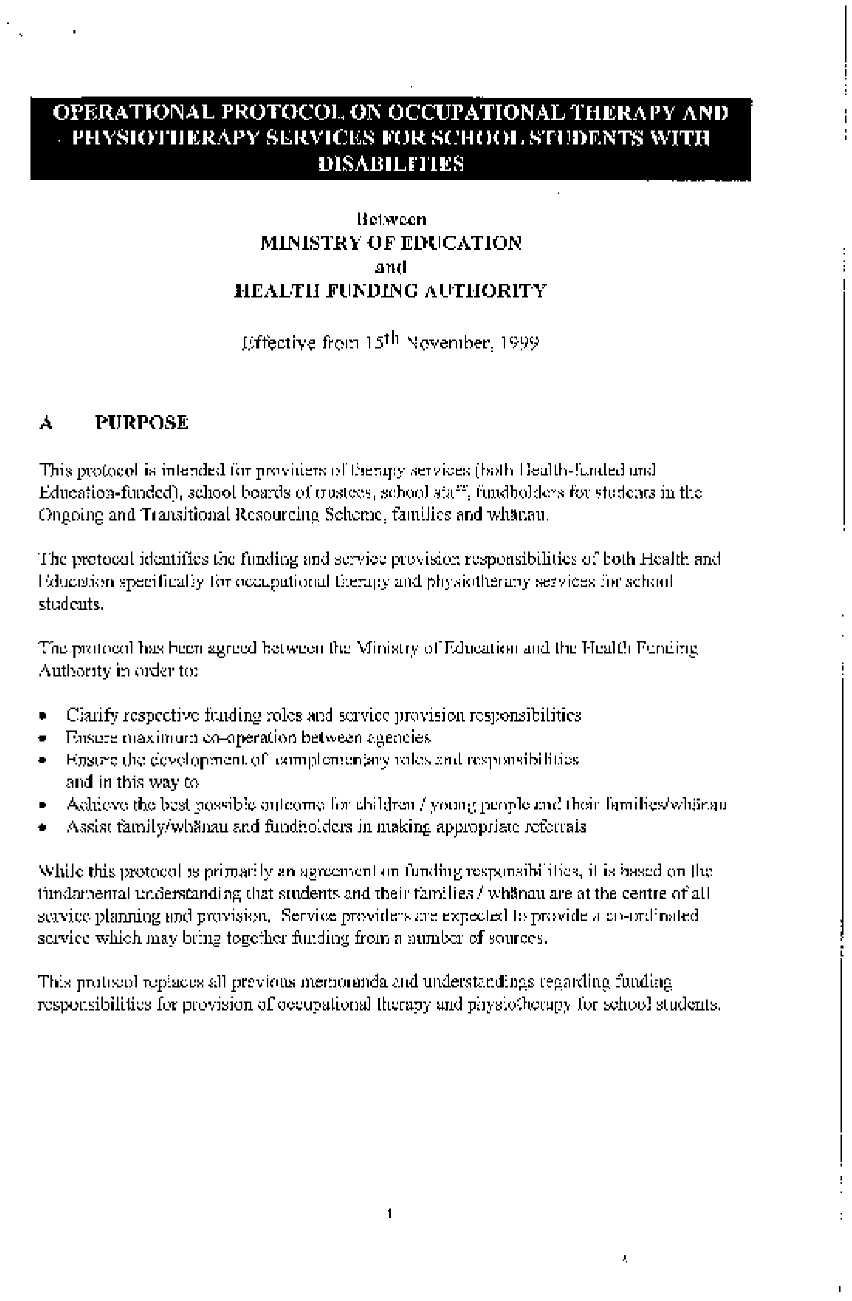
Ministry of Education and the Health Funding Authority



OPERATIONAL PROTOCOL ON OCCUPATIONAL THERAPY AND PHYSIOTHERAPY SERVICES FOR SCHOOL STUDENTS WITH DISABILITIES

Between
MINISTRY OF EDUCATION
and
HEALTH FUNDING AUTHORITY

Effective from 15th November, 1999

A PURPOSE

This protocol is intended for providers of therapy services (both Health-funded and Education-funded), school boards of trustees, school staff, fundholders for students in the Ongoing and Transitional Resourcing Scheme, families and whānau.

The protocol identifies the funding and service provision responsibilities of both Health and Education specifically for occupational therapy and physiotherapy services for school students.

The protocol has been agreed between the Ministry of Education and the Health Funding Authority in order to:

- Clarify respective funding roles and service provision responsibilities
- Ensure maximum co-operation between agencies
- Ensure the development of complementary roles and responsibilities
  and in this way to
- Achieve the best possible outcome for children / young people and their families/whānau
- Assist family/whānau and fundholders in making appropriate referrals

While this protocol is primarily an agreement on funding responsibilities, it is based on the fundamental understanding that students and their families / whānau are at the centre of all service planning and provision. Service providers are expected to provide a co-ordinated service which may bring together funding from a number of sources.

This protocol replaces all previous memoranda and understandings regarding funding responsibilities for provision of occupational therapy and physiotherapy for school students.

Ministry of Education and ACC

The *Operational Protocol Between the Ministry of Education and ACC* is available at

http://www.minedu.govt.nz/index.cfm?layout=document&documentid=4779&data=l

Operational Protocol between the Ministry of Education and ACC

On 1 June 2000 the Ministry of Education and ACC signed an operational protocol.

The protocol:
- applies to school students who, as a result of an accident, have cover under ACC legislation and have special education needs
- encourages and promotes co-operation, collaboration and co-ordination by all those working with the student
- clarifies funding and service provision responsibilities
- fosters effective support through an emphasis on identifying and overcoming barriers to achievement.

Why is there a need for a protocol?

- ACC and Education both fund specialist services and paraprofessional support for school students
- In the past, there have been gaps and overlaps in provision.

What will this protocol mean for students, their families / whanau, schools and providers of services?

- ACC and Education will work together, using a joint planning and service provision model
- The protocol will clarify funding responsibilities
- Interface queries will be resolved because there is an agreed framework of information

Education is responsible for funding:

- specialist services for students in any of the SE 2000 initiatives
- assistive equipment for students who meet the eligibility criteria
- transport for students who meet the eligibility criteria
- co-ordination both within the Education sector and as a joint partner across sectors

ACC is responsible for funding:

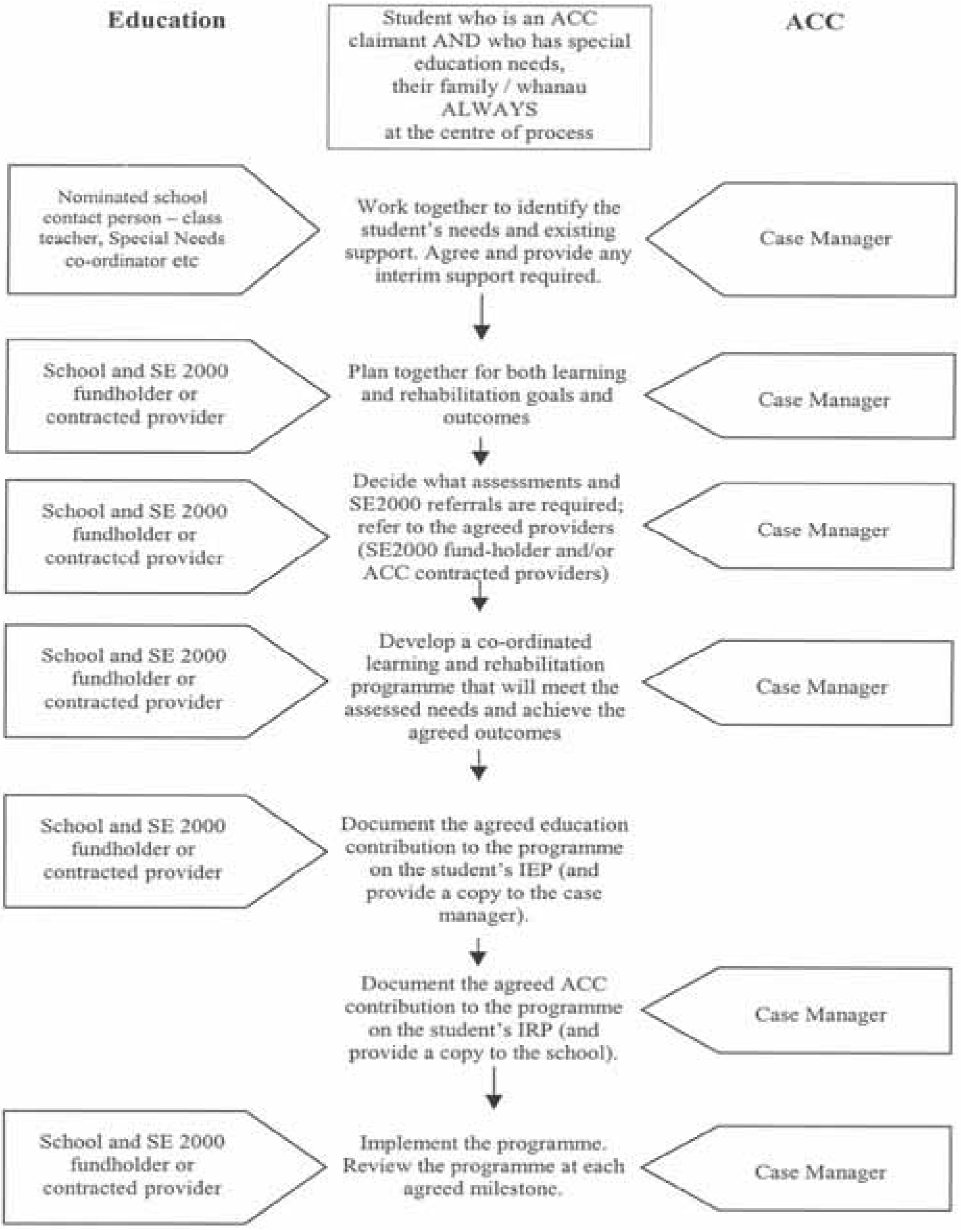
- paraprofessional support
- specialist services which are not available from within SE 2000 initiatives
- additional specialist services and transport assistance where support from SE 2000 is not sufficient to enable ACC to meet its legislative responsibilities to claimants

The protocol includes a process for dispute resolution, and will be both monitored and reviewed to find out how effective it is and gauge the impact. It will also be reviewed if there is any change to Government policy with respect to special education policy or ACC legislation.

For further information and a copy of the Protocol document you can contact your local Ministry of Education Management Centre. The Protocol Document can also be downloaded from the bottom of this page.

Operational Protocol between ACC and the Ministry of Education: Flowchart

(this is also available as a download Word document at the bottom of this page)



Student who is an ACC claimant AND who has special education needs, their family / whanau ALWAYS at the centre of process

Work together to identify the student's needs and existing support. Agree and provide any interim support required.

Plan together for both learning and rehabilitation goals and outcomes

Decide what assessments and SE2000 referrals are required; refer to the agreed providers (SE2000 fund-holder and/or ACC contracted providers)

Develop a co-ordinated learning and rehabilitation programme that will meet the assessed needs and achieve the agreed outcomes

Document the agreed education contribution to the programme on the student's IEP (and provide a copy to the case manager).

Document the agreed ACC contribution to the programme on the student's IRP (and provide a copy to the school).

Implement the programme. Review the programme at each agreed milestone.

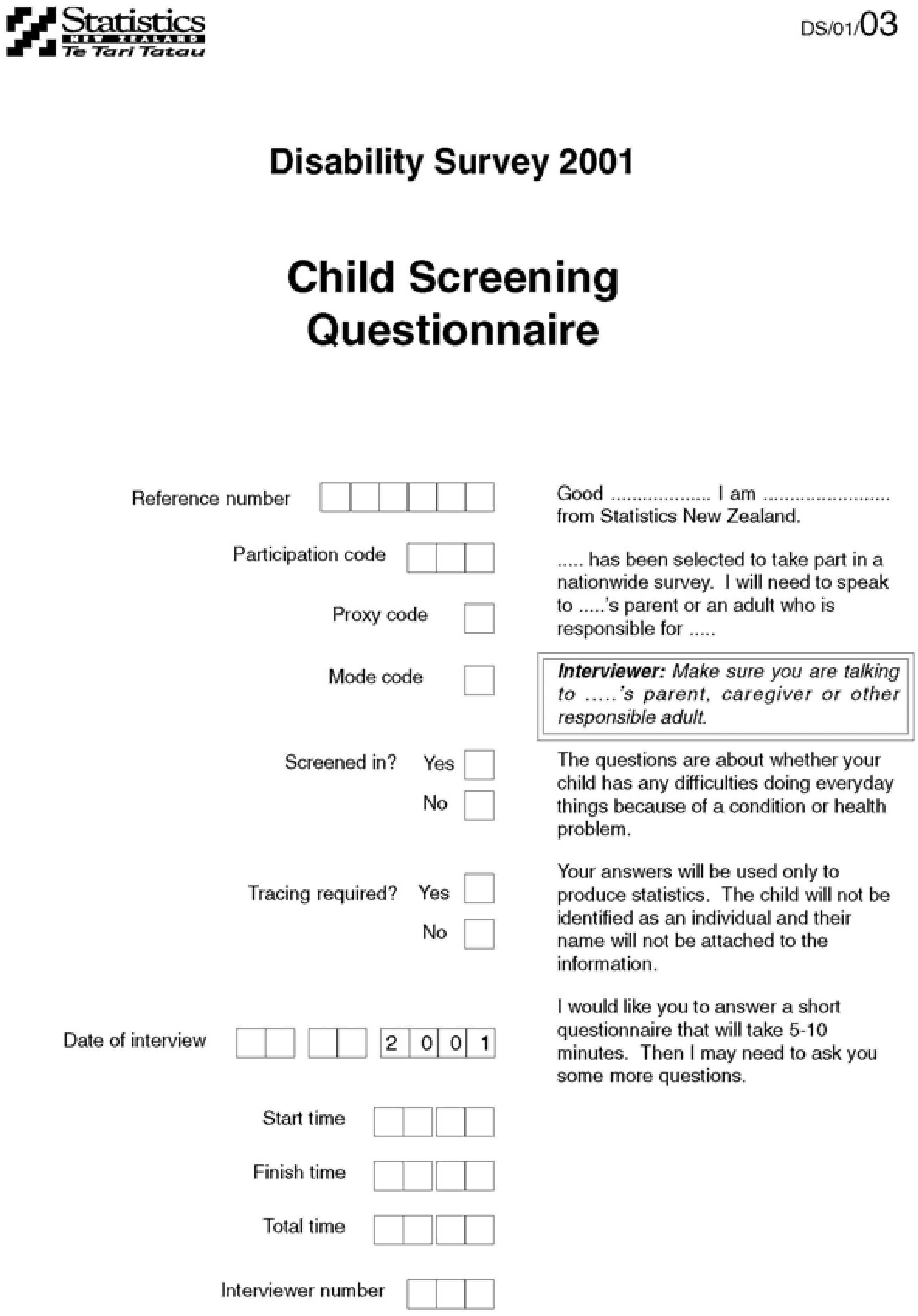
Appendix B: 2001 Household Disability Survey questionnaires

2001 Household Disability Survey Child Screening Questionnaire

http://www2.stats.govt.nz/domino/external/quest/sddquest.nsf/a0d89f655b2a49f64c256809000da4aa/afe0296c8e1fa069cc256ad8001d99f7?OpenDocument&Highlight=2,disability

2001 Household Disability Survey Child Content Questionnaire

http://www2.stats.govt.nz/domino/external/quest/sddquest.nsf/a0d89f655b2a49f64c256809000da4aa/90690d313a42c061cc256ad8001daec1?OpenDocument&Highlight=2,disability



Statistics
NEW ZEALAND
Te Tari Tatau

DS/01/03

Disability Survey 2001

Child Screening Questionnaire

Reference number ☐☐☐☐☐☐

Participation code ☐☐☐

Proxy code ☐

Mode code ☐

Screened in? Yes ☐ No ☐

Tracing required? Yes ☐ No ☐

Date of interview ☐☐ ☐☐ 2 0 0 1

Start time ☐☐☐☐

Finish time ☐☐☐☐

Total time ☐☐☐☐

Interviewer number ☐☐☐

Good .... I am .... from Statistics New Zealand.

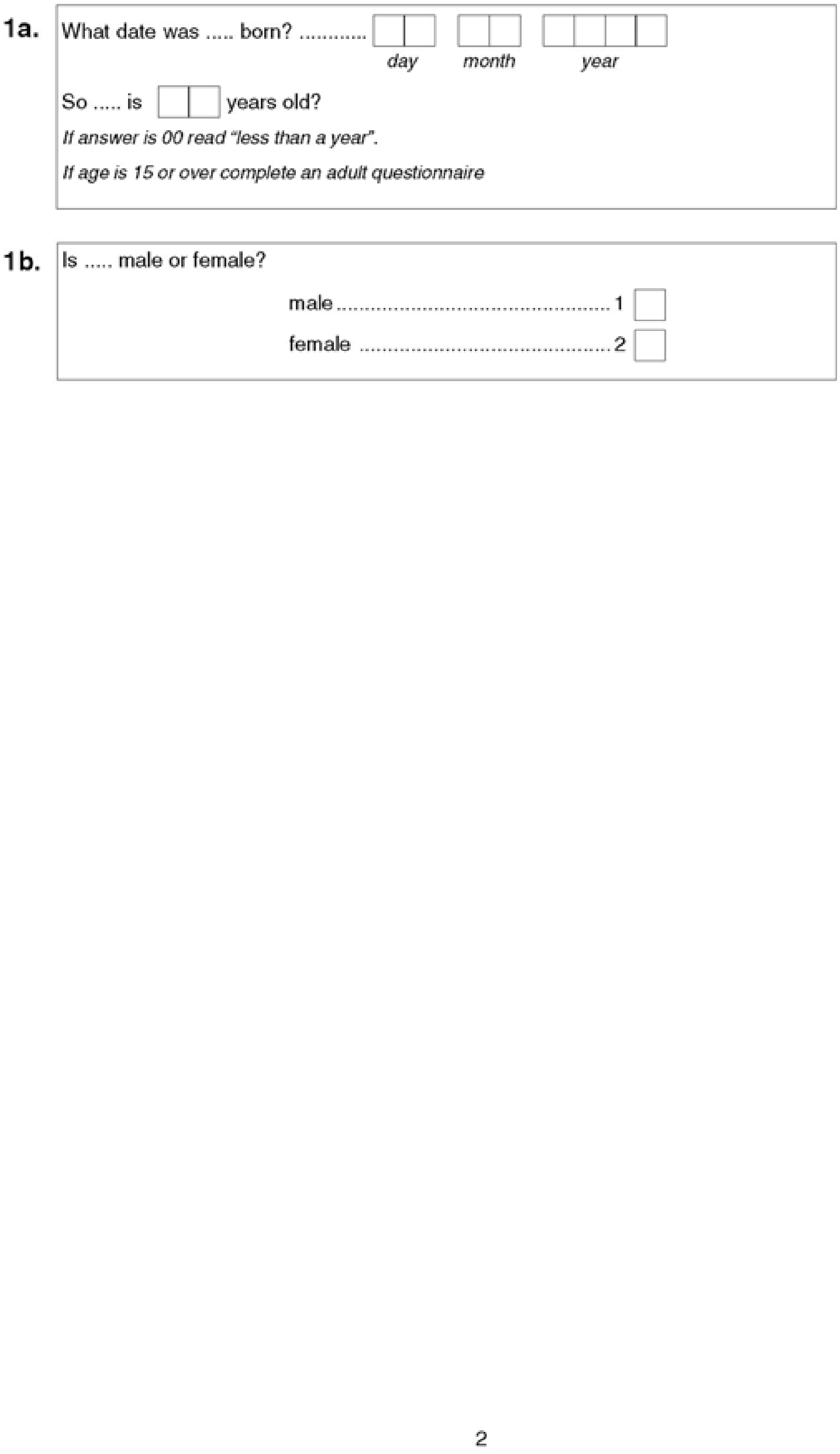
..... has been selected to take part in a nationwide survey. I will need to speak to .....'s parent or an adult who is responsible for .....

Interviewer: *Make sure you are talking to .....'s parent, caregiver or other responsible adult.*

The questions are about whether your child has any difficulties doing everyday things because of a condition or health problem.

Your answers will be used only to produce statistics. The child will not be identified as an individual and their name will not be attached to the information.

I would like you to answer a short questionnaire that will take 5-10 minutes. Then I may need to ask you some more questions.



1a. What date was ..... born? .... ☐☐ day ☐☐ month ☐☐☐☐ year

So ..... is ☐☐ years old?

If answer is 00 read "less than a year".

If age is 15 or over complete an adult questionnaire

1b. Is ..... male or female?

male .... 1 ☐

female .... 2 ☐

2

2a. Now I am going to ask some questions about long-term difficulties that some children have doing things. The questions cover a range of difficulties that some children will have.

By long-term, we mean difficulties that have lasted **6 months or more**, or are expected to last for **6 months or more**.

Is ..... blind or does ..... have trouble with her/his eyesight which is not corrected by glasses or contact lenses?

screening column

yes ....1 ☐

no .... 2 ☐ ➡ **GO TO 3a**

2b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year enter 00

If child has always been blind or always had trouble seeing which cannot be corrected, enter 00.

2c. What is the main condition or health problem which resulted in .....'s blindness/eyesight problems?

____

____

2d. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

2e. Has ..... been diagnosed by an eye specialist as being blind?

yes .... 1 ☐

no .... 2 ☐

2f. Does ..... use any equipment for seeing, other than glasses or contact lenses?

yes .... 1 ☐

no .... 2 ☐

3a. Is ..... deaf or does ..... have trouble hearing, which is not currently corrected?

Tick "no" for children who have grommets and have no hearing problems.

Tick "yes" for children who have grommets, but who still have trouble hearing.

Tick "yes" for children who wear hearing aids.

	screening column
yes	.....1 ☐
no .... 2 ☐ ➡ **GO TO 4**	

3b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00

If child has never been able to hear or has always had trouble hearing which cannot be corrected, enter 00

3c. What is the main condition or health problem which resulted in .....'s hearing problems?

____

____

Is that the same condition you told me about?

yes, same as question: .... 0 2 c ➡ **GO TO 3e**

no .... 2 ☐ ➡ **GO TO 3d**

3d. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

3e. Does ..... use any equipment for hearing such as a hearing aid or an FM system?

yes ....1 ☐

no ....2 ☐

4.

INTERVIEWER

Is the child aged 2 years or older?

yes .... 1 ☐ ➡ **GO TO 5a**

no .... 2 ☐ ➡ **GO TO 6a**

5a.

Because of a long-term condition or health problem, does ..... have any trouble speaking and being understood?

screening column

yes ....1 ☐

no / don't know .... 2 ☐ ➡ **GO TO 6a**

If child is too young to diagnose (or if respondent doesn't know) then enter 'no'.

5b.

At what age did this begin? .... *Enter age in years:* ☐☐

If child has never been able to do it, enter 00.

5c.

What is the main condition or health problem which resulted in .....'s difficulty speaking and being understood ?

____

____

Is that the same condition you told me about?

yes, same as question: ...... 0 ☐ c ➡ **GO TO 5e**

no .... 2 ☐ ➡ **GO TO 5d**

5d.

Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
  (includes burns, near drowning, poisoning) .... 3 ☐

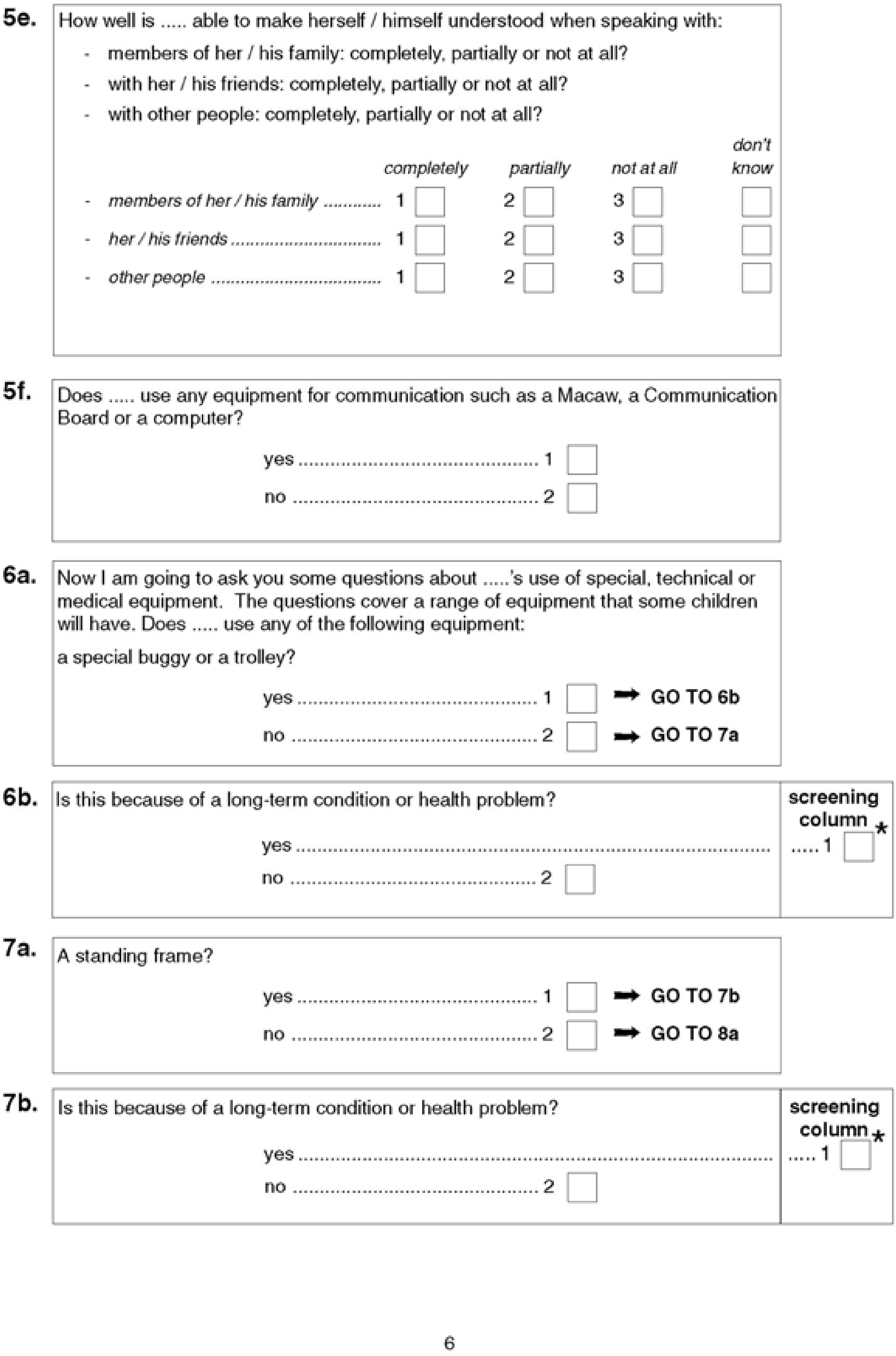
a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐



5e. How well is ..... able to make herself / himself understood when speaking with:

- members of her / his family: completely, partially or not at all?
- with her / his friends: completely, partially or not at all?
- with other people: completely, partially or not at all?

	completely	*partially*	*not at all*	*don't know*
- *members of her / his family*	1 ☐	2 ☐	3 ☐	☐
- *her / his friends*	1 ☐	2 ☐	3 ☐	☐
- *other people*	1 ☐	2 ☐	3 ☐	☐

5f. Does ..... use any equipment for communication such as a Macaw, a Communication Board or a computer?

yes .... 1 ☐
no .... 2 ☐

6a. Now I am going to ask you some questions about .....'s use of special, technical or medical equipment. The questions cover a range of equipment that some children will have. Does ..... use any of the following equipment:

a special buggy or a trolley?

yes .... 1 ☐ ➡ **GO TO 6b**
no .... 2 ☐ ➡ **GO TO 7a**

6b. Is this because of a long-term condition or health problem?

yes .... 1 ☐ **screening column** *
no .... 2 ☐

7a. A standing frame?

yes .... 1 ☐ ➡ **GO TO 7b**
no .... 2 ☐ ➡ **GO TO 8a**

7b. Is this because of a long-term condition or health problem?

yes .... 1 ☐ **screening column** *
no .... 2 ☐

6

8a. Any kind of braces, other than braces for teeth?

yes .... 1 ☐ ➡ **GO TO 8b**
no .... 2 ☐ ➡ **GO TO 9**

8b. Is this because of a long-term condition or health problem?

screening column

yes .... 1 ☐*
no .... 2 ☐

9. *INTERVIEWER*

Is the child aged 2 years or older?

yes .... 1 ☐ ➡ **GO TO 10**
no .... 2 ☐ ➡ **GO TO 13**

10. Does ..... use a wheelchair?

screening column

yes .... 1 ☐*
no .... 2 ☐

11a. Crutches, walking sticks, a walking frame or any other kind of walking aid?

yes .... 1 ☐ ➡ **GO TO 11b**
no .... 2 ☐ ➡ **GO TO 12**

11b. Is this because of a long-term condition or health problem?

screening column

yes .... 1 ☐*
no .... 2 ☐

12. An artificial leg, arm, hand or foot?

screening column

yes .... 1 ☐*
no .... 2 ☐

13. Does ..... use any other kind of equipment because of a condition or a health problem that has lasted or is expected to last for 6 months or more?
Don't count asthma inhalers, braces for teeth or grommets.

screening column

yes - *specify* .... 1 ☐*

no .... 2 ☐

14. *INTERVIEWER*

*Is "yes" ticked in the screening column for any of questions 6 - 13 marked with an asterisk *?*

yes .... 1 ☐ ➡ **GO TO 15a**

no .... 2 ☐ ➡ **GO TO 16a**

15a. What is the main condition or health problem which resulted in ..... needing that piece (those pieces) of equipment you told me about before?

____

____

Is that the same condition you told me about?

yes, same as question: .... 0 ☐ c ➡ **GO TO 16a**

no .... 2 ☐ ➡ **GO TO 15b**

15b. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

16a. Is there any equipment which ..... needs but does not have?

yes ....1 ☐ ➡ **GO TO 16b**
no ....2 ☐ ➡ **GO TO 17a**

16b. What types of equipment does ..... need but not have? I will read you a list.

Tick all that apply.

equipment to help with seeing? ....1 ☐
equipment to help with hearing? ....2 ☐
equipment to help with speaking or communicating? ....3 ☐
equipment to help with standing or moving around? ....4 ☐
or another type of equipment? - *specify* ....5 ☐

____

16c. Why doesn't ..... have this equipment? I will read you a list.

Tick all that apply.

it is only needed occasionally? .... 1 ☐
.....'s condition is not serious enough? .... 2 ☐
the equipment is not available? .... 3 ☐
you do not know where to get it? .... 4 ☐
it is too costly or you cannot afford it? .... 5 ☐
you applied for financial help to get it but were .... 6 ☐
not eligible?
you did not know you could apply for financial help .... 7 ☐
or where to apply?
..... has never been assessed? .... 8 ☐
or another reason? - *specify* ....9 ☐

____

17a. From time to time, most children have occasional emotional or nervous problems.

However, does ..... have any **long-term** emotional, behavioural, psychological, nervous or mental health condition which limits the kind or amount of activity that she/he can do at home, at school or at play?

screening column

yes .... 1 ☐

no / don't know .... 2 ☐ ➡ **GO TO 18**

If child is too young to diagnose (or if respondent doesn't know) then enter 'no'.

17b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

17c. What is the main condition or health problem which limits ..... in her / his activity at home, at school or at play?

____

____

Is that the same condition you told me about?

yes, same as question: .... ☐☐☐ ➡ **GO TO 18**

no .... 2 ☐ ➡ **GO TO 17d**

17d. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

18. Does ..... have any of these long-term conditions or health problems:
Allergies of any kind?

yes .... 1 ☐

no .... 2 ☐

19. Bronchitis?

yes .... 1 ☐
no .... 2 ☐

20a. Asthma?

yes .... 1 ☐ ➡ **GO TO 20b**
no .... 2 ☐ ➡ **GO TO 21a**

20b. Has a doctor told you that .....'s asthma is "severe asthma"?

screening column

yes .... 1 ☐
no .... 2 ☐ ➡ **GO TO 21a**

20c. At what age did this begin? .... *Enter age in years:* ☐☐
If age was less than 1 year, enter 00.

21a. Does ..... have a long-term lung condition or disease that limits her / his activities?

screening column

yes .... 1 ☐
no .... 2 ☐ ➡ **GO TO 22a**

21b. At what age did this begin? .... *Enter age in years:* ☐☐
If age was less than 1 year, enter 00.

21c. Which ONE of the following is the BEST description of the cause of this:
Tick one only.

a disease or illness? .... 1 ☐
it existed at birth or occurred during birth? .... 2 ☐
an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐
a motor vehicle accident? .... 4 ☐
a sports accident or injury? .... 5 ☐
or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

22a. Does ..... have diabetes?

screening column

yes .... 1 ☐

no .... 2 ☐ ➡ **GO TO 23a**

22b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

23a. Does ..... have a long-term heart condition or disease that limits his / her activities?

Don't count heart murmurs, unless they limit the child's activities.

screening column

yes .... 1 ☐

no .... 2 ☐ ➡ **GO TO 24a**

23b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

23c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

24a. Does ..... have a kidney condition or disease that limits her / his activities?

screening column

yes ....1 ☐

no .... 2 ☐ ➡ **GO TO 25a**

24b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

24c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

Don't know .... 99 ☐

25a. Does ..... have cancer?

screening column

yes ....1 ☐

no .... 2 ☐ ➡ **GO TO 26a**

25b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

26a. Does ..... have epilepsy?

An occasional seizure is not necessarily epilepsy.
Only tick "yes" if R has reason to believe it is epilepsy.

screening column

yes ....1 ☐

no .... 2 ☐ ➡ **GO TO 27a**

26b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year enter 00.

27a. Does ..... have cerebral palsy?

screening column

yes .... 1 ☐

no .... 2 ☐ ➡ **GO TO 27d**

27b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year , enter 00.

27c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness?.. 1 ☐

it existed at birth or occurred during birth?........................ 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify*.. 6 ☐

Don't know.. 99 ☐

27d. Does ..... have muscular dystrophy?

screening column

yes .... 1 ☐

no .... 2 ☐

27e. Does ..... have spina bifida?

screening column

yes .... 1 ☐

no .... 2 ☐

28a. Does ..... have a chronic gastro-intestinal condition which is long-term?

eg chronic diarrhoea

screening column

yes .... 1 ☐

no .... 2 ☐ ➡ **GO TO 29a**

28b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year , enter 00.

28c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?

(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

Don't know .... 99 ☐

29a. Does ..... have growth failure or failure to thrive?

		screening column
yes		..... 1 ☐
no .... 2 ☐	➡ **GO TO 30a**	

29b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

29c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?

(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

Don't know .... 99 ☐

30a. Does ..... have autism or asperger syndrome?

screening column

yes .... 1 ☐
no .... 2 ☐ ➡ **GO TO 31a**

30b. At what age did this begin? .... *Enter age in years:* ☐☐
If age was less than 1 year, enter 00.

31a. Does ..... have an intellectual disability or a general development delay?

screening column

yes .... 1 ☐
no .... 2 ☐ ➡ **GO TO 32a**

31b. At what age did this begin? .... *Enter age in years:* ☐☐
If age was less than 1 year, enter 00.

31c. Which ONE of the following is the BEST description of the cause of this:
Tick one only.

a disease or illness? .... 1 ☐
it existed at birth or occurred during birth? .... 2 ☐
an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐
a motor vehicle accident? .... 4 ☐
a sports accident or injury? .... 5 ☐
or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

32a. Does ..... have a learning difficulty such as dyslexia, attention deficit disorder or attention deficit hyperactivity disorder?

screening column

This question is about the child's mental capacity to learn.

Do not tick "yes" if the child only has difficulty because of physical barriers to learning a task, or physical limitations on attending a place of learning.

yes .... 1 ☐

no / don't know .... 2 ☐ ➡ **GO TO 33a**

If child is too young to diagnose (or respondent doesn't know) then enter 'no'.

32b. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

32c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

Don't know .... 99 ☐

33a. Does ..... have any other condition or health problem that you haven't already told me about, which limits what she / he can do at school, at play or in any other activity that children her / his age can usually do?

yes .... 1 ☐ ➡ **GO TO 33b**
no .... 2 ☐ ➡ **GO TO 34**

33b. Has ..... been limited in these activities for 6 months or more, or is she / he expected to be limited in them for 6 months or more?

screening column

yes .... 1 ☐
no .... 2 ☐ ➡ **GO TO 34**

33c. What is this condition or health problem?

If more than one, specify the most serious

____

____

33d. At what age did this begin? .... *Enter age in years:* ☐☐

If age was less than 1 year, enter 00.

33e. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐
it existed at birth or occurred during birth? .... 2 ☐
an accident or injury at home or school?
(includes burns, near drowning, poisoning) .... 3 ☐
a motor vehicle accident? .... 4 ☐
a sports accident or injury? .... 5 ☐
or another cause? - *specify* .... 6 ☐

____

Don't know .... 99 ☐

34. *INTERVIEWER*

Is the child aged 5 years or older?

yes .... 1 ☐ ➡ **GO TO 35a**
no .... 2 ☐ ➡ **GO TO 37a**

35a. Does ..... attend a special school, or a special unit or class at a regular school, or a regular class where special education services are provided?

yes .... 1 ☐ ➡ **GO TO 35b**

no .... 2 ☐ ➡ **GO TO 37a**

35b. Is this because of a long-term condition or health problem?

yes ....

no .... 2 ☐ ➡ **GO TO 37a**

screening column

..... 1 ☐

36a. At what age did ..... start receiving special education?

Enter age in years: ☐☐

36b. What is the main condition or health problem which makes it necessary for ..... to receive special education?

Is that the same condition you told me about?

yes, same as question: .... ☐☐☐ ➡ **GO TO 37a**

no .... 2 ☐ ➡ **GO TO 36c**

36c. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness? .... 1 ☐

it existed at birth or occurred during birth? .... 2 ☐

an accident or injury at home or school?

(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify* .... 6 ☐

Don't know .... 99 ☐

37a. Because of learning or developmental difficulties, does ..... have an **Individual Education Programme** (IEP), or **Individual Development Programme** (IDP)?

screening column

yes .... 1 ☐

no .... 2 ☐ ➡ **GO TO 38**

37b. At what age did ..... first get an individual programme?

Enter age in years: ☐☐

37c. What is the main condition or health problem which makes it necessary for ..... to have an individual programme?

____

____

Is that the same condition you told me about?

yes, same as question: ....☐☐☐ ➡ **GO TO 38**

no .... 2 ☐ ➡ **GO TO 37d**

37d. Which ONE of the following is the BEST description of the cause of this:

Tick one only.

a disease or illness?.. 1 ☐

it existed at birth or occurred during birth?........................ 2 ☐

an accident or injury at home or school?

(includes burns, near drowning, poisoning) .... 3 ☐

a motor vehicle accident? .... 4 ☐

a sports accident or injury? .... 5 ☐

or another cause? - *specify*.. 6 ☐

____

Don't know.. 99 ☐

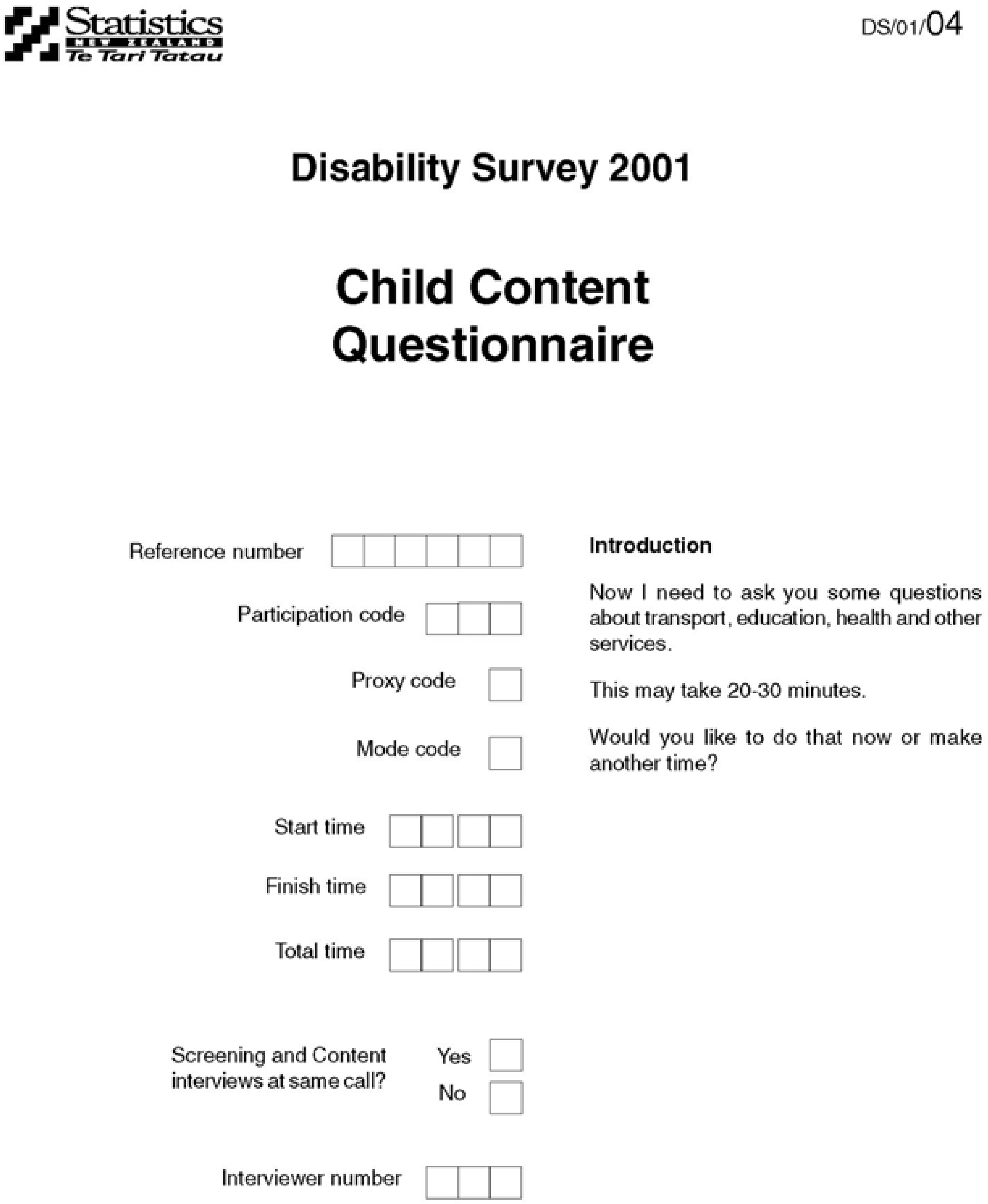
38. *INTERVIEWER*

Is "yes" ticked in the screening column of any question?

yes .... 1 ☐ ➡ **GO TO Content Questionnaire**

no .... 2 ☐ ➡ **GO TO 39**

39. That's all the questions. Thank you very much for taking part in this survey. I'd like to assure you that the information you have given will be kept confidential.



Statistics New Zealand
Te Tari Tatau

DS/01/04

Disability Survey 2001

Child Content Questionnaire

Reference number ☐☐☐☐☐☐

Participation code ☐☐☐

Proxy code ☐

Mode code ☐

Start time ☐☐☐☐

Finish time ☐☐☐☐

Total time ☐☐☐☐

Screening and Content interviews at same call?
Yes ☐
No ☐

Interviewer number ☐☐☐

Introduction

Now I need to ask you some questions about transport, education, health and other services.

This may take 20-30 minutes.

Would you like to do that now or make another time?

Section B - Services and assistance

1. I am going to read out a list of ethnic groups. Can you tell me which ethnic group or groups ..... belongs to:

Tick all that apply.

New Zealand European? .... 1 ☐
Māori? .... 2 ☐
Samoan? .... 3 ☐
Cook Island Maori? .... 4 ☐
Tongan? .... 5 ☐
Niuean? .... 6 ☐
Chinese? .... 7 ☐
Indian? .... 8 ☐
Other, such as Dutch, Japanese, Tokelauan - *specify*? .... 9 ☐

____

2. The next questions are about .....'s use of health services and help she/he may get managing everyday activities.

In the 12 months ending today, which of these has ..... had a consultation with?

Read out and tick each one R has been to in the past 12 months. Then go back and ask ***Q3*** *for each one that is ticked.*

3. How often has ..... seen a .... in the past 12 months:
1 or 2 times, 3 to 5 times, 6 to 10 times, or more than 10 times?

			1-2 times	*3-5 times*	*6-10 times*	*more than 10 times*
(a)	GP or family doctor	1 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(b)	a nurse, without also seeing a doctor	2 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(c)	chemist or pharmacist, for health advice or getting medication only	3 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(d)	dentist or dental nurse	4 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(e)	physiotherapist	5 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(f)	occupational therapist	6 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(g)	speech therapist	7 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(h)	medical specialist, the special kind of doctor that an ordinary doctor needs to refer you to	8 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(i)	counsellor, social worker or psychologist	9 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(j)	optician or optometrist	10 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(k)	chiropractor	11 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(l)	podiatrist or chiropodist	12 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(m)	alternative therapist such as homeopath, naturopath, iridologist	13 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(n)	traditional healer such as tohunga, rongoa Māori specialist or fofo	14 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(o)	Māori health worker, Pacific Island health worker	15 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(p)	any other health professional, therapist or healer *- specify* ______________	16 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(q)	*- specify* ______________	17 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(r)	*- specify* ______________	18 ☐	1 ☐	2 ☐	3 ☐	4 ☐
(s)	*None of these*	19 ☐				

4. In the 12 months ending today, has there been a time when ..... has needed to see any of those types of health professionals, therapists or healers but has not been able to?

yes .... 1 ☐ ➡ **GO TO 5**
no .... 2 ☐ ➡ **GO TO 6**

5. Which health professional has ..... needed but been unable to see?

Do NOT read out.

Tick all that apply.

GP or family doctor .... 1 ☐
a nurse, without also seeing .... 2 ☐
a doctor
chemist or pharmacist, for health ...... 3 ☐
advice or getting medication only
dentist or dental nurse .... 4 ☐
physiotherapist .... 5 ☐
occupational therapist .... 6 ☐
speech therapist .... 7 ☐
medical specialist, the special .... 8 ☐
kind of doctor that an ordinary
doctor needs to refer you to
counsellor, social worker or .... 9 ☐
psychologist
optician or optometrist .... 10 ☐
chiropractor ....11 ☐
podiatrist/chiropodist .... 12 ☐
alternative therapist such as .... 13 ☐
homeopath, naturopath, iridologist
traditional healer such as tohunga, . 14 ☐
rongoa Māori specialist or fofo
Māori health worker, Pacific Island . 15 ☐
health worker

other health professional,
therapist or healer

*- specify*________________________ .. 16 ☐

- specify _______________________ ... 17 ☐

*- specify*________________________ .. 18 ☐

6. In the last 12 months, has ..... taken medication or drugs - either prescribed for her/him or not?

An asthma inhaler is counted as medication.

yes .... 1 ☐ ➡ **GO TO 7**
no........... 2 ☐ ➡ **GO TO 11**

7. Does ..... take any prescription drugs:

Tick all that apply.

daily? ....1 ☐
once a week or more? ....2 ☐
less than once a week? ....3 ☐
as needed? ....4 ☐
None ....5 ☐

8. Does ..... take any non-prescription drugs. Include aspirin and herbal remedies but don't include vitamins:

Tick all that apply.

daily? ....1 ☐
once a week or more? ....2 ☐
less than once a week? ....3 ☐
as needed? ....4 ☐
None ....5 ☐

9. In the last 12 months, have you had the Disability Allowance or a Special Needs Grant to pay for medication for ..... because of her/his condition or health problem?

yes .... 1 ☐
no..................................... 2 ☐

10. In the last 12 months, have you had to pay for medication needed for .....'s condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no..................................... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ) and ACC.

11. In the last 12 months, has ..... needed medication which you were not able to get for her/him?

yes .... 1 ☐ ➡ **GO TO 12**
no........... 2 ☐ ➡ **GO TO 13**

12. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? .... 1 ☐
you applied for financial help and were not eligible? .... 2 ☐
you did not know you could apply for financial help or where to apply? ...... 3 ☐
or was there another reason? .... 4 ☐
- specify

____

____

13. In the last 12 months, has ..... needed anything special in her/his diet because of her/his condition or health problem?

yes .... 1 ☐ ➡ **GO TO 14**
no........... 2 ☐ ➡ **GO TO 18**

14. In the last 12 months, has she/he needed anything special in her/his diet which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 15**
no........... 2 ☐ ➡ **GO TO 16**

15. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? ....1 ☐
you applied for financial help and were not eligible? ....2 ☐
you did not know you could apply for financial help or where to apply? ....3 ☐
or was there another reason? ....4 ☐
- specify

____

____

16. In the last 12 months, have you had any financial help from a government agency to pay for any special dietary needs that ..... may have because of her/his condition or health problem?

yes .... 1 ☐
no .... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ) and ACC.

17. In the last 12 months, have you had to pay for special dietary needs related to .....'s condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no .... 2 ☐

18. In the last 12 months, has ..... needed any disposable items, such as hearing aid batteries, needles etc., because of her/his condition?

yes .... 1 ☐ ➡ **GO TO 19**
no........... 2 ☐ ➡ **GO TO 23**

19. In the last 12 months, has she/he needed any disposable items like that, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 20**
no........... 2 ☐ ➡ **GO TO 21**

20. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? .... 1 ☐

you applied for financial help and were not eligible? .... 2 ☐

you did not know you could apply for financial help or where to apply? .... 3 ☐

or was there another reason? .... 4 ☐
- specify

21. In the last 12 months, have you had any financial help from a government agency to pay for any disposable items that ..... may have needed, because of her/his condition or health problem?

yes .... 1 ☐
no .... 2 ☐

22. In the last 12 months, have you had to pay for disposable items needed for .....'s condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no .... 2 ☐

23. In the last 12 months, have you needed help with .....'s personal care or with household work, because of her/his condition?

yes .... 1 ☐ ➡ **GO TO 24**
no........... 2 ☐ ➡ **GO TO 31**

24. In the last 12 months, have you needed help with her/his personal care, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 25**
no........... 2 ☐ ➡ **GO TO 26**

25. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? .... 1 ☐

you applied for financial help and were not eligible? .... 2 ☐

you did not know you could apply for financial help or where to apply? .... 3 ☐

or was there another reason? .... 4 ☐
- specify

26. Because of .....'s condition, have you needed help with your household tasks, for example with housework or shopping, in the last 12 months, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 27**
no........... 2 ☐ ➡ **GO TO 28**

27. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? ....1 ☐
you applied for financial help and were not eligible? ....2 ☐
you did not know you could apply for financial help or where to apply? ....3 ☐
or was there another reason? ....4 ☐
- specify

____
____

28. In the last 12 months, have you had any **home support**, or the money to pay for home support, from a government agency?
By home support I mean help with .....'s personal care or help with housework etc.

yes .... 1 ☐
no.................................... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ) and ACC.

29. In the last 12 months, have you had to pay for help with .....'s personal care, because of her/his condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no.................................... 2 ☐

30. In the last 12 months, have you had to pay for help with household tasks such as housework or shopping, which you needed because of .....'s condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no.................................... 2 ☐

31. In the last 12 months, have you, because of .....'s condition or health problem, needed help with repairs or maintenance to your home or property, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 32**
no........... 2 ☐ ➡ **GO TO 33**

32. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? ....1 ☐
you applied for financial help and were not eligible? ....2 ☐
you did not know you could apply for financial help or where to apply? ....3 ☐
or was there another reason? ....4 ☐
- specify

____
____

33. Respite care or carer support is alternative care to give caregivers a break. In the last 12 months, have you needed **respite care** or carer support so that you / .....'s caregiver could have a break?

yes .... 1 ☐ ➡ **GO TO 34**
no........... 2 ☐ ➡ **GO TO 37**

34. In the last 12 months, have you needed **respite care** or carer support which you were unable to get?

yes .... 1 ☐ ➡ **GO TO 35**
no........... 2 ☐ ➡ **GO TO 36**

35. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? .... 1 ☐

you applied for free respite care but were not eligible? .... 2 ☐

you did not know you could apply for free respite care or where to apply? .... 3 ☐

no appropriate respite care service is available in this area? .... 4 ☐

you don't like the respite care services that are available? .... 5 ☐

you feel uncomfortable with the respite care services because of language or other cultural differences? .... 6 ☐

you had used up your free respite care and could not afford to pay for any more? .... 7 ☐

or was there another reason? .... 8 ☐
- specify

____

36. Thinking about any respite care or carer support you have had in the last 12 months,

(a) have you had any free respite care?

yes .... 1 ☐
no.................................... 2 ☐

(b) has a government agency, hospital or Ministry of Health service helped to pay for any?

yes .... 1 ☐
no.................................... 2 ☐

(c) have you had to pay for any, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no.................................... 2 ☐

37. In the last 12 months, has ... needed any special equipment, for example a special chair or blood glucose meter, because of her/his condition or health problem?

yes .... 1 ☐ ➡ **GO TO 38**
no........... 2 ☐ ➡ **GO TO 43**

38. In the last 12 months, has she/he needed any special equipment like that, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 39**
no........... 2 ☐ ➡ **GO TO 40**

39. Why couldn't you get it:

Tick all that apply.

it was too costly or you could not afford it? ....1 ☐

you applied for financial help and were not eligible? ....2 ☐

you did not know you could apply for financial help or where to apply? ....3 ☐

or was there another reason? ....4 ☐
- specify

____

____

40. In the last 12 months, have you had a **Special Needs Grant** to pay for any disability related equipment?

yes .... 1 ☐
no.................................... 2 ☐

41. In the last 12 months, have you had any other financial help from a government agency to lease or buy equipment related to .....'s condition or health problem?

yes .... 1 ☐
no.................................... 2 ☐

42. In the last 12 months, have you had to pay for that sort of special equipment without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no.................................... 2 ☐

43. In the last 12 months, have you had to pay for anything we haven't already talked about, because of .....'s condition or health problem?

yes .... 1 ☐ ➡ **GO TO 44**
no........... 2 ☐ ➡ **GO TO 45**

44. What other things have you paid for?

Do NOT read out.

Tick all that apply.

physiotherapy, speech therapy other therapy .... 1 ☐

psychologist, counselling .... 2 ☐

sport or recreation activities .... 3 ☐

special clothing .... 4 ☐

other - specify .... 5 ☐

____

____

45. Has ..... ever had what is called a **needs assessment**, where someone from a needs assessment agency asks you questions about the support ...... needs for everyday living, such as home help, personal care or respite care, which is not funded by ACC?

yes .... 1 ☐ ➡ **GO TO 46**

no .... 2 ☐ ➡ **GO TO 47**

don't know .... 99 ☐ ➡ **GO TO 47**

46. Did ..... have that assessment:

less than 6 months ago? .... 1 ☐ ➡ **GO TO C on next page**

less than 12 months ago? .... 2 ☐ ➡ **GO TO C on next page**

less than 2 years ago? .... 3 ☐ ➡ **GO TO 47**

2 or more years ago? .... 4 ☐ ➡ **GO TO 47**

47. Is ..... booked in to have a (another) needs assessment?

yes .... 1 ☐ ➡ **GO TO C on next page**

no .... 2 ☐ ➡ **GO TO 48**

48. Do you intend to have (another) one done for her/him?

yes .... 1 ☐

no .... 2 ☐

49. Why hasn't ..... had a needs assessment recently?

Do NOT read out.

Tick all that apply.

did not know about it .... 1 ☐

condition isn't serious enough .... 2 ☐

needs haven't changed since last assessment .... 3 ☐

not yet available to child .... 4 ☐

were offered one but refused it .... 5 ☐

another reason - specify .... 6 ☐

____

____

Section C - Education

1. Can you remind me if ..... has had their 5th birthday or is ..... still under 5?

under 5 years .... 1 ☐ ➡ **GO TO 2**

5 years or older .... 2 ☐ ➡ **GO TO 6**

2. The next questions are about education.

In the week ending Sunday 4 March 2001, was ..... enrolled in or getting early childhood education through any of the following:

Tick all that apply.

the Early Childhood Correspondence School? .... 1 ☐

a kindergarten? .... 2 ☐

a playcentre? .... 3 ☐

a childcare centre or creche? .... 4 ☐

a playgroup? .... 5 ☐

Te Kohanga Reo? .... 6 ☐

a Pacific Island Language Group? .... 7 ☐

or another type of Early Childhood Service? - *specify* ... 8 ☐

____

____

None of these .... 9 ☐

3. Has a professional assessment ever been done to determine .....'s developmental or educational needs?

yes .... 1 ☐ ➡ **GO TO 4**

no .... 2 ☐ ➡ **GO TO 20 on page 13**

4. Who were the professionals who did this assessment:

Tick all that apply.

a special education adviser or an educational psychologist? .... 1 ☐

a clinical psychologist or a paediatrician? .... 2 ☐

a special education teacher or an early intervention teacher? .... 3 ☐

a teacher? .... 4 ☐

a physiotherapist or an occupational therapist? .... 5 ☐

a speech and language therapist? .... 6 ☐

or someone else? - *specify* .... 7 ☐

____

5. *INTERVIEWER*

Now ➡ **GO TO 20 on page 13**

6. The next questions are about education.

In the week ending Sunday 4 March, was ..... enrolled in any of the following:

Tick all that apply.

a primary or intermediate school? .... 1 ☐

an area or composite school? .... 2 ☐
combined primary & secondary school

kura kaupapa Māori? .... 3 ☐

a secondary school? .... 4 ☐

a special school? .... 5 ☐ ➡ **GO TO 10**

home schooling? .... 6 ☐

the Correspondence School? .... 7 ☐

another type of education? - *specify* .... 8 ☐

____

____

7. Has ..... ever attended a special school?

yes .... 1 ☐
no .... 2 ☐

8. *INTERVIEWER*

Is Correspondence School and/or home schooling the <u>only</u> option(s) ticked in Q.6?

yes .... 1 ☐ ➡ **GO TO 13**
no .... 2 ☐ ➡ **GO TO 9**

9. Last week, was ..... attending:

Tick one only.

only mainstream classes? .... 1 ☐
only a special unit? .... 2 ☐
or a mixture of both? .... 3 ☐

10. Last week, could ..... only use special transport, or did ..... need help getting to school because of her/his condition or health problem?

yes .... 1 ☐
no .... 2 ☐

11. Last week, what was the ONE main way that ..... travelled to and from school? By this I mean the one that ..... used to travel the greatest distance.

Do NOT read out. Tick one only.

none, studied at home .... 1 ☐
private motor vehicle .... 2 ☐
regular school bus .... 3 ☐
public bus or train .... 4 ☐
subsidised special transport service or taxi .... 5 ☐
unsubsidised taxi .... 6 ☐
bicycle .... 7 ☐
walked to school .... 8 ☐
another way - specify .... 9 ☐

____

12. At the school that ..... was enrolled at last week, did her/his condition or health problem limit her/him in any of the following:

		Yes	**No**
(a)	taking part in sports or games?	1 ☐	2 ☐
(b)	playing?	1 ☐	2 ☐
(c)	making friends?	1 ☐	2 ☐
(d)	going on school outings or camps?	1 ☐	2 ☐
(e)	or did .....'s condition limit her/his participation in any other way at school? *- specify*	1 ☐	2 ☐

____

____

13. Since ..... has been old enough to go to school, have you always been able to enrol her/him in the school of your choice?

yes .... 1 ☐ ➡ **GO TO 15**
no .... 2 ☐ ➡ **GO TO 14**

If respondent says there was "no choice" ask:

Would you have preferred ..... to go to some other school?

If the answer to this is "yes" then tick "no" and go to 14.

14. Tell me about the last time that you were unable to enrol ..... in the school of your choice. What was the main reason for that?

Do NOT read out.
Tick one only.

school was unwelcoming .... 1 ☐
school had an enrolment scheme implemented because of overcrowding .... 2 ☐
physical access was poor .... 3 ☐
special services/equipment needed for ..... were not available .... 4 ☐
other reason - specify .... 5 ☐

____

____

15. Because of ......'s condition:

		Yes	No
(a)	did she/he begin school later than other children?	1 ☐	2 ☐
(b)	was her/his education ever interrupted for long periods of time?	1 ☐	2 ☐
(c)	did she/he ever change schools?	1 ☐	2 ☐
(d)	did she/he ever change the subjects or courses she/he studied?	1 ☐	2 ☐
(e)	did she/he ever take fewer courses or subjects at school than she/he otherwise would have?	1 ☐	2 ☐
(f)	did she/he ever take any courses by correspondence or home schooling?	1 ☐	2 ☐
(g)	did she/he ever have to live away from home to go to school?	1 ☐	2 ☐

16. The following questions are about equipment or services ..... might need, because of her/his condition or health problem, to help with her/his education:

Follow each "yes" to Q.16 with Q.17 before going on to the next part of Q.16.

17. Was this made available to .... by the place that she/he was studying at last week?

If child is home-schooling, ask if she/he has these at home.

		Yes	Yes
(a)	does ..... need people to take notes, write or read for her/him because of her/his condition?	1 ☐	1 ☐
(b)	does ..... need an itinerant teacher especially because of her/his condition?	1 ☐	1 ☐
(c)	does ..... need a teacher aide especially because of her/his condition?	1 ☐	1 ☐
(d)	does ..... need computer access especially because of her/his condition?	1 ☐	1 ☐
(e)	does ..... need magnifiers because of her/his condition?	1 ☐	1 ☐
(f)	does ..... need talking books because of her/his condition?	1 ☐	1 ☐
(g)	does ..... need sign language interpreters because of her/his condition?	1 ☐	1 ☐
(h)	does ..... need F.M. systems because of her/his condition?	1 ☐	1 ☐
(i)	does ..... need any other equipment or service because of her/his condition? - *specify*	1 ☐	1 ☐
(j)	*none of these*	☐	

12

18. Has a professional assessment ever been done to determine ....'s developmental or educational needs?

If the child has an IEP (Individual Education Programme) or IDP (Individual Development Programme) tick 'Yes'.

yes .... 1 ☐ ➡ **GO TO 19**
no........... 2 ☐ ➡ **GO TO 20**

19. Who were the professionals who did this assessment:

Tick all that apply.
Don't record family members.

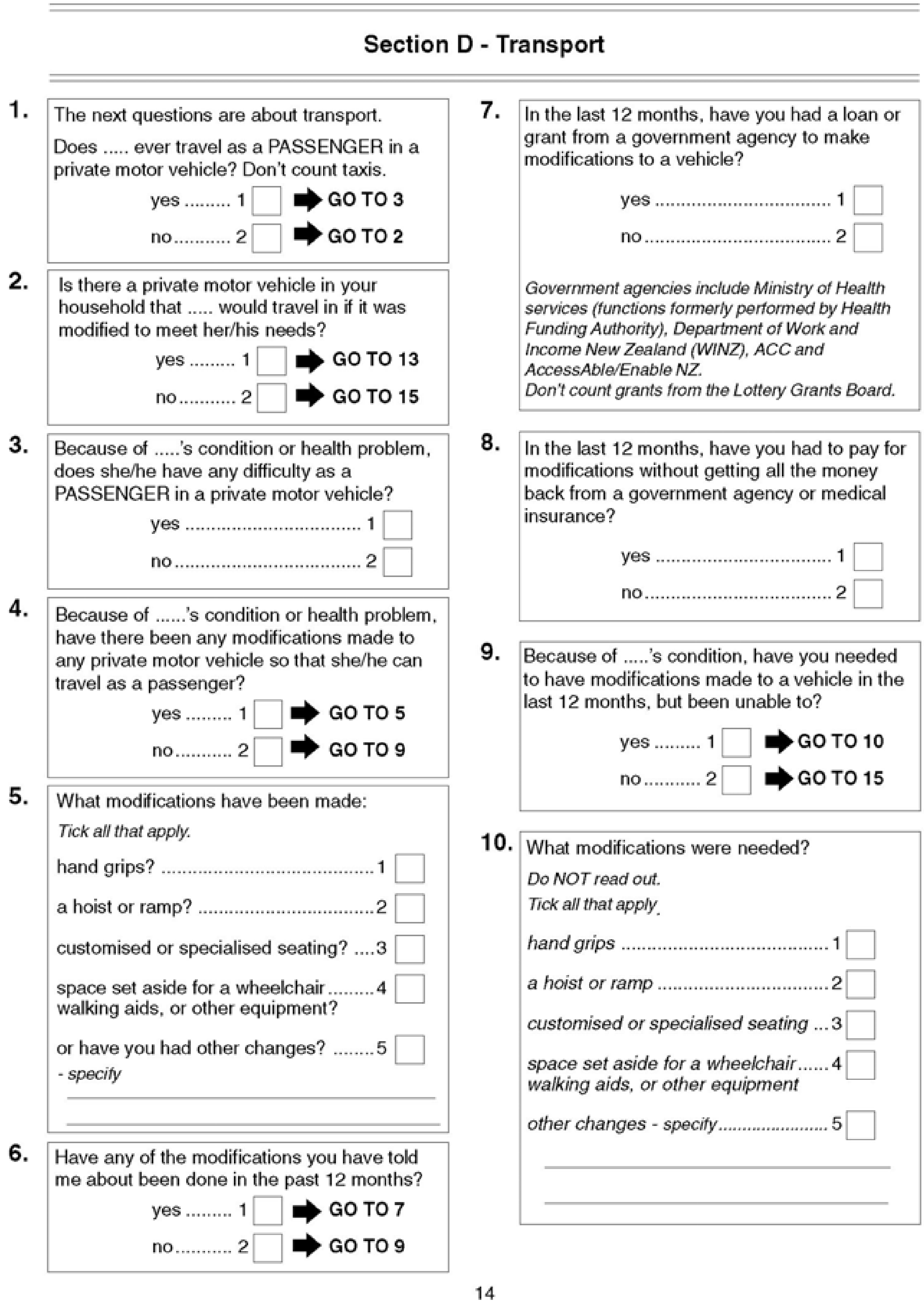
a special education adviser or an educational psychologist? .... 1 ☐
a clinical psychologist or a paediatrician? .... 2 ☐
a special education teacher or an early intervention teacher? .... 3 ☐
a teacher? .... 4 ☐
a physiotherapist or an occupational therapist? .... 5 ☐
a speech and language therapist? .... 6 ☐
or someone else? - *specify* .... 7 ☐

____

20. *INTERVIEWER*

Is the child aged 2 years or older?

yes .... 1 ☐ ➡ **GO TO D on next page**
no........... 2 ☐ ➡ **GO TO F on page 23**



Section D - Transport

1. The next questions are about transport.

Does ..... ever travel as a PASSENGER in a private motor vehicle? Don't count taxis.

yes .... 1 ☐ ➡ **GO TO 3**
no........... 2 ☐ ➡ **GO TO 2**

2. Is there a private motor vehicle in your household that ..... would travel in if it was modified to meet her/his needs?

yes .... 1 ☐ ➡ **GO TO 13**
no........... 2 ☐ ➡ **GO TO 15**

3. Because of .....'s condition or health problem, does she/he have any difficulty as a PASSENGER in a private motor vehicle?

yes .... 1 ☐
no.................................... 2 ☐

4. Because of ......'s condition or health problem, have there been any modifications made to any private motor vehicle so that she/he can travel as a passenger?

yes .... 1 ☐ ➡ **GO TO 5**
no........... 2 ☐ ➡ **GO TO 9**

5. What modifications have been made:

Tick all that apply.

hand grips? ....1 ☐
a hoist or ramp? ....2 ☐
customised or specialised seating? ....3 ☐
space set aside for a wheelchair.........4 ☐
walking aids, or other equipment?
or have you had other changes? ....5 ☐
- specify

____

____

6. Have any of the modifications you have told me about been done in the past 12 months?

yes .... 1 ☐ ➡ **GO TO 7**
no........... 2 ☐ ➡ **GO TO 9**

7. In the last 12 months, have you had a loan or grant from a government agency to make modifications to a vehicle?

yes .... 1 ☐
no.................................... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ), ACC and AccessAble/Enable NZ.
Don't count grants from the Lottery Grants Board.

8. In the last 12 months, have you had to pay for modifications without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no.................................... 2 ☐

9. Because of .....'s condition, have you needed to have modifications made to a vehicle in the last 12 months, but been unable to?

yes .... 1 ☐ ➡ **GO TO 10**
no........... 2 ☐ ➡ **GO TO 15**

10. What modifications were needed?

Do NOT read out.
Tick all that apply.

hand grips .... 1 ☐
a hoist or ramp ....2 ☐
customised or specialised seating ...3 ☐
space set aside for a wheelchair......4 ☐
walking aids, or other equipment
other changes - specify...................... 5 ☐

____

____

11. Why couldn't you get the modifications made:

Tick all that apply.

they were too costly or you could not afford them? .... 1 ☐

you applied for financial help but were not eligible? .... 2 ☐

you did not know you could apply for financial help or where to apply? .... 3 ☐

or was there another reason? .... 4 ☐

- specify

____

____

12. *INTERVIEWER*

Now ➡ **GO TO 15**

13. What modifications does ..... need to that car to be able to travel in it as a passenger?

Do NOT read out.
Tick all that apply.

hand grips .... 1 ☐

a hoist or ramp .... 2 ☐

customised or specialised seating ...... 3 ☐

space set aside for a wheelchair walking aids, or other equipment .... 4 ☐

other changes - specify .... 5 ☐

____

____

14. Why haven't those modifications been done:

Tick all that apply.

they were too costly or you could not afford them? .... 1 ☐

you applied for financial help and were not eligible? .... 2 ☐

you did not know you could apply for financial help or where to apply? .... 3 ☐

or was there another reason? .... 4 ☐

- specify

____

____

15. Because of .....'s condition, have you needed to buy a vehicle, in the last 12 months?

yes .... 1 ☐ ➡ **GO TO 16**

no........... 2 ☐ ➡ **GO TO 20**

16. Were you able to buy it?

yes .... 1 ☐ ➡ **GO TO 19**

no........... 2 ☐ ➡ **GO TO 17**

17. Why couldn't you buy it:

Tick all that apply.

it was too costly or you could not afford it? .... 1 ☐

you applied for financial help but were not eligible? .... 2 ☐

you did not know you could apply for financial help or where to apply? ...... 3 ☐

or was there another reason? .... 4 ☐

- specify

____

____

18. *INTERVIEWER*

Now ➡ **GO TO 20**

19. When you bought that vehicle, did you get all the money back from a government agency or medical insurance?

yes .... 1 ☐

no .... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ), ACC and AccessAble/Enable NZ.
Don't count grants from the Lottery Grants Board.

20. *INTERVIEWER*
Does ... travel as a passenger in a private car?
Refer to Q1 on previous page.

yes .... 1 ☐ ➡ **GO TO 21**

no........... 2 ☐ ➡ **GO TO 26**

21. When driving or travelling with .... as a passenger, do you need to park close to where you are going?

yes .... 1 ☐ ➡ **GO TO 22**
no .... 2 ☐ ➡ **GO TO 25**

22. In the last 6 months, when driving or travelling with ..... as a passenger, have there been any problems with finding a car park?

yes .... 1 ☐ ➡ **GO TO 23**
no .... 2 ☐ ➡ **GO TO 25**

23. Which of the following problems have you had:

Tick all that apply.

you have not been able to find parking close to where you wanted to go? .... 1 ☐

parking which was close to where you wanted to go, was in places which were too awkward for you to use? ...... 2 ☐

other people who have no disability using the carparks meant for people with a disability? .... 3 ☐

or have you had other problems with finding parking? - *specify* .... 4 ☐

____

____

24. *THERE IS NO 24*

25. Now some questions about long-distance travel. By long-distance travel, I mean trips of **80 kms or more**. That is about 50 miles, or one hour travelling on the open road.

In the last 12 months, has ... been on a trip that was 80kms or more?

yes .... 1 ☐ ➡ **GO TO 27**
no .... 2 ☐ ➡ **GO TO 26**

26. Does ....'s condition or health problem completely stop her/him from traveling long distances?

yes .... 1 ☐ ➡ **GO TO 28**
no .... 2 ☐ ➡ **GO TO 27**

27. Because of ....'s condition or health problem would she/he have any difficulty travelling long distances:

(a) by aeroplane?

yes .... 1 ☐
no .... 2 ☐
don't know.. 99 ☐

(b) by bus?

yes .... 1 ☐
no .... 2 ☐
don't know.. 99 ☐

(c) by train?

yes .... 1 ☐
no .... 2 ☐
don't know.. 99 ☐

(d) by ferry?

yes .... 1 ☐
no .... 2 ☐
don't know.. 99 ☐

(e) by car or van?

yes .... 1 ☐
no .... 2 ☐
don't know.. 99 ☐

28. And now some questions about the transport that ..... uses to travel short distances - either on her/his own or with someone else. By short distances, I mean trips which are **less than 80 kms** (or 50 miles). This includes trips to the doctor, to school, to the movies, to friends etc.

Has .... travelled short distances at all in the last 12 months?

yes .... 1 ☐ ➡ **GO TO 30**
no .... 2 ☐ ➡ **GO TO 29**

29. Does .....'s condition or health problem completely stop her/him from travelling short distances less than 80 kms?

yes .... 1 ☐ ➡ **GO TO E on page 20**
no .... 2 ☐ ➡ **GO TO 30**

30. Because of .....'s condition or health problem, does she/he need someone to help her/him on short trips?

yes .... 1 ☐
no .... 2 ☐

31. Because of .....'s condition or health problem, can she/he only use special transport for short trips, for example taxis or modified cars?

yes .... 1 ☐ ➡ **GO TO 41**
no .... 2 ☐

32. Public transport includes buses, trains, trams and ferries.
In the last 12 months, has .... used public transport to travel short distances?

yes .... 1 ☐ ➡ **GO TO 33**
no .... 2 ☐ ➡ **GO TO 36**

33. Because of .....'s condition or health problem, does she/he have any difficulty using any of those to travel short distances?

yes .... 1 ☐ ➡ **GO TO 34**
no .... 2 ☐ ➡ **GO TO 38**

34. In the last 12 months, what difficulties has ..... had when travelling short distances by public transport?

Do NOT read out.
Tick all that apply.

difficulty getting to or finding the stop .. 1 ☐
waiting at the stop .... 2 ☐
getting on or off .... 3 ☐
hearing announcements .... 4 ☐
identifying the right bus, train, tram or ferry .... 5 ☐
not enough space to sit or stand .... 6 ☐
standing in the vehicle while it is moving .... 7 ☐
identifying the right stop to get off the bus, train or tram .... 8 ☐
staff who are not supportive or helpful .... 9 ☐
transporting wheelchair or other special equipment .... 10 ☐
other difficulties - specify .... 11 ☐

____
____

35. *INTERVIEWER*
Now ➡ **GO TO 38**

36. Is that because ..... would have difficulty using public transport to travel short distances?

yes .... 1 ☐ ➡ **GO TO 37**
no .... 2 ☐ ➡ **GO TO 41**

37. Which of these difficulties would ...... have:

Tick all that apply.

difficulty getting to or finding the stop? 1 ☐

waiting at the stop? .... 2 ☐

getting on or off? .... 3 ☐

hearing announcements? .... 4 ☐

identifying the right bus, train, ... 5 ☐
tram or ferry?

not enough space to sit or stand? .... 6 ☐

standing in the vehicle while it is .... 7 ☐
moving?

identifying the right stop to get off .... 8 ☐
the bus, train or tram?

staff who are not supportive or .... 9 ☐
helpful?

transporting wheelchair or other .... 10 ☐
special equipment?

or would ..... have other difficulties? .. 11 ☐
- specify

38. Over the last 12 months, how often has ..... used a public bus to travel short distances: not at all, everyday or almost everyday, once a week or more, once a month, or less than once a month?

Tick one only.

not at all.................... 1 ☐ ➡ **GO TO 39**

everyday or .... 2 ☐ ➡ **GO TO 41**
almost everyday

once a week .... 3 ☐ ➡ **GO TO 41**
or more

once a month .... 4 ☐ ➡ **GO TO 41**
or more

less than once .... 5 ☐ ➡ **GO TO 41**
a month

39. Is there a bus service in your area?

yes .... 1 ☐ ➡ **GO TO 40**

no .... 2 ☐ ➡ **GO TO 41**

40. Would ..... use buses if they were made easier for people with disabilities to use, for example easier to get on and off?

This does not mean changes to timetables or routes.

yes .... 1 . ☐

no .... 2 . ☐

don't know .... 99 . ☐

41. Over the last 12 months, how often has ..... used a taxi to travel short distances: not at all, everyday or almost everyday, once a week or more, once a month, or less than once a month?

Tick one only.

not at all.................... 1 ☐ ➡ **GO TO 42**

everyday or .... 2 ☐ ➡ **GO TO 43**
almost everyday

once a week .... 3 ☐ ➡ **GO TO 43**
or more

once a month .... 4 ☐ ➡ **GO TO 42**
or more

less than once .... 5 ☐ ➡ **GO TO 42**
a month

42. What is the MAIN reason ..... has not used taxis at all over the last 12 months, or hasn't used them more often?

Do NOT read out. Tick one only.

because she/he doesn't need to ...... 1 ☐

they are too expensive .... 2 ☐

a taxi van with a hoist is not .... 3 ☐
always available when you need it

because you need to book in .... 4 ☐
advance

other reason - specify .... 5 ☐

43. Have you heard of the Total Mobility Scheme? The Scheme gives people who have a disability, taxi vouchers which entitle them to a discount on their taxi fares.

yes .... 1 ☐ ➡ **GO TO 44**

no .... 2 ☐ ➡ **GO TO 45**

44. Has ..... used Total Mobility taxi vouchers in the last 12 months?

yes .... 1 ☐
no .... 2 ☐

45. (Apart from the Total Mobility Scheme)
In the last 12 months have you had any financial help from a government agency with transport costs because of .....'s condition or health problem?

yes .... 1 ☐
no .... 2 ☐
don't know .... 99 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ), ACC and AccessAble/Enable NZ.
Don't count special transport provided by the Ministry of Education.

46. In the last 12 months, have you needed any financial help with transport costs because of .....'s condition or health problem, which you were not able to get?

yes .... 1 ☐ ➡ **GO TO 47**
no .... 2 ☐ ➡ **GO TO 48**

47. Why couldn't you get that:

Tick all that apply.

you applied for financial help and .. were not eligible? 1 ☐

you did not know you could apply .....2 for financial help or where to apply? ☐

or was there another reason? ....3 ☐
- specify

____

____

48. In the last 12 months, have you had transport costs because of .....'s condition or health problem that you have had to pay yourself without getting all the money back from a government agency or medical insurance? Don't count the cost of buying or modifying a vehicle.

yes .... 1 ☐
no .... 2 ☐

Section E - Accommodation

1. The next questions are about where ..... lives.

Because of her/his condition, does ..... use any special features to enter or leave her/his present home?

yes .... 1 ☐ ➡ **GO TO 2**
no .... 2 ☐ ➡ **GO TO 3**

2. Which special features does she/he use:

Tick all that apply.

easy-to-get-at driveways, ramps, ... 1 ☐
or street level entrances?

easy-to-get-at passenger .... 2 ☐
drop-off or pick-up areas?

elevator or lift devices? .... 3 ☐

widened doorways? .... 4 ☐

automatic or easy-to-open doors? ...... 5 ☐

hand rails at steps or doorway? .... 6 ☐

lever door handles? .... 7 ☐

or another special feature? .... 8 ☐
- specify

____

____

3. Does ..... **need** any special features to enter or leave her/his present home, which the home does not already have?

yes .... 1 ☐ ➡ **GO TO 4**
no .... 2 ☐ ➡ **GO TO 6**

4. Which special features does ..... need but not have?

Do NOT read list.
Tick all that apply.

easy-to-get-at driveways, ramps, ... 1 ☐
or street level entrances

easy-to-get-at passenger .... 2 ☐
drop-off or pick-up areas

elevator or lift devices .... 3 ☐

widened doorways .... 4 ☐

automatic or easy-to-open doors ...... 5 ☐

hand rails at steps or doorway .... 6 ☐

lever door handles .... 7 ☐

other - specify .... 8 ☐

____

____

5. Why doesn't the home have this/these features for ..... :

Tick all that apply.

you did not know the feature .... 1 ☐
existed?

you do not know where to get it? ...... 2 ☐

it is only needed occasionally? .... 3 ☐

.....'s condition is not serious .... 4 ☐
enough?

it is too costly or you cannot .... 5 ☐
afford it?

you applied for financial help but ...... 6 ☐
were not eligible?

you did not know you could apply ..... 7 ☐
for financial help or where to apply?

the landlord is not willing? .... 8 ☐

another reason? - *specify* .... 9 ☐

____

____

6. Because of her/his condition, does ....'s home have any special features inside?
Count ONLY things attached to the house.
Don't count portable household equipment or appliances, such as shower stools.

yes .... 1 ☐ ➡ **GO TO 7**
no .... 2 ☐ ➡ **GO TO 8**

7. Which special features does she/he use:

Tick all that apply.

grab or hand rails? .... 1 ☐
elevator or lift device? .... 2 ☐
widened doorways or hallways? .... 3 ☐
visual or flashing alarms? .... 4 ☐
audio warning devices? .... 5 ☐
automatic or easy-to-open doors ...... 6 ☐ or windows?
lowered benches or sinks? .... 7 ☐
lowered switches or power points? ... 8 ☐
wet area shower? .... 9 ☐
easy-to-get-at toilet? .... 10 ☐
lever door handles? .... 11 ☐
emergency call system? .... 12 ☐
any other special features? - *specify* ... 13 ☐

____

____

8. *INTERVIEWER*
Has R answered "Yes" to either of Q.1 or Q.6?

yes .... 1 ☐ ➡ **GO TO 9**
no .... 2 ☐ ➡ **GO TO 12**

9. Were any of these special features or changes, either on the inside or outside of your home, introduced in the last 12 months?

yes .... 1 ☐ ➡ **GO TO 10**
no .... 2 ☐ ➡ **GO TO 12**

10. In the last 12 months, have you had a loan or grant from a government agency for alterations to ....'s home because of her/his condition or health problem?

yes .... 1 ☐
no .... 2 ☐

Government agencies include Ministry of Health services (functions formerly performed by Health Funding Authority), Department of Work and Income New Zealand (WINZ), ACC and AccessAble/Enable NZ.
Don't count grants from the Lottery Grants Board.

11. In the last 12 months, have you had to pay for alterations needed to ....'s home because of her/his condition or health problem, without getting all the money back from a government agency or medical insurance?

yes .... 1 ☐
no .... 2 ☐

12. Does .... **need** any special features inside her/his home which the home does not already have?
Count ONLY things attached to the house.
Don't count portable household equipment or appliances, such as shower stools.

yes .... 1 ☐ ➡ **GO TO 13**
no .... 2 ☐ ➡ **GO TO F on page 23**

13. What are the special features which ..... needs but does not have?

Do NOT read list.
Tick all that apply.

grab or hand rails .... 1 ☐
elevator or lift device .... 2 ☐
widened doorways or hallways .... 3 ☐
visual or flashing alarms .... 4 ☐
audio warning devices........................ 5 ☐
automatic or easy-to-open doors or windows .... 6 ☐
lowered benches or sinks .... 7 ☐
lowered switches or power points ...... 8 ☐
wet area shower................................. 9 ☐
easy-to-get-at toilet .... 10 ☐
lever door handles............................ 11 ☐
emergency call system .... 12 ☐
other - specify....................................... 13 ☐

____

____

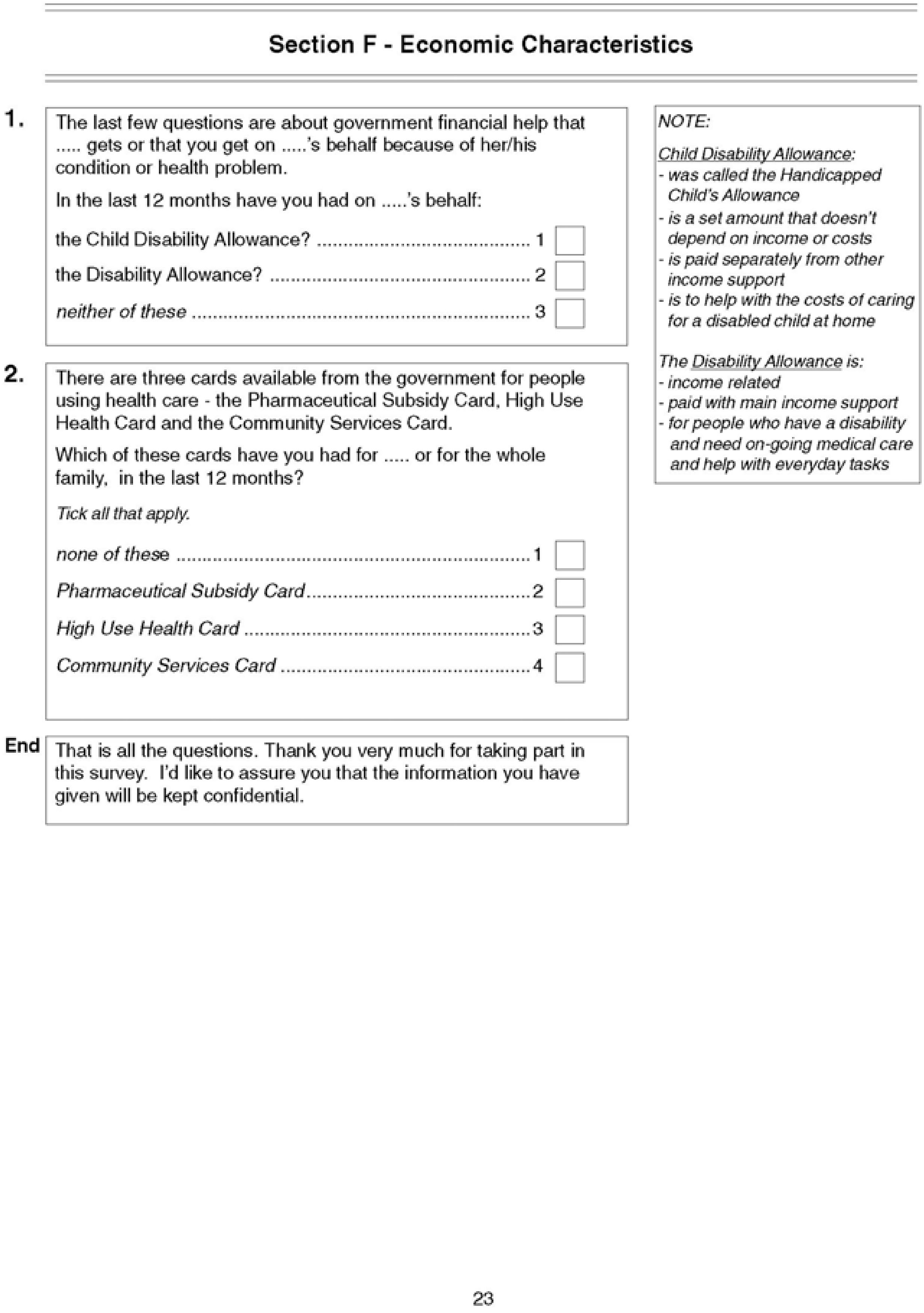
14. Why doesn't the home have this/these features for ..... :

Tick all that apply.

you did not know the feature existed? .... 1 ☐
you do not know where to get it? ....2 ☐
it is only needed occasionally? ....3 ☐
.....'s condition is not serious enough? .... 4 ☐
it is too costly or you cannot afford it? ....5 ☐
you applied for financial help but were not eligible? ....6 ☐
you did not know you could apply for financial help or where to apply? ....7 ☐
the landlord is not willing? ....8 ☐
other reason? - *specify*........................... 9 ☐

____

____



Section F - Economic Characteristics

1. The last few questions are about government financial help that ..... gets or that you get on .....'s behalf because of her/his condition or health problem.

In the last 12 months have you had on .....'s behalf:

the Child Disability Allowance? .... 1 ☐

the Disability Allowance? .... 2 ☐

neither of these .... 3 ☐

NOTE:

Child Disability Allowance:
- *was called the Handicapped Child's Allowance*
- *is a set amount that doesn't depend on income or costs*
- *is paid separately from other income support*
- *is to help with the costs of caring for a disabled child at home*

The Disability Allowance is:
- *income related*
- *paid with main income support*
- *for people who have a disability and need on-going medical care and help with everyday tasks*

2. There are three cards available from the government for people using health care - the Pharmaceutical Subsidy Card, High Use Health Card and the Community Services Card.

Which of these cards have you had for ..... or for the whole family, in the last 12 months?

Tick all that apply.

none of these .... 1 ☐

Pharmaceutical Subsidy Card .... 2 ☐

High Use Health Card .... 3 ☐

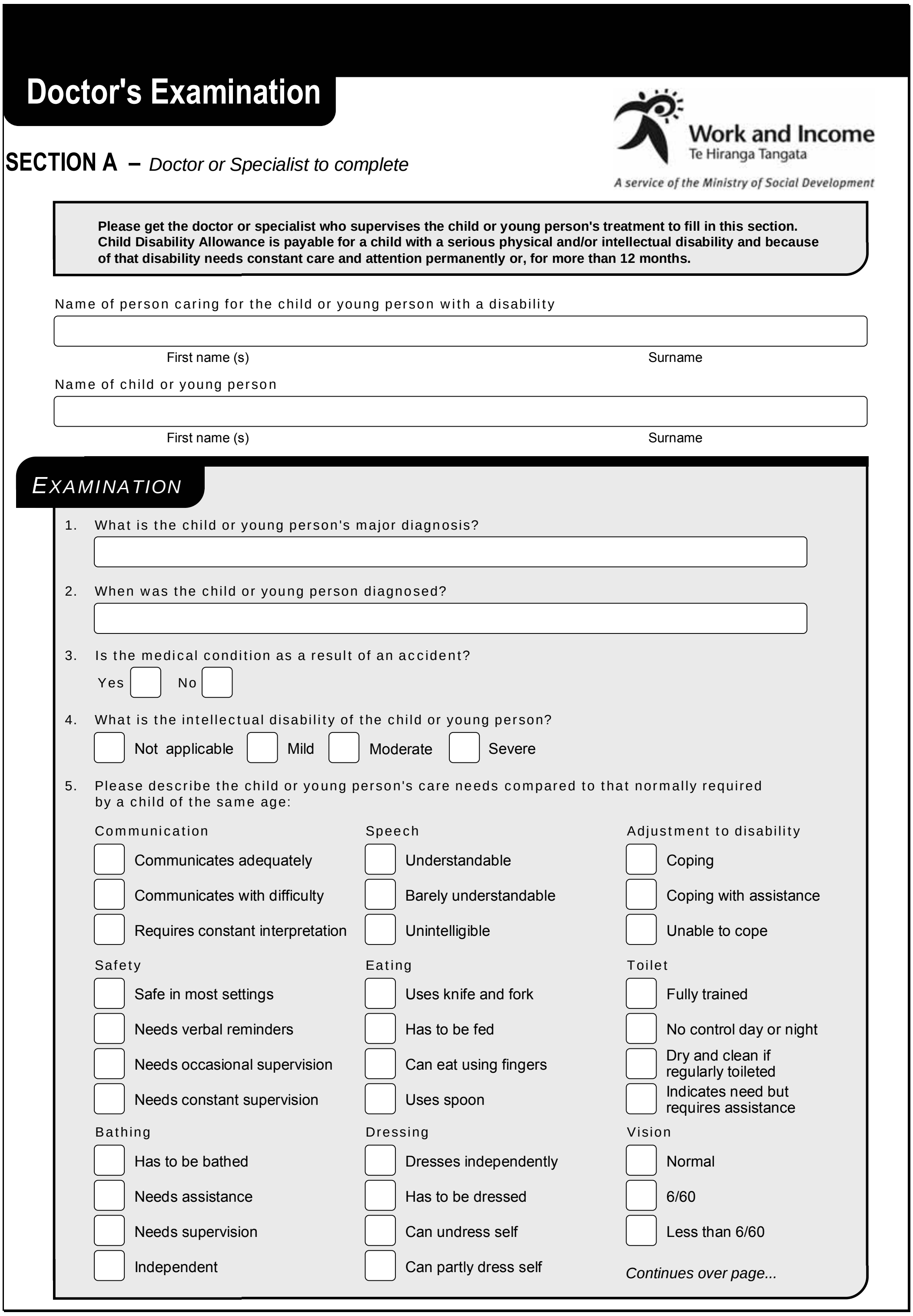
Community Services Card .... 4 ☐

End That is all the questions. Thank you very much for taking part in this survey. I'd like to assure you that the information you have given will be kept confidential.

Appendix C: Further information on the Child Disability Allowance

Child Disability Allowance application form

Slide 1



Doctor's Examination

Work and Income
Te Hiranga Tangata
A service of the Ministry of Social Development

SECTION A – *Doctor or Specialist to complete*

Please get the doctor or specialist who supervises the child or young person's treatment to fill in this section. Child Disability Allowance is payable for a child with a serious physical and/or intellectual disability and because of that disability needs constant care and attention permanently or, for more than 12 months.

Name of person caring for the child or young person with a disability

First name (s) Surname

Name of child or young person

First name (s) Surname

EXAMINATION

1. What is the child or young person's major diagnosis?

2. When was the child or young person diagnosed?

3. Is the medical condition as a result of an accident?

   Yes ☐ No ☐

4. What is the intellectual disability of the child or young person?

   ☐ Not applicable ☐ Mild ☐ Moderate ☐ Severe

5. Please describe the child or young person's care needs compared to that normally required by a child of the same age:

Communication
- ☐ Communicates adequately
- ☐ Communicates with difficulty
- ☐ Requires constant interpretation

Speech
- ☐ Understandable
- ☐ Barely understandable
- ☐ Unintelligible

Adjustment to disability
- ☐ Coping
- ☐ Coping with assistance
- ☐ Unable to cope

Safety
- ☐ Safe in most settings
- ☐ Needs verbal reminders
- ☐ Needs occasional supervision
- ☐ Needs constant supervision

Eating
- ☐ Uses knife and fork
- ☐ Has to be fed
- ☐ Can eat using fingers
- ☐ Uses spoon

Toilet
- ☐ Fully trained
- ☐ No control day or night
- ☐ Dry and clean if regularly toileted
- ☐ Indicates need but requires assistance

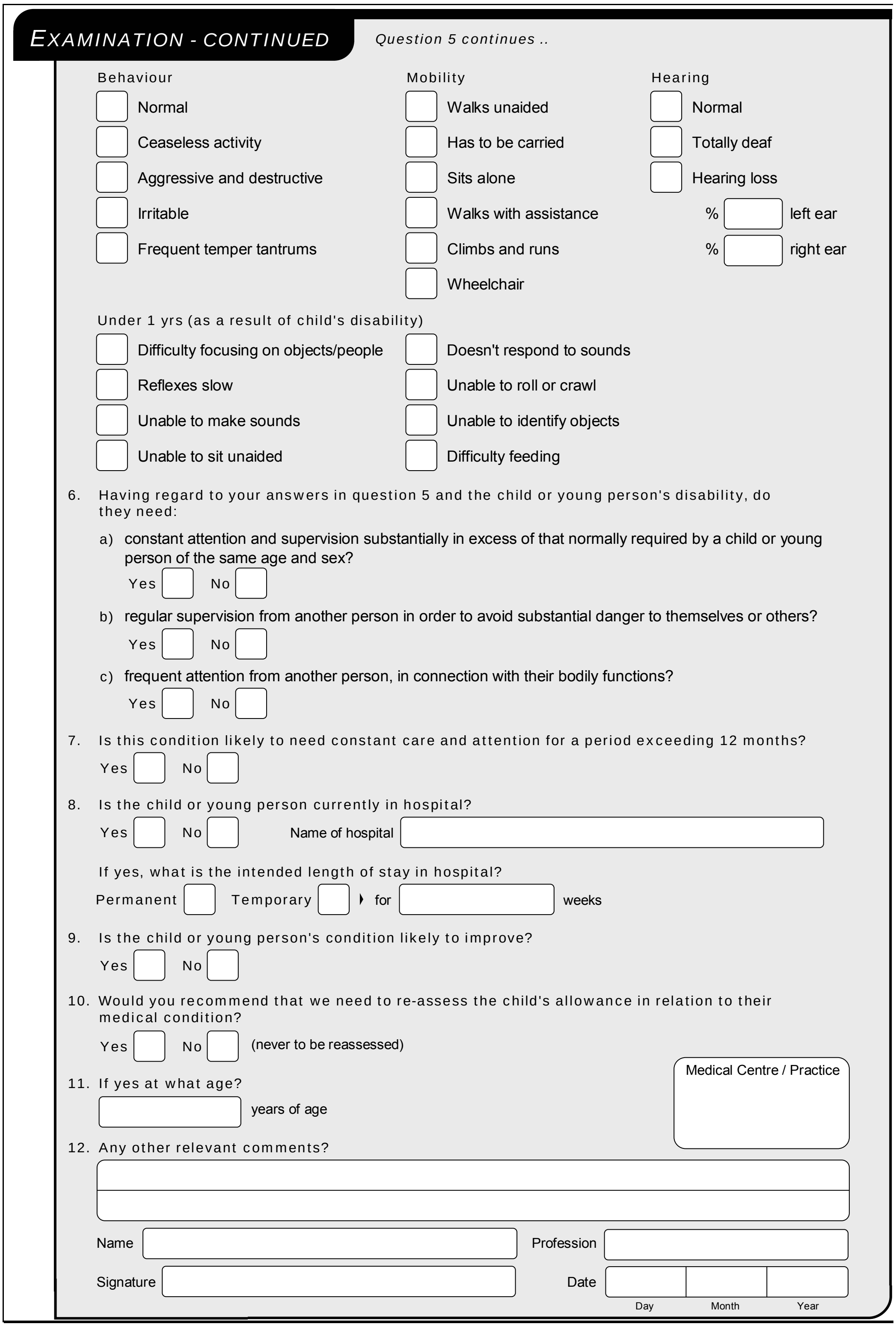
Bathing
- ☐ Has to be bathed
- ☐ Needs assistance
- ☐ Needs supervision
- ☐ Independent

Dressing
- ☐ Dresses independently
- ☐ Has to be dressed
- ☐ Can undress self
- ☐ Can partly dress self

Vision
- ☐ Normal
- ☐ 6/60
- ☐ Less than 6/60

Continues over page...

Slide 2



EXAMINATION - CONTINUED Question 5 continues ..

Behaviour
- ☐ Normal
- ☐ Ceaseless activity
- ☐ Aggressive and destructive
- ☐ Irritable
- ☐ Frequent temper tantrums

Mobility
- ☐ Walks unaided
- ☐ Has to be carried
- ☐ Sits alone
- ☐ Walks with assistance
- ☐ Climbs and runs
- ☐ Wheelchair

Hearing
- ☐ Normal
- ☐ Totally deaf
- ☐ Hearing loss
- % ☐ left ear
- % ☐ right ear

Under 1 yrs (as a result of child's disability)
- ☐ Difficulty focusing on objects/people
- ☐ Reflexes slow
- ☐ Unable to make sounds
- ☐ Unable to sit unaided
- ☐ Doesn't respond to sounds
- ☐ Unable to roll or crawl
- ☐ Unable to identify objects
- ☐ Difficulty feeding

6. Having regard to your answers in question 5 and the child or young person's disability, do they need:

a) constant attention and supervision substantially in excess of that normally required by a child or young person of the same age and sex?
Yes ☐ No ☐

b) regular supervision from another person in order to avoid substantial danger to themselves or others?
Yes ☐ No ☐

c) frequent attention from another person, in connection with their bodily functions?
Yes ☐ No ☐

7. Is this condition likely to need constant care and attention for a period exceeding 12 months?
Yes ☐ No ☐

8. Is the child or young person currently in hospital?
Yes ☐ No ☐ Name of hospital ☐

If yes, what is the intended length of stay in hospital?
Permanent ☐ Temporary ☐ for ☐ weeks

9. Is the child or young person's condition likely to improve?
Yes ☐ No ☐

10. Would you recommend that we need to re-assess the child's allowance in relation to their medical condition?
Yes ☐ No ☐ (never to be reassessed)

11. If yes at what age?
☐ years of age

Medical Centre / Practice

12. Any other relevant comments?

Name ☐ Profession ☐

Signature ☐ Date ☐ ☐ ☐

Day Month Year

Words related to physical disabilities appearing on the application form

The following information expands on results of the analysis of words that appeared in 24,000 Child Disability Allowance (CDA) application forms, further to the overview given in Section 1.3.

In the free fields of the 24,000 CDA applications forms analysed, the 215 most commonly used words (omitting words such as 'and' and 'of') included only 29 that appear to relate to possible physical disability. These words (with the number of forms on which they are mentioned in brackets) included: palsy (846), palsey (52), spastic (167), hemiplegia (132), diplegia (56), talipes (122), hydrocephalus (117), muscular (115), dystrophy (92), arthritis (72), juvenile (probably chronic juvenile arthritis) (66), dysplasia (70), hip (81), physical (63), deformity (62), leg (56), gross (probably as in gross motor) (63), physical (63), spinal (54), dyspraxia (328), club (251), motor (249), spina (210), spinal (54), and bifida (194).

In addition, it is reasonable to expect that a fair proportion of premature babies go on to develop a disability with a physical component. The following words relate to children who were born prematurely: prematurity (153) and premature (59). 'Multiple', which was mentioned 139 times, may relate to multiple disabilities, where a physical component could well be inferred.

Four further potentially relevant terms concerned cleft lip and palate, which may be related to physical difficulties with communication and feeding. Related terms were mentioned as follows: cleft (271), lip (114), palate (204) and feeding (77).

If we only look at the applications containing a medical term that suggests physical disability, the number of children and young people affected appears to be somewhere between 1,000 and 2,600. A more precise estimate within this range depends on a best guess of whether some children and young people had several of the terms on one application form. Thus muscular (115) and dystrophy (92) probably referred to a maximum of 115 children and young people with a possible physical disability, rather than to over 200.

Appendix D: Further data on children and young people with a disability due to an accident

Education-based rehabilitation: Summary of issues highlighted in the serious injury satisfaction survey[33]

The serious injury satisfaction survey is a face-to-face interview carried out by an independent research firm on an annual basis which provides seriously injured claimants and their support people with an opportunity to indicate their degree of satisfaction with the Accident Compensation Corporation (ACC) in terms of:

- the application process
- the information provided
- the services received.

This year the survey included questions relating to education-based rehabilitation for the first time. The respondents were 23 main support people of school-age children, and the key findings are summarise below.

Type of class

- Twelve children were in regular classes.
- Nine children were in a specialised unit.
- Two children were in a setting classified as ‘other’ (no further details provided).

Assessments

Injury-related needs

- Sixteen respondents agreed that the assessment accurately identified their child’s injury-related needs.
- Four respondents disagreed with the above statement.
- No information was provided for the remaining three respondents.

Personal care needs during the school day

- Twelve respondents agreed that the assessment accurately identified their child’s personal care needs during the school day.
- Six respondents disagreed with the above statement.
- No information was provided for the remaining five respondents.

Outside organisations

- There were some concerns in relation to assessments being completed by outside organisations who were not familiar with the children concerned.

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[33] Source: ACC

Education-based rehabilitation

Teacher aides

- Seventeen respondents agreed that the teacher aide service was the most appropriate way to meet their child's injury-related needs.
- Four respondents disagreed with the above statement and felt that more specialised care, information and flexibility were required.
- Two respondents were unsure.

Problems experienced

- Eight respondents had experienced problems with education-based rehabilitation services, including lack of or delays in assessments being undertaken, insufficient support for their children during the school day, or ineligibility for special funding.
- Fifteen respondents had not experienced any problems.

Suggested improvements

- The areas where improvements were suggested included:
  - improved communication and co-ordination between the parties concerned
  - an improved assessment process
  - additional teacher aide hours
  - additional equipment (e.g. computer)
  - more flexible criteria for education-based rehabilitation.
- Eight respondents were unsure or did not have any suggestions.

Cause of accident, by age at accident, for children and young people with physical disabilities

Further to the overview given in Section 1.5, the following data (abstracted in July 2002) expand on ACC database information concerning the causes of accidents that resulted in a physical disability, and the age at which these accidents occurred.

Table D1: Causes of accidents resulting in disability, by age

Cause of accident	Age at accident (years)			
	0–5	6–10	11–17	Total
Medical treatment	118	12	3	133
Other or unclear cause	75	16	9	100
Other loss balance / personal control	45	20	13	78
Collision with / knocked over by object	25	21	5	51
Other loss of control of vehicle	18	8	14	40
Struck by person/animal	21	6	2	29
Loss of hold	13	1	1	15
Tripping or stumbling	10	3	2	15
Slipping, skidding on foot	5	5	4	14
Fire	9	2	1	12
Swerving / evasive action	5	2	1	8
Boiling (violent and inadvertent)	6			6
Other collapse/overturning/inundation	1	2	3	6
Pushed or pulled	3	2	1	6
Driving into hole/object/animal/etc	3	1		4
Criminal act	2	1		3
Flooding/overflow/escape of liquid	3			3
Object coming loose / goods shifting	2		1	3
Skid	1	1	1	3
(Blank)		1	3	4
Explosion/blasting/implosion	1	1		2
Exposure to elements	1	1		2
Lifting/carrying/strain	1		1	2
Other or unclear fire or explosion	1		1	2
Recoil/ejection	2			2
Struck by hand-held tool/implement	1	1		2
Work property or characteristics		2		2
Bursting/breakage/distortion	1			1
Electrical shock/short circuit		1		1
Inadvertent machine/vehicle movement	1			1
Loss of consciousness / sleep / giddy	1			1
Lurching / jerks in vehicles, etc	1			1
Mechanical malfunction	1			1
Misjudgement of support	1			1
Puncture	1			1
Shooting			1	1
Something giving way underfoot	1			1
Total	380	110	67	557

Appendix E: Number of ORRS-funded students per 1,000 population in each territorial local authority, 2000

The following data were used to generate the figures on ORRS funding per 1,000 population that are reported in Section 1.6.

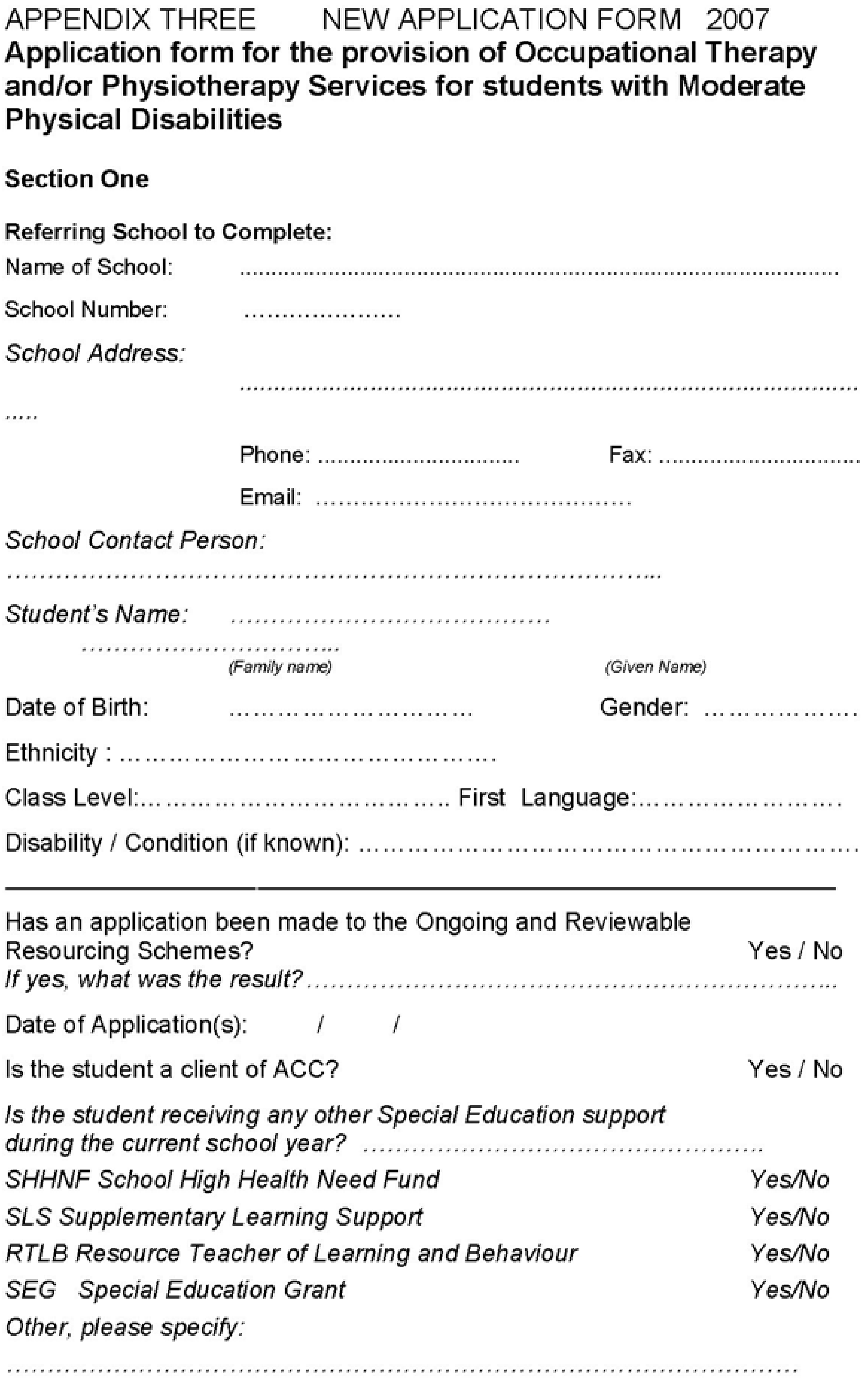
Table E1: Rate of ORRS-funded students, by territorial local authority

Territorial local authority (TLA)	Total ORRS per 1,000	Male ORRS per 1,000	Female ORRS per 1,000
Far North District	5.23	6.04	4.37
Whangarei District	10.08	11	9.12
Kaipara District	5.45	7.22	3.57
Rodney District	5.40	6.13	4.63
North Shore City	7.33	8.56	6.04
Waitakere City	15.56	18.34	12.65
Auckland City	11.48	13.58	9.27
Manukau City	7.15	8.15	6.11
Papakura District	11.27	13.87	8.51
Franklin District	7.86	10.50	5.04
Thames–Coromandel District	5.08	6.45	3.64
Hauraki District	11.74	12.84	11.27
Waikato District	3.95	4.86	2.96
Matamata–Piako District	7.62	7.76	7.49
Hamilton City	14.81	17.39	12.17
Waipa District	4.38	5.61	3.09
Otorohanga District	11.94	12.85	10.96
South Waikato District	10.76	11.81	9.65
Waitomo District	6.59	10.50	2.63
Taupo District	8.25	9.43	7.05
Western Bay of Plenty District	6.91	7.82	5.93
Tauranga District	9.35	11.24	7.36
Rotorua District	10.42	12.69	8.02
Whakatane District	10.77	11.65	9.85
Kawerau District	7.84	10.13	5.43
Opotiki District	5.04	6.50	3.49
Gisborne District	9.43	10.03	8.81
Wairoa District	7.96	11.40	4.42
Hastings District	7.67	8.40	6.90
Napier City	11.42	13.95	8.824
Central Hawke's Bay District	5.29	5.58	4.94
New Plymouth District	10.32	11.98	8.57
Stratford District	12.45	16.19	8.62
South Taranaki District	5.98	7.59	4.18
Ruapehu District	14.87	12.28	17.84

Wanganui District	10.87	12.67	8.96
Rangitikei District	4.28	6.01	2.39
Manawatu District	4.87	6.29	3.32
Palmerston North City	11.99	14.29	9.73
Tararua District	6.58	4.49	8.88
Horowhenua District	7.88	10.11	5.56
Kapiti Coast District	6.45	8.47	4.42
Porirua City	9.25	13.22	4.98
Upper Hutt City	8.15	9.35	6.82
Lower Hutt City	8.51	9.68	7.27
Wellington City	10.24	12.15	8.32
Masterton District	14.16	14.97	13.31
Carterton District	4.78	4.03	5.64
South Wairarapa District	4.03	5.57	2.36
Tasman District	11.90	10.73	13.13
Nelson City	10.06	12.49	7.50
Marlborough District	6.48	6.66	6.29
Kaikoura District	7.58	9.34	5.60
Buller District	4.43	6.41	2.11
Grey District	3.99	5.82	2.18
Westland District	4.50	5.06	3.90
Hurunui District	2.39	3.77	0.96
Waimakariri District	6.26	8.19	4.23
Christchurch City	13.13	15.94	10.22
Banks Peninsula District	3.71	4.32	3.04
Selwyn District	3.44	3.86	2.98
Ashburton District	9.09	10.89	7.09
Timaru District	8.55	11.59	5.34
Mackenzie District	7.00	7.93	5.74
Waimate District	4.15	5.08	3.00
Chatham Islands District	14.49	10.75	15.87
Waitaki District	10.74	14.59	6.42
Central Otago District	4.36	4.82	3.81
Queenstown-Lakes District	4.77	4.37	5.16
Dunedin City	9.71	12.61	6.78
Clutha District	7.03	9.46	4.17
Southland District	3.44	3.21	3.71
Gore District	4.41	6.35	2.28
Invercargill City	13.66	16.80	10.44
Area outside TLA	4,060.61	5,444.44	2,000
Total NZ by TLA/area unit	9.61	11.38055	7.750068

Appendix F: Students with moderate physical disabilities application form

The application form for students with moderate physical disabilities is available at www.minedu.govt.nz/index.cfm?layout=document&documentid=12279&data=l



APPENDIX THREE NEW APPLICATION FORM 2007

Application form for the provision of Occupational Therapy and/or Physiotherapy Services for students with Moderate Physical Disabilities

Section One

Referring School to Complete:

Name of School: ....

School Number: …………………

School Address:

……………………………………………………………………………………

.....

Phone: .... Fax: ....

Email: ……………………………………

School Contact Person:

……………………………………………………………………...

Student's Name: …………………………………

…………………………...

(Family name) *(Given Name)*

Date of Birth: ………………………… Gender: ……………….

Ethnicity : …………………………………………….

Class Level:……………………………….. First Language:…………………….

Disability / Condition (if known): ……………………………………………………….

Has an application been made to the Ongoing and Reviewable Resourcing Schemes? Yes / No

If yes, what was the result?……………………………………………………...

Date of Application(s): / /

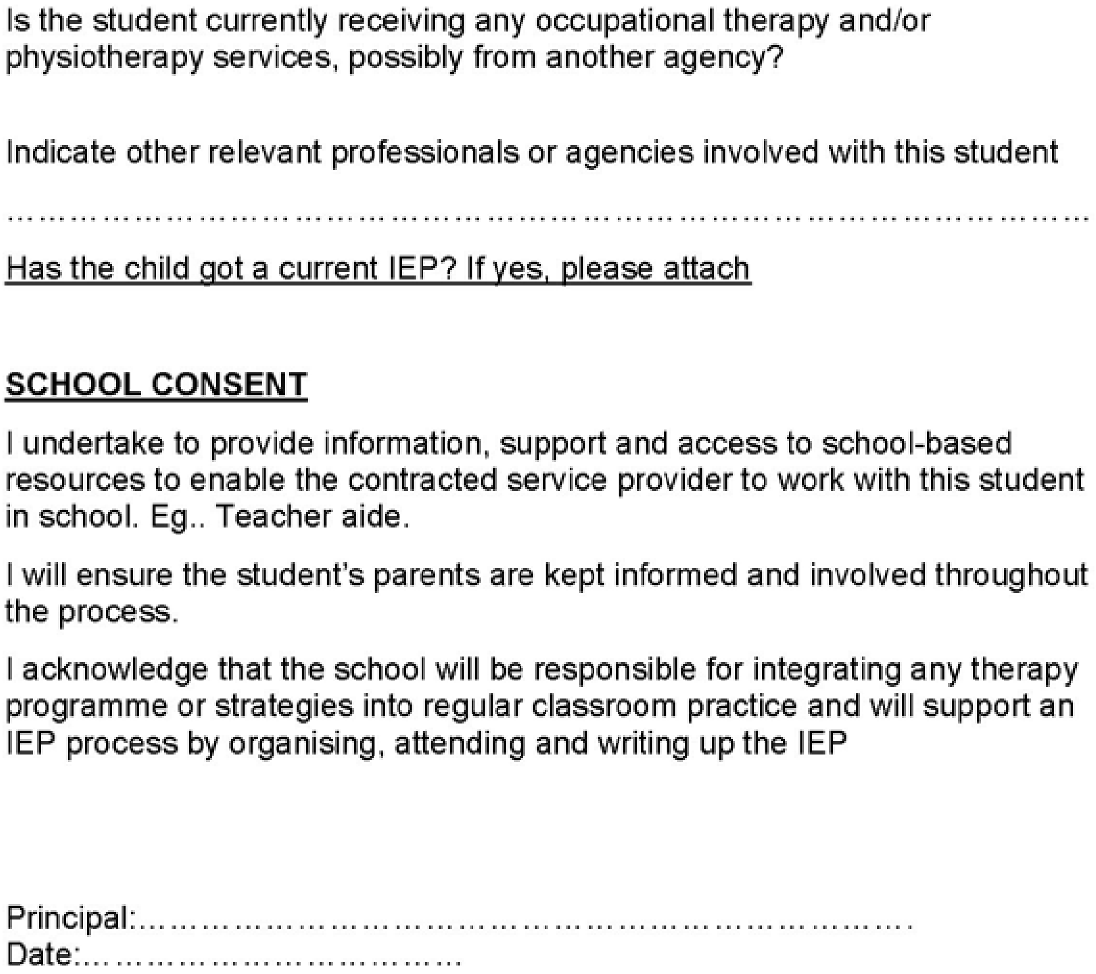
Is the student a client of ACC? Yes / No

Is the student receiving any other Special Education support during the current school year? …………………………………………….

SHHNF School High Health Need Fund	*Yes/No*
SLS Supplementary Learning Support	*Yes/No*
RTLB Resource Teacher of Learning and Behaviour	*Yes/No*
SEG Special Education Grant	*Yes/No*

Other, please specify:

……………………………………………………………………………………



Is the student currently receiving any occupational therapy and/or physiotherapy services, possibly from another agency?

Indicate other relevant professionals or agencies involved with this student

……………………………………………………………………………………………………

Has the child got a current IEP? If yes, please attach

SCHOOL CONSENT

I undertake to provide information, support and access to school-based resources to enable the contracted service provider to work with this student in school. Eg.. Teacher aide.

I will ensure the student's parents are kept informed and involved throughout the process.

I acknowledge that the school will be responsible for integrating any therapy programme or strategies into regular classroom practice and will support an IEP process by organising, attending and writing up the IEP

Principal:…………………………………………………………………….
Date:………………………………

Parent/Caregiver to Complete:

What concerns do you have regarding your child's participation and learning related to their physical skills?
....
....
....
....
....
....

Which of these concerns would you consider priority for therapy support?..
....
....
....
....
....

I give consent for this application to be made on behalf of my son / daughter. I agree to a therapist visiting my child in their classroom and consulting with their teacher for the purpose of determining eligibility for services.
(Name of student)……………………………………………………………………….
Student's Home Contact Details:
....
....

I give permission for the Ministry of Education or their contracted service providers to have access to information regarding
……………………………………………………………………*(name of student).*

This information is being collected by the Ministry of Education. The information is collected for the purpose of providing services to meet the special educational needs of students. The collected information may also be used for statistical and research purposes but if used in this way the information will be in a form that means the individual person is not able to be identified. None of the information concerning any individual will be passed on to any other agency without the permission of the individual concerned. Any individual about whom the information is collected is able to access the information and has the right of correction in relation to that information.

Parent/Caregiver Name: ……………………………………………………………..
Parent/Caregiver Signature:……………………………………………………….
Date: …………………………………………………………………………………
Phone number:………………………………………………………………………
Email:…………………………………………………………………………………

TEACHERS:

Within the context of the National Curriculum framework, please consider how the student's physical impairment impacts on their participation and learning in each curriculum area

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For this student which issues would you like the therapist support to focus on?

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Describe how the student:

1. Moves around the school environment (eg. in class, accessing the desk, steps, through doors, transitioning between areas/classes, recreational movement(games and playground). Please comment on any equipment/aids used

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2. Uses materials and tools for learning eg. writing tools and materials, art material, technology, maths equipment. Describe any adaptations made to tools or material

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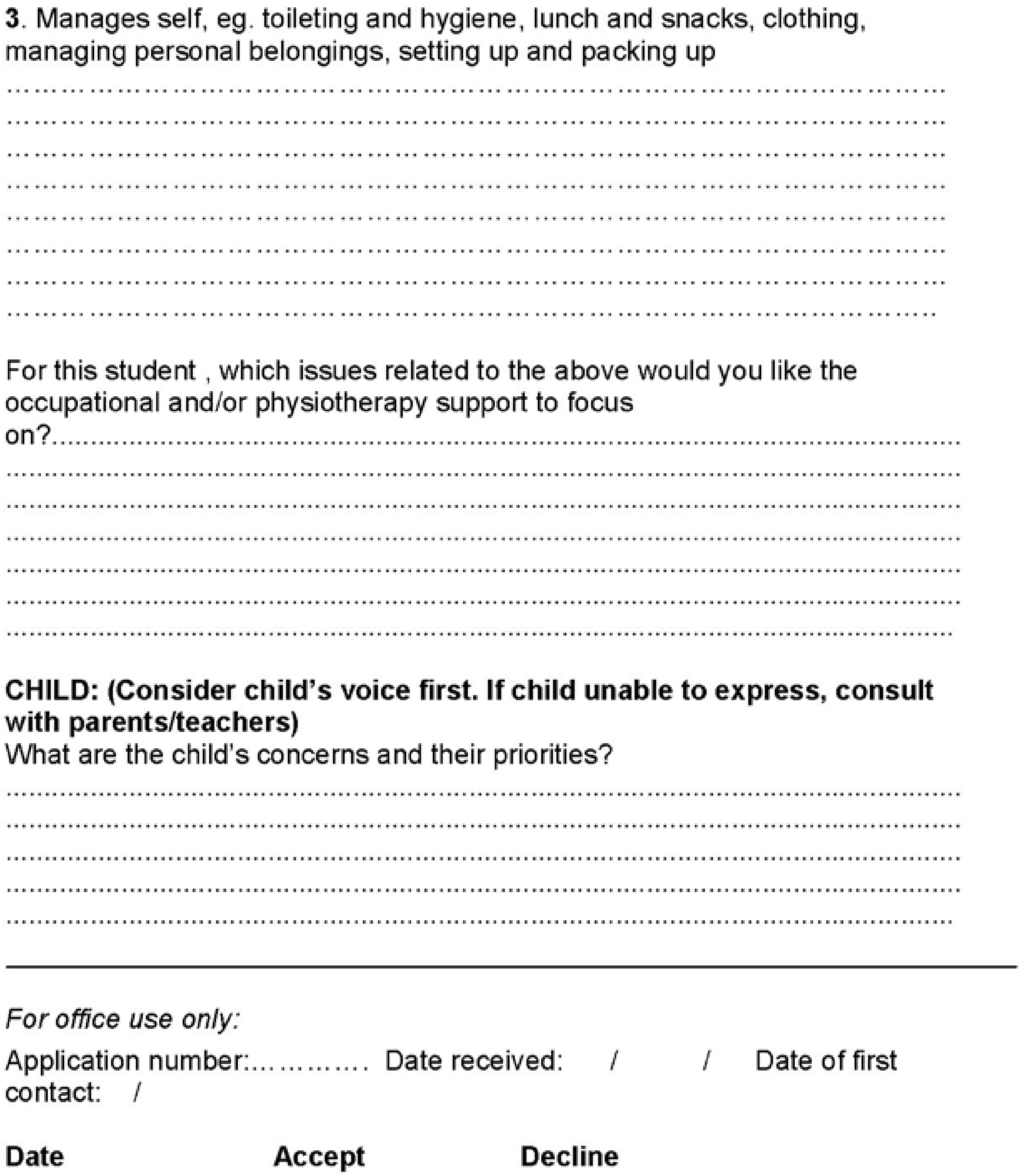

3. Manages self, eg. toileting and hygiene, lunch and snacks, clothing, managing personal belongings, setting up and packing up

……………………………………………………………………………………………
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For this student , which issues related to the above would you like the occupational and/or physiotherapy support to focus on?..

....
....
....
....
....
....

CHILD: (Consider child's voice first. If child unable to express, consult with parents/teachers)
What are the child's concerns and their priorities?

....
....
....
....
....

For office use only:

Application number:…………. Date received: / / Date of first contact: /

Date **Accept** **Decline**

Appendix G: Questionnaire used in survey of schools

Cover letter 1

National Office
Group Special Education
45-47 Pipitea Street
Thorndon
P O Box 1666
Wellington
New Zealand

Phone: 0-4-463 8000
Direct: 04 463 8260
Fax: 04 463 8254
www.minedu.govt.nz

24 June 2003

«Name»
«Title»
«Organisation»
«Address_1»
«Address_2»
«Address_3»
☐
Dear «Title»

Research on resourcing for students with physical disabilities

I am writing to ask you to complete the enclosed questionnaire from Dr Phillipa Clark of the University of Auckland. It is part of a research project that has been commissioned by the Ministry of Education, through the Advisory Reference Group for Students with Physical Disabilities. The Reference Group's brief includes promoting and supporting robust research into effective integrated teaching, learning and therapy practices so that children and young people with physical disabilities successfully overcome barriers to learning and develop their potential to participate effectively in life.

Dr Clark's research project is designed to obtain and synthesise the available information on the distribution of resources/funding streams for children and young people with physical disabilities, and the quantum of resourcing on a national/regional basis. The questionnaire mainly deals with the provision of therapy services to enrolled students in your school. It is closely linked to another research project contracted by the Reference Group to the Donald Beasley Institute at Dunedin on case studies of integrated effective service provision for children and young people with physical disabilities. Both projects build on an earlier scoping report commissioned by the Reference Group and published in April last year (**www.educationcounts.govt.nz/publications/special_education/15734**).

I strongly encourage you complete the questionnaire – it will provide important information that will be a foundation for the Ministry to make well-informed decisions about future resourcing for students with physical disabilities.

If you have any questions about the research project, please contact Dr Clark (**p.clark@auckland.ac.nz)**, Melissa Weenink of the Ministry's Research Division (**melissa.weenink@minedu.govt.nz)**, or myself (**joanna.curzon@minedu.govt.nz)**.

Kind regards

Joanna Curzon
Senior Adviser, Group Special Education

Cover letter 2

24 June 2003

National Office
Group Special Education
45-47 Pipitea Street
Thorndon
P O Box 1666
Wellington
New Zealand

Phone: 0-4-463 8000
Direct: 04 463 8260
Fax: 04 463 8254
www.minedu.govt.nz

«Name»
«Title»
«Organisation»
«Address_1»
«Address_2»
«Address_3»

Dear «Title»

Research on resourcing for students with physical disabilities

I am writing to ask you to complete the enclosed questionnaire from Dr Phillipa Clark of the University of Auckland. It is part of a research project that has been commissioned by the Ministry of Education through the Advisory Reference Group for Students with Physical Disabilities. The Reference Group's brief includes promoting and supporting robust research into effective integrated teaching, learning and therapy practices so that children and young people with physical disabilities successfully overcome barriers to learning and develop their potential to participate effectively in life.

Schools and units like yours, which are receiving additional resourcing support for students with physical disabilities (the so-called Three Year Package), agreed to participate in research and evaluation of effective therapy practice as a condition of receiving this additional support.

Dr Clark's research project is designed to obtain and synthesise the available information on the distribution of resources/funding streams for children and young people with physical disabilities, and the quantum of resourcing on a national/regional basis. It is closely linked to another research project contracted by the Reference Group to the Donald Beasley Institute at Dunedin on case studies of integrated effective service provision for children and young people with physical disabilities. Both projects build on an earlier scoping report commissioned by the Reference Group and published in April last year **(**www.educationcounts.govt.nz/publications/special_education/15734**).**

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If you have any questions about the research project, please contact Dr Clark (p.clark@auckland.ac.nz), Melissa Weenink of the Ministry's Research Division (melissa.weenink@minedu.govt.nz), or myself (joanna.curzon@minedu.govt.nz).

Kind regards

Joanna Curzon
Senior Adviser, Group Special Education

Appendix H: Summary of case study sites and students

Schools with therapy provision on site

Table H1: Self-contained school

SCHOOL	
Type and level	Self-contained special school; year 1–
Decile	1
FOCUS STUDENT: Simon	
Age / year at school	18 years / year 14
Disability	Cerebral palsy (spastic diplegia), epilepsy, learning disability; uses wheelchair
Funding stream and level	ORRS very high need
Supports (at school)	Specialist teacher, teacher aide, special education assistant, PT, OT, SLT, music teacher. Cost of these services = $11,500 plus teacher component.
Supports (itinerant)	
Transport	Taxi funded by Ministry of Education
FOCUS STUDENT: Selena	
Age / year at school	12.8 years / year 9
Disability	Physical and learning disability, scoliosis; uses wheelchair
Funding stream and level	ORRS, very high needs
Supports (at school)	Specialist teacher, teacher aide, special education assistant, PT, OT, SLT, music teacher. Cost of these services = $11,500 plus teacher component.
Supports (itinerant)	–
Transport	–

Table H2: Secondary school with an attached unit

SCHOOL	
Type and level	Secondary school with attached unit – **u**nit has **transitional funding;** years 9–13
Decile	6
FOCUS STUDENT: Heather	
Age / year at school	14 years / year 10
Disability	Cerebral palsy, learning needs; uses wheelchair, learning to use power chair
Funding stream and level	ORRS, high needs
Supports (at school)	Teacher aide, physiotherapy 2 x week (swimming at the public pool, and PT in the unit), OT support approx. 2 x week for writing and positioning, independent living, independent mobility
Supports (itinerant)	
Transport	Taxi funded by Ministry of Education
Other	Combined programme in regular classes and unit, adapted curriculum, home-care support
FOCUS STUDENT: Harry	
Age / year at school	16 years / year 12
Disability	Spinal bifida; uses wheelchair independently
Funding stream and level	ORRS, high needs
Supports (at school)	Teacher aide in study lines, OT and PT 3 x week, primarily in the unit
Supports (itinerant)	–
Transport	Taxi funded by Ministry of Education
Other	Education is in regular classroom, and regular curriculum

Table H3: Primary school with an attached unit (urban)

SCHOOL	
Type and level	Primary school with attached unit – unit has transitional funding. Years 1–8; 22 students on unit roll; unit staffing = 3 full-time teachers, 2.5 therapy positions, 22 full- or part-time teacher aides
Decile	2
FOCUS STUDENT: Penny	
Age / year at school	11 years / year 7
Disability	Spastic cerebral palsy, visual impairment, autism spectrum disorder; uses wheelchair independently
Funding stream and level	ORRS, funded as an 'over'
Supports (at school)	I hour per day integrated therapy in the unit
Supports (itinerant)	–
Transport	Private
Other	In regular class; home-care support
FOCUS STUDENT: Paul	
Age / year at school	8 years / year 4
Disability	Cerebral palsy, visual impairment, serious illness
Funding stream and level	ORRS, very high needs
Supports (at school)	Teacher aide support – 30 hours
Supports (itinerant)	
Transport	Taxi funded by Ministry of Education
Other	In unit full-time; private SLT paid for by parents

Table H4: Intermediate school with attached unit

SCHOOL	
Type and level	Intermediate with attached unit. Years 7 & 8; 31 students on unit roll (some in regular classes); unit has transitional funding; staffing = 3 teachers, 1.5 OT positions, part-time SLT, 1 full-time PT, one therapy assistant, several teacher aides and special ed. assistants.
Decile	3
FOCUS STUDENT: Isobel	
Age / year at school	12 years / year 8
Disability	Hemiplegia, seizures
Funding stream and level	ORRS, high needs
Supports (at school)	SLT: • 1 hour individual per week • 3 group oral-motor sessions per week. OT: • 45 mins per week 1:1 • community integration group 1 hour per week (with 7 others) for 2 terms PT: • 1 hour per week 1:1 per week • hydrotherapy 1 x per week. Counselling from teaching staff; RDA 1x per week; special ed. assistant and teacher aide support in class (aide shared between 4 students). Total cost = $10,250.
Supports (itinerant)	–
Transport	Taxi funded by Ministry of Education
Other	In unit full-time except for reading (in regular class); reads 2 years above chronological age
FOCUS STUDENT: Ian	
Age / year at school	11 years old / year 7
Disability	Cerebral palsy (spastic diplegia)
Funding stream and level	ORRS, high needs
Supports (at school)	Full-time teacher aide (shared with 3 other children); therapies provided mostly in school hours. PT: • 3 x weekly (individual) • 3 x weekly stretches • daily walking.

	OT: • monitoring assistive technology • assessing and prescribing Total cost of aide and therapy = $10,200
Supports (itinerant)	–
Transport	Taxi funded by Ministry of Education
Other	In regular class, academically very able; currently has weekly post-operative PT (health)

Schools with itinerant therapy provision

Table H5: Health-provided Child Development Service in a rural area

SCHOOL	
Type and level	Rural college; years 7–13
Decile	6
FOCUS STUDENT: Ricky	
Age / year at school	11 years / year 7
Disability	Low tone, unstable gait, poor motor and visual-perceptual development, post-accident skin grafts, behavioural and social challenges
Funding stream	Health funding for in-school OT
Supports (at school)	Post-accident ACC-funded teacher aide time of 12.5 hrs/week, now withdrawn
Supports (itinerant)	OT once every 3 weeks; RTLB consults with teacher; RDA in school time
Transport	Private
Other	Recent PT at home (result of parental advocacy)

SCHOOL	
Type and level	Rural primary; years 1–6
Decile	7
FOCUS STUDENT: Rose	
Age / year at school	6 years / year 2
Disability	Sensory integration and motor-planning problems; speech problems; ASD
Funding stream	No funding; turned down twice for ORRS high needs
Supports (at school)	Full-time teacher aide paid for by family ($3,500 per term); Health-funded OT
Supports (itinerant)	RTLB consults with teacher by telephone as needed
Transport	School bus – put on bus then met at school by mother
Other	At-home learning support from independent organisation (paid for by family)

Table H6: Health-provided Child Development Service in an urban area

SCHOOL	
Type and level	Local urban primary school; years 1–8
Decile	5
FOCUS STUDENT: Caitlin	
Age / year at school	8 / year 4
Disability	Cerebral palsy (spastic diplegia), visual perception and memory problems; receives Botox treatment
Funding stream and level	ORRS, medical high needs (following parental advocacy after being turned down for ORRS)
Supports (at school)	Teacher aide – 5 hrs per week for daily stretching and learning support; PT – 1 due to shortage of therapists; special needs teacher – 1.5 hrs for remedial maths in a group, additional time for writing a remedial reading programme, setting up social opportunities in playground
Supports (itinerant)	–
Transport	

SCHOOL	
Type and level	Local urban primary school; years 1–6
Decile	8
FOCUS STUDENT: Christopher	
Age / year at school	7 years / year 3
Disability	Cerebral palsy (spastic diplegia); receives Botox treatment
Funding stream and level	Recently approved for moderate contract for joint therapy; turned down 3 x for ORRS
Supports (at school)	Teacher aide for 1:1 reading 40 mins per week; RTLB consults with teacher for maths adaptation
Supports (itinerant)	1 hour every 2 weeks for joint OT/PT
Transport	Private

Table H7: GSE service providing itinerant services

SCHOOL	
Type and level	Rural area school; years 1–13
Decile	5
FOCUS STUDENT: Ashley	
Age / year at school	16 years / year 10 for a second year
Disability	Cerebral palsy, learning disability; uses a wheelchair and K-walker
Funding stream and level	ORRS, very high needs; $12,583
Supports (at school)	Correspondence school maths; CCS funding for support with eating at lunchtime; RDA in school time
Supports (GSE itinerant)	PT OT SLT Vision support – 6 x per year
Transport	School bus (no hoist)
Other	Home-care support
FOCUS STUDENT: Alan	
Age / year at school	10 years / year 6
Disability	Cerebral palsy, fine motor control problems
Funding stream and level	ORRS, high needs; $8,300
Supports (at school)	Teacher aide – 18 hours per week class support and community mobility support; 0.1 special education needs teacher for: • 1:1 reading support (daily) • stretching • programme assessment and planning. Special music – 1:1
Supports (GSE itinerant)	PT OT SLT Vision support – once a fortnight
Transport	School bus

Table H8: GSE service providing itinerant services

SCHOOL	
Type and level	Local rural primary; years 1–8
Decile	10
FOCUS STUDENT: Laura	
Age / year at school	12 years / year 8
Disability	Cerebral palsy affecting all parts of her body; uses a wheelchair
Funding stream and level	ORRS high needs; $6,760
Supports (at school)	Teacher aide – mornings only; school tops up from SEG to get this much; 0.1/0.2 teacher (principal) does specialist programming to support learning
Supports (GSE itinerant)	OT 2 x per term; PT 2 x per term
Transport	

SCHOOL	Rural primary
Type and level	Local rural primary; years 1–8
Decile	2
FOCUS STUDENT: Leah	
Age / year at school	8 years; year 4
Disability	Athetoid cerebral palsy; uses a wheelchair and Hart Walker
Funding stream and level	ORRS high needs; $10,584
Supports (at school)	Teacher aide – full-time, shared by 2 people
Supports (GSE itinerant)	OT PT SLT: very small amount 0.1/0.2 special education needs teacher (used flexibly by own class teacher)
Transport	Taxi funded by Ministry of Education

Notes to tables: ORRS = Ongoing and Reviewable Resourcing Schemes; PT = physiotherapy; OT = occupational therapy; SLT = speech-language therapy; GSE = Ministry of Education, Special Education; SEG = Special Education Grant; RTLB = Resource Teachers: Learning and Behaviour: ASD = Autism Spectrum Disorder; RDA = Riding for the Disabled Association

Appendix I: Brief for schools

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

INFORMATION BRIEF FOR POTENTIAL CASE STUDY SITES (SCHOOLS)

Background to the project

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather understandings which will contribute to improving policy and service provision for students with physical disabilities, their families and whānau.

The present study emerges out of recommendations from the research programme's scoping study. The scoping study suggested that it would be valuable to explore the different ways in which support teams work to provide education and support for children and young people with physical disabilities. In particular it suggested that the project should look at support teams which are using best practice (usually referred to as 'integrated effective practice'). The main components of effective integrated practice are described below. It is hoped that this focus will provide some useful information about the various ways in which teams can work best to support students with physical disabilities and their families. In addition, the project could identify some of the barriers encountered by teams in their attempts to provide integrated effective practice. The project is centred particularly on the experiences of children and their families, and on the impact of various services and supports on children's and families' daily lives.

What will the project involve?

The project aims to describe and explore integrated effective service provision in practice in schools and related settings for students with physical disabilities. Nine case studies will be undertaken across a range of school and other settings (e.g. home; health; education; private therapy; welfare; ACC-supported settings). The project will try to cover the following range of school settings: inclusive, where students are included and taught in the regular classroom alongside their age peers; special school; special unit; high/low decile; urban/rural; primary/ secondary/ intermediate/ area school. If you agree to participate, a researcher will spend one week in your school observing two students with physical disabilities for two days each, as they move through the school day.

Observations of focus children. Observations will take place in the child's classroom(s), and will focus on all aspects of their school day, including their interactions with teachers and other adults, and with children. The researcher will also observe the students outside school hours at home and in other community settings.

Interviews with the support team. The work of the support team will be observed as it impacts on the child's daily life. The remaining day and some evenings will be used to informally interview team members, including the child's teacher(s), other school-based support staff and the school principal. The child and their parents will also be interviewed, as will two recent school leavers with physical disabilities who have attended your school.

A proposal for the study has been approved by the University of Otago Human Ethics Committee. The results from this project will be written into a research report for the Ministry of Education, and may be used in conference presentations, teacher professional development, and written publications in teacher-focused and academic publications. In any of these forms of dissemination, confidentiality and anonymity will prevail. Your school, and the children, parents, teachers and support staff who participate in the study, will not be identified. However, it is important for you to understand that some staff in the Research Division of the Ministry of Education and members of the Ministry of Education's Reference Group on Physical Disabilities will know the research sites, and may therefore be able to identify some case studies. Adult participants in the project will be informed of this point.

What is integrated effective practice?

The Scoping Project on Integrated Effective Service Provision for Children and Young People with Physical Disabilities (McDonald, Caswell & Penman, 2002), reviewed the international literature in this area, and the researchers also asked students, parents, and support team members to describe what they considered effective integrated practice to look like.

The Scoping Project provides an extensive and detailed discussion about integrated effective practice, and stresses that any discussion must take into account the uniqueness of New Zealand's population and context. In summary, it concluded that integrated effective practice is indicated and achieved when:

- the wishes of families are respected and trusting relationships are built over time
- there is effective inter-agency collaboration
- there is raised awareness of disability issues within schools and the wider community
- teams collaborate effectively in the planning and implementation of individualised programmes
- client-centred meaningful goals are developed and functional skills are learnt in natural settings
- service providers are willing to consider new ideas, pay respect to alternative forms of intervention and assist families in making informed decisions
- there is recognition that staffing concerns about workload, training and ongoing supervision need to be addressed
- policy, funding and resource allocation support the diverse needs of children and young people with physical disabilities.

The literature review also suggested some ways that effective practice could be identified. The Scoping Report suggested that in New Zealand, practices could be said to be working in integrated, effective ways if there is:

- extensive family involvement
- learning and achievement by the student
- acceptance, inclusion and friendship with peers
- the availability of supports to adapt the curriculum
- a focus in education and other areas on quality of life which recognises the multiple ways in which quality of life can be determined
- a commitment to accountability and a means for ensuring accountability.

People interviewed for the Scoping Project said that an integrated effective model of service provision would mean that students with physical disabilities would:

- have opportunities to develop relationships with peers which are supported by sensitive arrangements for the provision of necessary therapies
- be happy

- receive support that is practically oriented and directed towards the improvement of their physical skills
- have equitable access to and choice between good-quality services
- access services that respond to their individual needs.

Further enquiries

If you have any questions about the project please feel free to contact:

Dr Jude MacArthur
Senior Researcher
Donald Beasley Institute
(03) 479 2162.

Appendix J: Brief for Child Development Teams

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

INFORMATION BRIEF FOR POTENTIAL CASE STUDY SITES (CHILD DEVELOPMENT TEAMS)

Background to the project

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather understandings which will contribute to improving policy and service provision for students with physical disabilities, their families and whānau.

The present study emerges out of recommendations from the research programme's scoping study. The scoping study suggested that it would be valuable to explore the different ways in which support teams work to provide education and support for children and young people with physical disabilities. In particular it suggested that the project should look at support teams which are using best practice (usually referred to as 'integrated effective practice'). The main components of effective integrated practice are described below. It is hoped that this focus will provide some useful information about the various ways in which teams can work best to support students with physical disabilities and their families. In addition the project could identify some of the barriers encountered by teams in their attempts to provide integrated effective practice. The project is centred particularly on the experiences of children and their families, and on the impact of various services and supports on children's and families' daily lives.

What will the project involve?

The project aims to describe and explore integrated effective service provision in practice in schools and related settings for students with physical disabilities. Nine case studies will be undertaken across a range of school and other settings (e.g. home; health; education; private therapy; welfare; ACC-supported settings). The project will try to cover the following range of school settings: inclusive, where students are included and taught in the regular classroom alongside their age peers; special school; special unit; high/low decile; urban/rural; primary/ secondary/ intermediate/ area school. If your Child Development team agrees to participate, a researcher will spend one week with your team and, in particular, with two focus students who receive the services of your team.

Observations of focus children Observations will take place in the child's school and classroom(s), and will focus on all aspects of their school day, including their interactions with teachers and other adults, and with children. The researcher will also observe the students outside school hours at home and in other community settings.

Interviews with the support team. The work of the support team will be observed as it impacts on the child's daily life. The remaining day and some evenings will be used to informally interview team members, including the child's teacher(s), other school-based support staff and the school principal. The child and their parents/whānau will also be interviewed, as will two recent school leavers with physical disabilities who have recently left school and received support from your Child Development team .

A proposal for the study has been approved by the University of Otago Human Ethics Committee. The results from this project will be written into a research report for the Ministry of Education, and may be used in conference presentations, teacher and therapist professional development, and written publications in teacher-focused and therapist-focused and academic publications. In any of these forms of dissemination, confidentiality and anonymity will prevail. Your team, and the children, parents, teachers and support staff who participate in the study, will not be identified. However, it is important for you to understand that some staff in the Research Division of the Ministry of Education and members of the Ministry of Education's Reference Group on Physical Disabilities will know the research sites, and may therefore be able to identify some case studies. Adult participants in the project will be informed of this point.

What is integrated effective practice?

The Scoping Project on Integrated Effective Service Provision for Children and Young People with Physical Disabilities (McDonald, Caswell & Penman, 2002), reviewed the international literature in this area, and the researchers also asked students, parents, and support team members to describe what they considered effective integrated practice to look like.

The Scoping Project provides an extensive and detailed discussion about integrated effective practice, and stresses that any discussion must take into account the uniqueness of New Zealand's population and context. In summary, it concluded that integrated effective practice is indicated and achieved when:

- the wishes of families are respected and trusting relationships are built over time
- there is effective inter-agency collaboration
- there is raised awareness of disability issues within schools and the wider community
- teams collaborate effectively in the planning and implementation of individualised programmes
- client-centred meaningful goals are developed and functional skills are learnt in natural settings
- service providers are willing to consider new ideas, pay respect to alternative forms of intervention and assist families in making informed decisions
- there is recognition that staffing concerns about workload, training and ongoing supervision need to be addressed
- policy, funding and resource allocation support the diverse needs of children and young people with physical disabilities.

The literature review also suggested some ways that effective practice could be identified. The Scoping Report suggested that in New Zealand, practices could be said to be working in integrated, effective ways if there is:

- extensive family involvement
- learning and achievement by the student
- acceptance, inclusion and friendship with peers
- the availability of supports to adapt the curriculum
- a focus in education and other areas on quality of life which recognises the multiple ways in which quality of life can be determined
- a commitment to accountability and a means for ensuring accountability.

People interviewed for the Scoping Project said that an integrated effective model of service provision would mean that students with physical disabilities would:

- have opportunities to develop relationships with peers which are supported by sensitive arrangements for the provision of necessary therapies

- be happy
- receive support that is practically oriented and directed towards the improvement of their physical skills
- have equitable access to and choice between good-quality services
- access services that respond to their individual needs.

Further enquiries

If you have any questions about the project please feel free to contact:

Dr Jude MacArthur
Senior Researcher
Donald Beasley Institute
(03) 479 2162
jude.macarthur@stonebow.otago.ac.nz

Appendix K: Information sheets and consent forms

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

INFORMATION SHEET FOR PARENTS/CAREGIVERS/WHĀNAU OF CHILDREN/YOUTH WITH DISABILITIES

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather information which will help to improve policy, services and supports for students with physical disabilities, their families and whānau.

What is the aim of the project?

The overall purpose of the case studies is to gather information which will contribute to improving service provision for students with physical disabilities, their families and whānau and inform both policy development and decisions about resourcing. The study will look at the various ways in which support team members in schools, at home and in the community (e.g. teachers, therapists, teacher aides, counsellors and others) can best work together to support students with physical disabilities and their families. The project also hopes to identify some of the barriers faced by these teams as they work to provide effective and integrated practice, and to comment on the overall impact of resourcing for students on the student and their family. Nine schools will participate in the study around New Zealand, covering a range of settings (inclusive; special school; special unit; high/low decile; urban/rural; primary/secondary).

What type of participants are being sought?

Participants in each school will be two children with physical disabilities. I may also talk with friends of the children with disabilities at school. Other participants include parents/caregivers of the two children with physical disabilities; and members of the educational support team, including the principal, class teacher, teacher aide, therapists, and any other support staff working as part of the team both within and outside the school.

What will participants be asked to do?

If you agree to participate, you and your child will be asked to sign a consent form which shows that you understand the study and wish to participate. I will spend one week in your child's school. observing him or her and one other student who has a physical disability. I would like to find out as much as I can about your child's daily life, at school, home and in the community, and how members of your child's educational support team fit into and support your child's day. To do this I will observe and talk with your child for two days, moving with them as they go through an ordinary day. At school I will observe in the classroom and in the school grounds, looking at all aspects of their school day, including their interactions with teachers and other adults, and with children. I may at times talk with adults if I need clarification about what is happening. I may also talk to your child's friends, providing they and their parents agree to take part in the project. A letter describing the project will be sent to all families in the school so that everyone knows why I am there. I would like to see what your child's life is like outside school hours, by coming home with them after school and/or going with them to other places such as clubs, sports groups, or friends' homes.

I will be talking with adults who support your child's education and general development, including the school principal; your child's teacher(s); therapists; teacher aide; and any other adults who provide support through either education, health or ACC funding. These discussions will focus on the type of support provided to your child; the resourcing your child receives; the impact of that resourcing; your child's educational and other goals; planning for your child's education; the various ways in which team members work together to support you and your child; and the kinds of links and relationships the team has with you, your child and the rest of your family. I will look at some of the resourcing, planning and teaching documents used to support your child's education, including his/her IEP.

I will interview both you and your child at home. In the interviews I will be asking you about your child's life at school, at home and in the community, and how the support team works to support your child's education and development, and your family life.

Can participants change their mind and withdraw from the project?

You or your child may withdraw from participation in the project at any time and without any disadvantage to yourself or your child of any kind.

What data or information will be collected and what use will be made of it?

The data I collect will include observations and interview transcripts. As I observe your child's day at school and elsewhere, I will write down notes to describe what he/she is doing, their interactions with others (adults and children), and their comments in relation to any questions I might ask them about what they are doing. I may at times record my observations on a tape recorder, however I will go somewhere private to do this.

I will be using an open-questioning approach in my interviews with children and adults in the project. This means that it is not possible to say exactly what questions will be asked in the interview beforehand. Some questions will come up as we talk. Consequently, although the Ethics Committee is aware of the general areas we will cover in the interview, the Committee has not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that you or your child feels hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you or your child may withdraw from the project at any stage without any disadvantage to yourself of any kind.

The results from this project will be written into a report for the Ministry of Education. They may also be used in conference presentations and teacher training, and be published in written material for teachers, other professionals and researchers to learn from. Any data included will in no way be linked to any specific participant. Some staff in the Research Division of the Ministry of Education, and members of the Ministry of Education's Reference Group on Physical Disabilities will know which schools have participated in the project, however this information will remain confidential to these groups. All of my observations and any interviews will be confidential to myself and to the other researchers on the team (Dr Trevor McDonald, Ms Pat Caswell, Ms Carolyn Simmons Carlsson and Teina Boasa-Dean . I will send you a summary of the study's results, and you are most welcome to request a copy of the results of the project from me should you wish.

The data from the study (observation notes and interview transcripts) will be securely stored so that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for five years, after which time it will be destroyed.

What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact either:

Researcher's name and telephone or Dr Jude MacArthur

Donald Beasley Institute

PO Box 6189

Dunedin

Telephone Number: (03) 479 8080

This project has been reviewed and approved by the Ethics Committee

of the University of Otago

INFORMATION SHEET FOR PARENTS/CAREGIVERS OF FRIENDS OF FOCUS CHILD

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather information which will help to improve policy, services and supports for students with physical disabilities, their families and whānau.

What is the aim of the project?

The overall purpose of the case studies is to gather information which will contribute to improving service provision for students with physical disabilities, their families and whānau and inform both policy development and decisions about resourcing. The study will look at the various ways in which support team members in schools, at home and in the community (e.g. teachers, therapists, teacher aides, counsellors and others) can best work together to support students with physical disabilities and their families. The project also hopes to identify some of the barriers faced by these teams as they work to provide effective and integrated practice, and to comment on the overall impact of resourcing for students on the student and their family. Nine schools will participate in the study around New Zealand, covering a range of settings (inclusive; special school; special unit; high/low decile; urban/rural; primary/secondary).

What type of participants are being sought?

Participants in each school will be two children with physical disabilities. I may also talk with friends of the children with disabilities at school. Other participants include parents/caregivers of the two children with physical disabilities; and members of the educational support team, including the principal, class teacher, teacher aide, therapists, and any other support staff working as part of the team both within and outside the school. I have given you this information sheet because your child is a friend of x [one of the children participating in the project]. If it is all right with you I would like to talk with your child about the things he/she and x like to do together at school and outside of school.

What will participants be asked to do?

If you and your child agree to participate, you and your child will be asked to sign a consent form which shows that you understand the study and wish to participate. I will come to your home to talk with your child. In the interview I will be asking your child about their friendship with x, and about the things that he/she and x like to do at school. I am also interested in finding out what your child thinks about life at school both for themselves and for x.

Can participants change their mind and withdraw from the project?

Your child may withdraw from participation in the project at any time and without any disadvantage to yourself or your child of any kind.

What data or information will be collected and what use will be made of it?

I will tape the interview with your child so the data I collect from your child will include interview transcripts. I will be using an open-questioning approach in my interviews with children and adults in the project. This means that it is not possible to say exactly what questions will be asked in the interview beforehand. Some questions will come up as we talk. Consequently, although the Ethics Committee is aware of the general areas we will cover in the interview, the Committee has not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that your child feels hesitant or uncomfortable they will be reminded of their right to decline to answer any particular question(s) and also that they may withdraw from the project at any stage without any disadvantage of any kind.

The results from this project will be written into a report for the Ministry of Education. They may also be used in conference presentations and teacher training, and be published in written material for teachers, other professionals and researchers to learn from. Any data included will in no way be linked to any specific participant. Some staff in the Research Division of the Ministry of Education, and members of the Ministry of Education's Reference Group on Physical Disabilities, will know which schools have participated in the project, however this information will remain confidential to these groups. All of my observations and any interviews will be confidential to myself and to the other researchers on the team (Dr Trevor McDonald, Ms Pat Caswell, Ms Carolyn Simmons Carlsson and Teina Boasa-Dean . I will send you a summary of the study's results, and you are most welcome to request a copy of the results of the project from me should you wish.

The data from the study (observation notes and interview transcripts) will be securely stored so that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for five years, after which time it will be destroyed.

What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact either:

[Researcher's name and telephone] or **Dr Jude MacArthur**

Donald Beasley Institute

PO Box 6189

Dunedin

Telephone Number:

(03) 479 8080

This project has been reviewed and approved by the Ethics Committee

of the University of Otago

UNIVERSITY
of
OTÁGO

Te Whare Wānanga o Otāgo

CONSENT FORM FOR PARENTS/CAREGIVERS/ YOUNG ADULTS WHO HAVE LEFT SCHOOL

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

My participation (and my child's participation) in the project is entirely voluntary;

1. I/We are free to withdraw from the project at any time without any disadvantage;
2. The data [audio-tapes and notes] will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed;
3. This project involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance. Instead questioning will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.
4. The results of the project may be published but our anonymity will be preserved.

I AGREE TO TAKE PART IN THIS PROJECT.

(I HAVE SPOKEN WITH MY CHILD ABOUT THE PROJECT AND S/HE AND I AGREE S/HE CAN TAKE PART)

.... …………..……… (Signature /signature of Parent)
(Date)

I/WE DO NOT WANT TO PARTICIPATE IN THIS PROJECT

.... …………………..

(Signature/signature of Parent) (Date)

This project has been reviewed and approved by the Ethics Committee

of the University of Otago

INFORMATION FOR CHILDREN/YOUTH IN THE STUDY

Note: The language in these appendices is appropriate to primary-age children. The language was adapted for older youth participating in the project, and for young adults who had left school. The format of these appendices was also adapted to meet the needs of participants who used alternative forms of communication.

The 'Help at School' Project

Children's Information Sheet (Primary)

Dear ……………………………………………

I would like you to read this information sheet to help you decide whether you would like to take part in a study I am doing.

What It's About

I am doing a study about what children think about the help they get from adults at school and outside of school (at home and in other places like MUSIC OR CUBS OR SPORT). My report is going to be about how some of the adults who work at school (like your principal, your teacher, your physio, or OT) and in other places can really help kids with physical disabilities to have a good life. I'm interested in what you think, and in what happens for you at school.

Who I Want To Talk To

I am going to be spending two days with you. That's a long time, and I hope we can have some fun and that you don't get sick of me! I will visit you at home, and then I will go with you to school. I will spend the day with you at school and come back home with you after school. I want to see what your day is like and what you do in an ordinary day. I will talk to you about some of the things that happen at school. I will ask you to tell me about some of the things that are happening and for your opinion about things. I will also be talking to your Mum and Dad, your teacher(s) and the other adults who help you (such as your physio, OT, teacher aide, etc.). I want to know what they think about the help you get from all these people as well.

What You Would Have To Do

You and your Mum or Dad (or a caregiver) will sign a special form, called a Consent Form, which tells me you understand about the study and you want to be in it. Then I will talk to you about school, about the things you like to do at school, or don't like! I will talk to you a little bit when I come to school, like I might ask you to tell me about things you are doing. But I would really like to come and talk with you at home if that's OK. If you want Mum or Dad to be there when we talk that's fine, you can choose. When I am at school I will be around for most of the day. I want to see what your day is like. I would like to write down some of the things I see you doing, and I might write down some of the things you tell me as well. Sometimes I might talk to your friends, that is if they want to talk to me.

You Can Change Your Mind

Even if you sign the form, you can change your mind later if you don't want to be in the study anymore and if you don't want to talk to me sometimes (you might have other things you want to do), or if you just want me to go away, that's all OK.

If you have any worries after our talks you can come and talk to me. I will keep everything private but if I'm not sure about something you've told me I might want to talk to your Mum or Dad or someone at school but I will check that's OK with you first.

How I Will Do The Study

When I am at home and school with you I will be writing things down. I will be writing down what is happening in class – what you are doing, and who with, what the adults are doing. When we are talking I will write things down too. I will also write down notes in my book about what I see you and your friends doing at playtime and lunchtime.

When I talk to you at home I may put a tape on so that I can remember what you have said for my report. But at anytime you can tell me to turn it off and I will. The tape and the copy of your words from the tape will only be seen by me, and four of my workmates who are talking with other kids a bit like you and I are. When I have written the report the tape will be wiped clean. The copy of the words will be kept locked up at my office in Dunedin for five years and then it will be shredded.

When I write my report I might write about some of the things you have talked about but I won't use your name, or the name of the school so people won't know they are your words.

If You Want To Know More About The Study

If you, or Mum or Dad (or your caregivers), want to know more about the study you can ask me or my boss, Jude. Our names are written here with our phone numbers.

Researcher	**Jude MacArthur**
Phone	**(03) 479 80808**

Thank you for reading this Information Sheet.

This project has been reviewed and approved by the Ethics Committee

of the University of Otago.

The 'Help and Support at School' Project

Children's Information Sheet (Secondary)

Dear……………………………

I would like you to read this information sheet to help you decide whether you would like to take part in a study I am doing.

What It's About

I am doing a study about what children and young people think about the help and support they get from adults at school and outside of school (at home and in other places like music, clubs or sports). My report is going to be about how some of the adults who work at school (like your principal, your teacher, and others such as therapists) and in other places can help children and young people with physical disabilities to have a good life. I'm interested in what you think, and in what happens for you at school.

Who I Want To Talk To

If you agree to be in my study, I will be spending two days with you. I will visit you at home, and then I will go with you to school. I will spend the day with you at school and come back home with you after school. I want to see what your day is like and what you do in an ordinary day. I will talk to you about some of the things that happen at school and I will ask you to tell me about some of the things that are happening and for your opinion about things. I will also be talking to your parents, your teacher(s) and the other adults who help you (such as your physio, OT, teacher aide, etc.). I want to know what they think about the help you get from all these people as well.

What You Would Have To Do

You and your parents will sign a special form called a Consent Form, which tells me you understand about the study and you want to be in it. After that I will make a time to talk to you about school. I will also talk to you a little bit when I come to school. For example, I might ask you to tell me about things you are doing. I would also like to come and talk with you at home for a bit longer, if that's OK. If you want your parents to be there when we talk that's fine, you can choose.

When I am at school I will be around for most of the day so I can see what your day is like. I would like to write down some of the things I see you doing, and I might write down some of the things you tell me as well. Sometimes I might talk to your friends, that is if they want to talk to me.

You Can Change Your Mind

Even if you sign the form, you can change your mind later if you don't want to be in the study anymore or if you don't want to talk to me sometimes (you might have other things you want to do), or if you just want me to go away, that's all OK.

If you have any worries after our talks you can come and talk to me. I will keep everything private but if I'm not sure about something you've told me I might want to talk to your parents or someone at school but I will check that's OK with you first.

How I Will Do The Study

When I am at home and school with you I will be writing things down. I will be writing down what is happening in class – what you are doing, and who with, what the adults are doing. When we are talking I will write things down too. I will also write down notes in my book about what I see you and your friends doing at break times.

When I talk to you at home I may put a tape on so that I can remember what you have said for my report. But at any time you can tell me to turn it off and I will. The tape and the copy of your words from the tape will only be seen by me, and four of my workmates who are talking with other young people like you and I are. When I have written the report the tape will be wiped clean. The copy of the words will be kept locked up at my office in Dunedin for five years and then it will be shredded.

When I write my report I might write about some of the things you have talked about but I won't use your name, or the name of the school. No one will know that they are your words.

If You Want To Know More About The Study

If you, or your parents, want to know more about the study you can ask me. My name is written below with my phone number.

Researcher	**Jude MacArthur**
Phone	**(03) 4798080**

Thank you for reading this Information Sheet.

This project has been reviewed and approved by the Ethics Committee
of the University of Otago.

INFORMATION SHEET FOR FRIENDS

The 'Help at School' Project

Friends' Information Sheet

Dear …………………………………………….

I would like you to read this information sheet to help you decide whether you would like to take part in a study I am doing.

What It's About

I am doing a study about what children think about the help they get from adults at school and outside of school (at home and in other places like MUSIC OR CUBS OR SPORT). My report is going to be about how some of the adults who work at school (like your principal, your teacher, and other adults like the physio, or OT who help X) can really help kids with physical disabilities like X to have a good life. I'm interested in what you and X do together at school, in what you think about school yourself, and in what you think school is like for X.

Who I Want To Talk To

I am going to be spending two days at school. I will be talking to X and to some adults at school about the help X and other kids get at school. I would like to talk to you about some of the things that happen at school. I will ask you to tell me about some of the things that are happening and for your opinion about things.

What You Would Have To Do

You and your Mum or Dad (or a caregiver) will sign a special form, called a Consent Form, which tells me you understand about the study and you want to be in it. Then I will talk to you about school, about the things you like to do at school, or don't like! I will talk to you about the things you do with X at school and at home. I might also talk to you a little bit when I am at school, like I might ask you to tell me about things you are doing. But I would really like to come and talk with you at home if that's OK. If you want Mum or Dad to be there when we talk that's fine, you can choose.

You Can Change Your Mind

Even if you sign the form, you can change your mind later if you don't want to be in the study anymore and if you don't want to talk to me sometimes (you might have other things you want to do), or if you just want me to go away, that's all OK.

If you have any worries after our talks you can come and talk to me. I will keep everything private but if I'm not sure about something you've told me I might want to talk to your Mum or Dad or someone at school but I will check that's OK with you first.

How I Will Do The Study

When I talk to you at home I may put a tape on so that I can remember what you have said for my report. But at anytime you can tell me to turn it off and I will. The tape and the copy of your words from the tape will only be seen by me, and four of my workmates who are talking with other kids a bit like you and I are. When I have written the report the tape will be wiped clean. The copy of the words will be kept locked up at my office in Dunedin for five years and then it will be shredded.

When I write my report I might write about some of the things you have talked about but I won't use your name, or the name of the school so people won't know they are your words.

If You Want To Know More About The Study

If you, or Mum or Dad (or your caregivers), want to know more about the study you can ask me or my boss, Jude. Our names are written here with our phone numbers.

Researcher ***(name)***

Phone ***(phone)***

My Boss **Jude MacArthur 03 479 8080**

Thank you for reading this Information Sheet.

This project has been reviewed and approved by the Ethics Committee

of the University of Otago.

INFORMATION SHEET FOR YOUNG ADULTS WHO HAVE LEFT SCHOOL

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather information which will help to improve policy, services and supports for students with physical disabilities, their families and whānau.

What is the aim of the project?

The overall purpose of the case studies is to gather information which will contribute to improving service provision for students with physical disabilities, their families and whānau and inform both policy development and decisions about resourcing. The study will look at the various ways in which support team members in schools, at home and in the community (e.g. teachers, therapists, teacher aides, counsellors and others) can best work together to support students with physical disabilities and their families. The project also hopes to identify some of the barriers faced by these teams as they work to provide effective and integrated practice, and to comment on the overall impact of resourcing for students on the student and their family. Nine schools will participate in the study around New Zealand, covering a range of settings (inclusive; special school; special unit; high/low decile; urban/rural; primary/secondary).

What type of participants are being sought?

Participants in each school will be two children with physical disabilities. I may also talk with friends of the children with disabilities at school. Other participants include parents/caregivers of the two children with physical disabilities; and members of the educational support team, including the principal, class teacher, teacher aide, therapists, and any other support staff working as part of the team both within and outside the school. I have given you this information sheet because you are an ex-pupil of the school. I would like to talk with you about your experience at school.

What will participants be asked to do?

If you agree to participate, you will be asked to sign a consent form which shows that you understand the study and wish to participate. I will talk with you at a time and place that suits you. I am particularly interested in how school has helped you in your transition to adult life, and in what you are doing now and/or would like to be doing now as a young adult.

Can participants change their mind and withdraw from the project?

You may withdraw from participation in the project at any time and without any disadvantage of any kind.

What data or information will be collected and what use will be made of it?

I will tape the interview with you so the data I collect from you will include interview transcripts. I will be using an open-questioning approach in my interviews with children and adults in the project. This means that it is not possible to say exactly what questions will be asked in the interview beforehand. Some questions will come up as we talk. Consequently, although the Ethics Committee is aware of the general areas we will cover in the interview, the Committee has not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that you feel hesitant or uncomfortable you will be reminded of your right to decline to answer any particular question(s) and to withdraw from the project at any stage without any disadvantage of any kind.

The results from this project will be written into a report for the Ministry of Education. They may also be used in conference presentations and teacher training, and be published in written material for teachers, other professionals and researchers to learn from. Any data included will in no way be linked to any specific participant. Some staff in the Research Division of the Ministry of Education, and members of the Ministry of Education's Reference Group on Physical Disabilities, will know which schools have participated in the project, however this information will remain confidential to these groups. Any interviews will be confidential to myself and to the other researchers on the team (Dr Trevor McDonald, Ms Pat Caswell, Ms Carolyn Simmons Carlsson and Teina Boasa-Dean). I will send you a summary of the study's results, and you are most welcome to request a copy of the results of the project from me should you wish.

The data from the study (observation notes and interview transcripts) will be securely stored so that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for five years, after which time it will be destroyed.

What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact either:

Researcher's name and telephoneor **Dr Jude MacArthur**

Donald Beasley Institute

PO Box 6189

Dunedin

Telephone Number: (03) 479 8080

This project has been reviewed and approved by the Ethics Committee

of the University of Otago

CONSENT FORM FOR CHILDREN

I have read the information sheet about the 'Help at School' project and I understand it.

I know that……….

I don't have to be in the project unless I want to be.

Later on I can change my mind if I don't want to be in the project anymore.

I don't have to answer any of the questions if I don't want to.

I can tell (researcher) I have had enough watching and I want him/her to go.

I can change my mind and go and play or ask for the tape to be turned off anytime I want.

If I ever have any questions I can ask [researcher name] about them or get Mum or Dad or my carer to phone [researcher's] boss, Jude, to ask her.

No bad things will happen to me if I change my mind about anything to do with the project.

I would like to be part of the project.

…………………………………………My signature

…………………………………. The date

I don't want to be part of the project

…………………………………………My signature

…………………………………THE DATE

INFORMATION FOR SUPPORT TEAM MEMBERS IN THE STUDY

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

This project is part of a larger research programme commissioned and funded by the Ministry of Education, and overseen by the Ministry's Reference Group on Physical Disabilities. The aim of this larger programme is to gather information which will help to improve policy, services and supports for students with physical disabilities, their families and whānau.

What is the aim of the project?

The overall purpose of the case studies is to gather information which will contribute to improving service provision for students with physical disabilities, their families and whānau and inform both policy development and decisions about resourcing. The study will look at the various ways in which support team members in schools, at home and in the community (e.g. teachers, therapists, teacher aides, counsellors and others) can achieve effective integrated practice in the support of students with physical disabilities and their families/whānau. The project also hopes to identify some of the barriers faced by these teams as they work to achieve effective integrated practice, and to comment on the overall impact of resourcing for students on the student and their family. Nine schools will participate in the study around New Zealand, covering a range of settings (inclusive; special school; special unit; high/low decile; urban/rural; primary/secondary).

What type of participants are being sought?

Participants in each school will be two focus children with physical disabilities. I may also talk with friends of the children with disabilities at school. Other participants include parents/caregivers of the two children with physical disabilities; and all members of the educational support team, including the principal, class teacher, teacher aide, therapists, educational psychologist, counsellor, and any other support staff working as part of the team both within and outside the school.

What will participants be asked to do?

If you agree to participate, you will be asked to sign a consent form which shows that you understand the study and wish to participate. I will spend one week in your school observing the focus children for a period of two days each. I would like to find out as much as I can about the children's daily lives, at school, home and in the community, and how members of the support team support the child's learning and development as they move through their day. To do this I will observe and talk with the children, moving with them as they go through an ordinary day. At school I will observe in the classroom and in the school grounds, looking at all aspects of their school day, including their interactions with teachers and other adults, and with children. I may at times talk with adults if I need clarification about what is happening. I may also talk to the focus child's friends. A letter describing the project will be sent to all families in the school so that everyone knows why I am there. I will also observe the focus child's life outside school hours, by accompanying them home after school and/or by going with them to other places such as clubs, sports groups, or friends' homes.

I will be talking with adults who support the focus child's education and general development, including the school principal; teacher(s); therapists; teacher aide; and any other adults who provide support through either education, health or ACC funding. These discussions will focus on the type of support provided to the child; the resourcing the child receives; the impact of that resourcing; the child's educational and other goals; planning for the child's education; the various ways in which team members work together to support the child and their family; the team's philosophy and general approach to providing support; and the kinds of links and relationships the team has with the child and their family. I will also look at some of the resourcing, planning and teaching documents used to support the child's education, including his/her IEP. I will interview support team members individually about some of these issues outside school hours and at a time and place that suits them.

Can participants change their mind and withdraw from the project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What data or information will be collected and what use will be made of it?

The data I collect will include observations and interview transcripts. As I observe the child's day at school and elsewhere, I will write down notes to describe what he/she is doing, their interactions with others (adults and children), and their comments in relation to any questions I might ask them or adults about what they are doing. I may at times record my observations on a tape recorder, however I will go somewhere private to do this. I will be using an open-questioning approach in my interviews with children and adults in the project. This means that it is not possible to say exactly what questions will be asked in the interview beforehand. Some questions will come up as we talk. Consequently, although the Ethics Committee is aware of the general areas we will cover in the interview, the Committee has not been able to review the precise questions to be used. In the event that the line of questioning does develop in such a way that you or your child feels hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you or your child may withdraw from the project at any stage without any disadvantage to yourself of any kind.

The results from this project will be written into a report for the Ministry of Education. They may also be used in conference presentations and teacher training, and be published in written material for teachers, other professionals and researchers to learn from. Any data included will in no way be linked to any specific participant. Some staff in the Research Division of the Ministry of Education, and members of the Ministry of Education's Reference Group on Physical Disabilities will know which schools have participated in the project, however this information will remain confidential to these groups. All of my observations and any interviews will be confidential to myself and to the other researchers on the team (Dr Trevor McDonald, Ms Pat Caswell, Ms Carolyn Simmons Carlsson and Teina Boasa-Dean). I will send you a summary of the study's results, and you are most welcome to request a copy of the results of the project from me should you wish.

The data from the study (observation notes and interview transcripts) will be securely stored so that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be kept in secure storage for five years, after which time it will be destroyed.

What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact either:

Researcher's name and telephone or Dr Jude MacArthur
Donald Beasley Institute
PO Box 6189
Dunedin
Telephone Number: (03) 479 8080

This project has been reviewed and approved by the Ethics Committee

of the University of Otago.

CONSENT FORM FOR SUPPORT TEAM MEMBERS

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. The data [audio-tapes and notes] will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed;
4. This project involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance. Instead questioning will depend on the way in which the interview develops and that in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind.
5. The results of the project may be published but my anonymity will be preserved.

I AGREE TO TAKE PART IN THIS PROJECT.

.... ………..……… (Signature)
(Date)

I DO NOT WANT TO PARTICIPATE IN THIS PROJECT

.... …………………..

(Signature) (Date)

This project has been reviewed and approved by the Ethics Committee

of the University of Otago.

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OTAGO

Te Whare Wānanga o Otāgo

Appendix L: Interview guides

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

Interview Guides

Checklist

Interview for each focus child:

Parents/Caregivers Of Children With Physical Disabilities

Focus Children

Friends Of Focus Children

Young Adults Who Have Left School

Therapists

Class Teacher (Primary) Or Special Needs Co-Ordinator / Hod Special Needs (Secondary – The Person With Whom The Student Has The Closest Relationship)

Teacher Aides

Principal

Questionnaire On Funding

INTERVIEW GUIDE FOR PARENTS/CAREGIVERS OF CHILDREN WITH PHYSICAL DISABILITIES

(If two parents are interviewed, interview them together)

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

Thank you for your interest in this study. As you know I and a team of other researchers are undertaking a project for the Ministry of Education. You will be familiar with the project from reading the Information sheet. I want to talk with you about your child's life at school, at home and in the community, and about the ways in which the support team works to support your child and your family. (X denotes the child/youth's name)

Background

Tell me about X. His/her age, your family and their place in it, what they are like as a person, a little bit about their disability – type, impact, etiology.

Describe their everyday life for me. What does a typical day look like? How happy are you with the way X's daily life looks at the moment? What are the best aspects of their life? The areas where you would like to see change?

School experiences

Tell me about their school experience – history to date. What do they say about school? What do they like/dislike? Interests at school? Academic progress? Progress in other areas? Friendships and relationships? What are the good things about his/her school experience? What things would you like to see changed?

Leisure time

How would you describe their out-of-school time? Leisure and recreation activities? Locations (home, community, friends' homes)? Friendships and relationships? Segregated or community based?

Resourcing

Tell me what level of resourcing your child receives currently. Through what stream? How is the resourcing used? How happy are you with the level of resourcing? What areas are well supported by resourcing? Are there any areas of shortfall? Where would you like to see additional or different resourcing?

What for you are the reasons for X receiving these services? i.e. why do they have physio/OT/SLT etc.?

Who makes the decisions about what services X receives? What is your involvement in that process?

How do you feel about the balance between therapy time and learning time? How well do the two work together?

The support team

Who is involved in your child's support team?

How would you describe the work of the various people in the team? of the team itself?

How would you describe the way in which the team works? (e.g. integrated? piecemeal?)

How would you describe the team's role in and contribution to your child's life? (at school? at home? in the community?); what about their role in and contribution to the family's life?

What is your role in the team? How happy are you with that role/level of involvement?

What do you value most about the team?

Where would you like to see changes made?

The future

How well do you think X's education is preparing him/her for life as an adult? To do the things they want to do when they are an adult?

As you look ahead, what would you really like to see X doing when they leave school? What sort of life? Any concerns? nightmares? about what might happen in the future?

Do you see your child being supported in ways which make it likely that the goals you have for them will be met?

INTERVIEW GUIDE FOR FOCUS CHILDREN

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

I want to talk to you for a few minutes about school, and after school, and the adults who help you and your family. I am writing a report for the Ministry of Education. The Ministry is like the big boss of all the schools in New Zealand. People in the Ministry would really like to make sure that kids with physical disabilities have a good time at school, and at home. They want to make sure that the adults who help you at school and in other places really do make life better for you and for your family, and that they help you to learn lots of important things. They have asked me and some of my workmates to go to schools and talk to kids like you and their Mums and Dads and teachers and therapists about what happens at school and after school.

I will write a report for the Ministry of Education about what school is like for kids with physical disabilities, and what adults can do to make school and home life even better. They will use the report to make good changes at school so that you and other kids like you can learn a lot and have a life which is the best it can be.

Are you happy to tell me a bit about what school is like for you?

Requesting consent

It is your choice to talk with me about school and adults at school. If you don’t want to talk to me, that’s fine, you can tell me and we will stop now.

Are you happy to tell me a bit about school? If yes, then:

If, when we are talking, you want to stop talking or go that’s ok. If you don’t want to answer any of the questions that’s OK too. When we are talking I will put the tape on so that I can remember what everyone said for my report. But at anytime you can tell me to turn it off and I will. I won’t tell anyone else what you have said unless you tell me that it’s OK to tell someone else. I might want to talk to Mum and Dad or (teacher or child with disability’s teacher aide) about some of the things you say but I will always ask you first. Also, you can tell me if there is anything you don’t want me to tell them.

I will be writing a report (like homework) about the things we talk about but I won’t use your real name or the name of the school, so no-one will know that you said it. When I have finished writing my report I will clean the tape and take off the things you said. Is it OK if I use the tape recorder? If I ask you a question and you don’t want to answer it, that’s OK, you can just tell me that. If I ask you a question and you're not sure about how to answer it, it’s OK to say ‘I don't know’ or ‘I'm not sure’. If you want me to turn off the tape while you are talking, that’s OK too.

Sign the consent form (this part should be negotiated with the family in the case of primary school children and children/youth who use alternative communication)

If you are happy about all these things we will sign this special form (consent form). This tells me that you know what we are going to be talking about and you are happy with that.

Do you have any questions you want to ask me? ***Sign the consent form.***

Interview

Family

Tell me about your family. Have you got brothers and sisters at this school?

School history

Have you always gone to this school? Tell me about your other schools.

Current school

What is this school like?

What kind of things do you like doing at school?

What are you learning about just now?

What do you like best about school? What do you look forward to?

Are there things you don't like about school? Tell me about them.

Tell me about the things you like to do at playtime. Are you always able to do the things you like doing? Are there things you don't like to do at playtime or lunchtime?

Friends

Who do you usually get around with at playtime and lunchtime?

Who would you say were your best friends?

Tell me about the things you like to do with your friends (at school and after school).

Do your friends ever help/support you at school?

Next school (for children about to transition)

What school are you going to next?

Are you looking forward to going to that school?

> What are you looking forward to?
>
> (If concerns are mentioned…) Can you tell me about your worries/concerns?

Are any of your friends going there? Brothers or sisters?

Adults on the support team

Who are the adults who help/support you at school?

Can you tell me about them and about what each of them does? ***(Ensure the range of adults who provide support are covered.)***

Tell me first of all why you have a physio/OT/SLT?

What do they do with you?

What do the ‘good’ ones do / what are they like? / how did they support/help you?

What do the ‘not so good’ ones do/ what were they like? / how do they support you?

Where do you have therapy? Do you have it in or out of school time? What do you think about having therapy at school?

Do therapists work with your teacher or is therapy provided out of the classroom?

After school

What about after school? Who are the adults that help you there? Can you tell me about them and about what each of them does? (Check during this discussion about adult behaviour which is approved or disapproved of).

What would the best school in the world look like?

What do you want to do/be when you leave school?

Post school (for secondary students only)

HOW DO YOU THINK SCHOOL WILL HELP YOU TO DO WHAT YOU WANT TO DO WHEN YOU LEAVE SCHOOL?

INTERVIEW GUIDE FOR FRIENDS OF FOCUS CHILDREN

(Interview children at their home – let them choose whether to be interviewed alone or with parents)

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

I want to talk to you for a few minutes about school. I am writing a report for the Ministry of Education. The Ministry is like the big boss of all the schools in New Zealand. People in the Ministry would really like to make sure that kids with physical disabilities like your friend X have a good time at school, and at home. They want to make sure that the adults who help kids like X at school and in other places really do make life better for them. They have asked me and some of my workmates to go to schools and talk to kids like you and teachers and other adults who help at school about what happens at school and after school. I would like to talk with you about what you think school is like – both for yourself and for X. I'm also interested in hearing about the things you and X like to do together at school and after school.

I will write a report for the Ministry of Education about what school is like for kids with physical disabilities, and what adults can do to make school and home life even better. You might have some good ideas too about what would make school the best place it can be for X. The Ministry will listen to what people in my study say, and they will use the report to make good changes at school. Are you happy to tell me a bit about what school is like for you and for X?

Requesting consent

It is your choice to talk with me about school and adults at school. If you don't want to talk to me, that's fine, you can tell me and we will stop now.

Are you happy to tell me a bit about school? If yes, then:

If, when we are talking, you want to stop talking or go that's ok. If you don't want to answer any of the questions that's ok too. When we are talking I will put the tape on so that I can remember what everyone said for my report. But at any time you can tell me to turn it off and I will. I won't tell anyone else what you have said unless you tell me that it's OK to tell someone else. I might want to talk to Mum and Dad or (teacher or child with disability's teacher aide) about some of the things you say but I will always ask you first. Also, you can tell me if there is anything you don't want me to tell them.

I will be writing a report (like homework) about the things we talk about but I won't use your real name or the name of the school, so no-one will know that you said it. When I have finished writing my report I will clean the tape and take off the things you said. Is it OK if I use the tape recorder? If I ask you a question and you don't want to answer it, that's OK, you can just tell me that. If I ask you a question and you're not sure about how to answer it, it's OK to say 'I don't know' or 'I'm not sure'. If you want me to turn off the tape while you are talking, that's OK too.

If you are happy about all these things we will sign this special form (consent form). This tells me that you know what we are going to be talking about and you are happy with that.

Do you have any questions you want to ask me? Sign the consent form.

Interview

Friendship

How do you know X?

How long have you known him/her?

What things do you like doing together at school?

Do you ever play together after school or do other things together out of school? How easy is it to get together outside of school? What sorts of things do you like to do together?

School experiences

How would you describe your usual day at school? What are the best things about school? Worst things?

Does X's day at school look like yours? Similarities? Differences? What do you think are X's favourite things about school? The things he/she dislikes about school?

Adult support for X

I'm interested in what you think about the adults who support/help X at school. What sorts of things do you see adults doing with X?

What do you think about the way other adults at school help X?

What do you think are the reasons for X having help from adults like the PT/OT/SLT?

INTERVIEW GUIDE FOR YOUNG ADULTS WHO HAVE LEFT SCHOOL

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

Tell me about yourself. Tell me about your family, your friends.

Tell me about the schools you have been to. What were they like?

What were the best things about school?

The worst things?

What did you dream of doing when you left school?

What are you doing now?

What do you do/where do you work?

What is the relationship to your aspirations?

What is your memory of the adults who supported you through school? Who were they?

> What sorts of things did they do with you?
>
> When you look back at your school days, do any of these people who supported you stand out for you as being very special? What did these 'good' ones do/what were they like? how did they support/help you?
>
> What did the 'not so good' ones do / what were they like?
>
> Can you tell me what therapists did with you? Where was the therapy provided? Was it provided in or out of school time?
>
> Did therapists work with your teacher or was therapy provided out of the classroom?
>
> How well did these people work together for you?
>
> What about the other adults who supported you outside of school? Did they work with the adults at school? Did they know what the others were doing with you at school?

The present and future

How well have your teachers and others (therapists etc.) helped you to be an adult and to do the things you want to do as an adult? What were the most helpful things? Where were the gaps?

If you could give advice to adults who work in schools supporting students with disabilities like yourself, what would it be? Advice for teachers/therapists? principals? teacher aides/others?

INTERVIEW GUIDES FOR SUPPORT TEAM MEMBERS

THERAPISTS (PT, OT, SLT)

TEACHERS (class teacher in primary schools, and special needs co-ordinator / HoD special needs in secondary schools)

PRINCIPALS

QUESTIONNAIRE ON FUNDING

This questionnaire should be given to one person in the school to complete.

INTERVIEW GUIDE FOR THERAPISTS

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

Education, therapy and service provision

Who do you work with in order to support X's education (i.e. people on the team). What are their roles? Relationships to each other?

How many children do you provide support/services for?

How many schools and community settings do you provide this support in?

In general, how often would you see most of your students?

Can you describe the range of children (in terms of needs / complexity of disability)?

In general, how well do you feel able to support these students?

Areas where you feel support works well for the students?

Areas where you would like to see some changes?

General questions relating to the team

How would you describe the approach to education and service provision used with X and with others? (e.g. is the team student-based or do you use a whole-school approach?)

What are the things that make your team work well? (If others tried to do what you do, what would they need to do that?)

Who is the leader of the team? What does it mean to be the leader? What are the leader's roles and responsibilities?

How is the team linked to the school? (e.g. through the principal, DP, AP, class teacher?)

What are the key principles underlying the support team's approach to service provision, and the key components of the support team's approach to service provision (e.g focus on inclusive education; clear and complementary roles and responsibilities; regular team meetings; co-ordinated visits) ?

Does the team have a shared framework ? (i.e. shared vision of the future, common goals and understandings, an evolving framework based on reflection and change). How do you ensure that there is a shared framework? Do you have opportunities to discuss and renegotiate the framework?

What areas would you describe as having general team agreement? What about areas where there is disagreement? What happens when there is disagreement?

What are the specific attributes of your team's practice that have made a difference? (e.g. professional development; regular meetings; being part of a learning community).

How do you and the team stay up to date?

Have you ever changed the way you work as a team / the approach that you use?

Do you ever draw on outside support? If so, give examples.

How do you know that what you are doing is working for the children and young people with physical disabilities whom you support?

How happy are you with the overall team approach?

How well does your work relate to the other services and supports X receives?

Do you ever have a chance to reflect on, review and revise the overall services provided for X. If so, how is this done?

Any areas for improvement?

Questions relating to the individual's own role and approach

Roles and responsibilities

Tell me first of all about your role as a (physio/occupational/SL) therapist. How would you describe what you do?

What specific responsibilities do you have on the team? to X?

How would you describe your personal philosophy in providing support to X?

What do you try to achieve – as a therapist? – as a team member?

Accessing the curriculum

Tell me what you do with X to support her/his access to the curriculum.

Tell me how the support you provide supports her/his access to the curriculum.

To what extent do you think X benefits from the supports and resources he/she receives? (i.e. in relation to meeting their learning goals and accessing the curriculum?). Any areas where change is needed?

How well do you think X's learning goals and overall needs are met by the curriculum. I would like you to think about X's overall development as a child/young person, their academic, social (friendship) and future needs (including their needs to move into adulthood and to have a good adult life).

In what ways do you see X's education benefiting him/her in the longer term?

Therapy and education

How much time is X engaged in work directly related to the curriculum, versus time in therapy? What is your impression about the balance achieved between the two?

Where is therapy usually provided? How happy are you with this arrangement? Would you want to make any changes in this area?

Role of teacher aide and 0.1/0.2 teacher

How much teacher aide support does X receive?

How is this teacher aide support used for X?

How well does this work for X? for you as (therapist)? for the classroom as a whole?

Who makes decisions about the TA's roles and responsibilities in the classroom and elsewhere? What is your role in that process?

How is the 0.1/0.2 teacher position used to support X?

How happy are you with the way this position is used? Would you want to make any changes to this? If so, what kinds of changes?

Effective integrated practice

What to you are the components of effective integrated practice for children with physical disabilities? Tell me why you think these things are important.

(Show the components from the scoping project) (insert)

How in your view is the therapy and service provision you are involved in related to the principles and components of effective integrated practice?

What are the barriers to achieving effective integrated practice for your team?

INTERVIEW GUIDE FOR CLASS TEACHER (PRIMARY)

SPECIAL NEEDS CO-ORDINATOR/HoD SPECIAL NEEDS (SECONDARY)

Own role and responsibilities

How would you describe your role as X's teacher? How would you describe what you do?

What specific responsibilities do you have on the team? to X?

How would you describe your personal philosophy in providing support to X?

What do you try to achieve – as a teacher? as a team member?

Accessing the curriculum

Tell me what you do with X to support her/his access to the curriculum.

How are learning goals identified for X?

Once learning goals are determined for X who makes the decisions about the supports that are needed for X to meet those goals? How are these decisions made?

Tell me how the support you provide supports her/his access to the curriculum.

To what extent do you think the various supports provided to X support him/her to access the curriculum? Any areas where change is needed?

How well do you think X's learning goals and overall needs are met by the curriculum? I would like you to think about X's overall development as a child/young person, their academic, social (friendship) and future needs (including their needs to move into adulthood and to have a good adult life).

In what ways do you see X's education benefiting him/her in the longer term?

To what extent do you think X benefits from the supports and resources he/she receives? (i.e. in relation to meeting their learning goals and accessing the curriculum?).

The role of other teachers in the school (secondary only)

How would you describe the role of other subject teachers in the school in relation to X's education?

How would you describe your role with these teachers?

How well do other teachers in the school support X's education? What needs do these other teachers and classrooms have in order to support X well?

Therapy and education

How much time is X engaged in work directly related to the curriculum, versus time in therapy? What is your impression about the balance achieved between the two?

Where is therapy usually provided? How happy are you with this arrangement? Would you want to make any changes in this area?

Role of teacher aide and 0.1/0.2 teacher

How much teacher aide support does X receive?

How is this teacher aide support used for X?

How well does this work for X? for you as teacher? for the classroom as a whole?

Who makes decisions about the TA's roles and responsibilities in the classroom and elsewhere? What is your role in that process?

How is the 0.1/0.2 teacher position used to support X?

How happy are you with the way this position is used? Would you want to make any changes to this? If so, what kinds of changes?

Effective integrated practice

What to you are the components of effective integrated practice for children with physical disabilities? Tell me why you think these things are important.

(Show the components from the scoping project)

How in your view is the education, therapy and service provision you are involved in related to the principles and components of effective integrated practice?

What are the barriers to achieving effective integrated practice for your team?

INTERVIEW GUIDE FOR TEACHER AIDES

Roles and responsibilities

How much time do you have to support X at school?

Tell me first of all about your role as a TA. How would you describe what you do?

Who makes decisions about your role and responsibilities in the classroom and elsewhere? What is your role in that process?

What specific responsibilities do you have to X? and on the team as a whole?

How happy are you with your role? How well does your role support X? How well does it support the classroom as a whole?

How would you describe your personal philosophy in providing support to X?

What do you try to achieve – as a TA? as a team member?

Accessing the curriculum

Tell me what you do with X to support her/his access to the curriculum.

Tell me how the support you provide supports her/his access to the curriculum.

To what extent do you think X benefits from the supports and resources he/she receives? (i.e. in relation to meeting their learning goals and accessing the curriculum?). Any areas where change is needed?

How well do you think X's learning goals and overall needs are met by the curriculum? I would like you to think about X's overall development as a child/young person, their academic, social (friendship) and future needs (including their needs to move into adulthood and to have a good adult life).

Therapy and education

How much time is X engaged in work directly related to the curriculum, versus time in therapy? What is your impression about the balance achieved between the two?

Where is therapy usually provided? How happy are you with this arrangement? Would you want to make any changes in this area?

Who do you work most closely with? Who provides you with support in your work with X? What training have you had, including access to professional development?

Effective integrated practice

What to you are the components of effective integrated practice for children with physical disabilities? Tell me why you think these things are important.

(Show the components from the scoping project)

How in your view is the therapy and service provision you are involved in related to the principles and components of effective integrated practice?

What are the barriers to achieving effective integrated practice for your team?

INTERVIEW GUIDE FOR PRINCIPALS

School's role

Tell me first of all how you see the school's role in supporting and teaching students with physical disabilities. What is your school's underlying philosophy in this area? Could you give me a copy of your school's Special Needs Policy? How was this policy developed and when was it last reviewed?

What to you are the most important outcomes for students with physical disabilities who attend your school? (academic, social, physical, transition)? What would you like to see students achieve by the time they leave your school?

How well do the supports and resources your school receives for students with physical disabilities help them to access the curriculum?

Have you identified any gaps in the area of supports and resources? What are these? What solutions would you suggest for bridging these gaps?

Principal's own role

Could you describe the role that you play in supporting students with physical disabilities in your school? Are you involved in the support team? If so, how would you describe your involvement?

How well do you think the support team in your school works to support students with physical disabilities? Are there any areas you have questions about or which you would like to see changed? If so tell me about those.

Effective integrated practice

What to you are the components of effective integrated practice for children with physical disabilities? Tell me why you think these things are important.

(Show the components from the scoping project)

How in your view is the therapy and service provision you are involved in related to the principles and components of effective integrated practice?

What are the barriers to achieving effective integrated practice for your team?

Integrated Effective Service Provision for Children and Young People with Physical Disabilities: Case Studies

QUESTIONNAIRE ON FUNDING

We will discuss the following questions together in the interview. It would be very helpful if you could look over these questions beforehand, and think about (and record where possible) any relevant information and responses.

School____

Name of Focus Student____________________________________

Year at school____

Year of class they attend___________________________________

Age_________________

Focus Students and funding/resourcing

What services is X receiving (including education, ACC, health provided services)? (If known record the level of funding, funding streams and the level of support provided)

What is the actual cost of these services ? (if known)

Explain why X is receiving these services. What is the rationale for provision, and what is the process involved in making decisions and choices about service provision? How are X and his/her family involved in this process?

On what basis are decisions made about the allocation of funding resources to services and supports (e.g. are decisions based on supports needed to access the curriculum? the amount of money available? the child's needs? family preferences? teacher preferences?)

Who contributes to these decisions; and how are the decisions made (e.g. a team approach? individual decision? parent/child involvement)?

Have you ever had to make any trade-offs in relation to resource use (e.g. so that needs can be met as best as possible within the available resourcing)?

What is the impact of X's resourcing (funding) on child and family outcomes?

How well does X's resourcing (including funding, provision of and access to services) meet his/her identified and perceived needs?

Impact of resourcing on effective integrated practice

What is the impact of X's resourcing (funding) on the team's ability to provide effective integrated practice?

Do you think that the resources and associated services/supports for X result in integrated effective practice as described in the scoping report (attached)?

(i) How would you describe X's strengths and needs?

(ii) How happy are you with the type and level of service provision? To what extent are the needs of X met within available resources/ service provision?

If they are not well met, then answer the next 2 questions

(iii) Ideally, what services/supports would you like to see X receive in relation to their strengths/needs/IEP goals? Why would you choose to have these supports?

(iv) If there are perceived areas of funding shortfall, where are these?

What services/supports would you describe as critically important for X both now and in the future?

Are there any areas where X needs additional support? What are these and why do you think they are needed?

In general (i.e. not specifically relating to ‘X’), how do you feel about the level of resourcing and support available to the students you work with? What areas would you describe as being well resourced/supported, under- or unresourced? Where would you like to see some different or additional support and why would you want to see these?