The Best of Care?

An Independent Review of Issues at the Interface of Disability Support and Care and Protection

April 2006

A report for
the Department of Child, Youth and Family
and
the Disability Services Directorate
of the Ministry of Health

Adele Carpinter
Chris Harrington

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Terms of reference – two components of the task

The Baseline Review of the Department of Child, Youth and Family identified service access and inter-agency collaboration as problems in the provision of services for children with disabilities and their families. CYF and the Ministry of Health were directed to work together to develop solutions and, in response to this directive, they obtained Cabinet approval and funding to undertake:

- A first principles review and analysis of the legislative and policy frameworks for children with disabilities; and
- A review of the operational interface between CYF and the Disability Services Directorate (DSD) of the Ministry of Health, based on the Memorandum of Understanding co-signed in 1999.

The authors were contracted by CYF and DSD and were assisted by an inter-agency working group. This report outlines the work that has been done and the proposals that have been developed in response to this directive.

Method

We considered that the best approach was to focus on the processes described in sections 139 to 145 of the CYPF Act, the related legislation and policy, and the roles of CYF, DSD and contracted organisations before, during, and after out-of-home placements. This involved a detailed drill-down to expose the underlying drivers of the issues, and has wider application to the issues at the interface between CYF and DSD.

Components of the review

The main components of our analysis and review were:

- A review of departmental papers
- A data-gathering exercise
- Focus groups and key informant interviews
- A literature review.

Although our review involved a significant amount of research and consultation, the focus of the report is on discussing the underlying issues and setting out our proposals for addressing them. Extensive appendices are attached to ensure that the research and thinking underpinning the recommendations are captured.

Background – defining the group of children and young people

The review focuses on children and young people with disabilities under the age of 17 who are involved with both CYF and DSD.[1] Sometimes the disability is incidental to a care and protection issue. Sometimes it is the needs of family members rather than the needs of the child or young person with disabilities that are most pressing. Sometimes the disability may be a critical factor, especially where the disability support needs are high and/or complex.

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[1] The CYPF Act may cover young people up to the age of 20 in some circumstances.

Previous attempts to define the group of children and young people with disabilities who are involved with CYF and DSD have focused on cause (ie, whether their need for an out-of-home placement is caused by their disability or by care and protection concerns in the family situation) but this has not proved helpful. Our working definition for the group is:

> *"Children and young people with disabilities[2] who are the subject of a process under Part Two the CYPF Act, or who are receiving care and other services in terms of Part Two of the CYPF Act."*

Numbers and costs

Based on data supplied by CYF, DSD and the section 141 certifiers, we estimate that the number of children and young people in this group is in the vicinity of:

- 140 children and young people with disabilities in out-of-home placements under section 141
- 350 children and young people with disabilities under other care and protection arrangements
- The number requiring high levels of input at any given point in time is only a small proportion of this total. We estimate that there are likely to be no more than 50 section 141 placements a year, nationwide, and possibly 100 placements of children and young people with disabilities under other care and protection arrangements.

We were not able to get a good grasp on the cost of services for this group of children and young people. The partial information we obtained indicated that for the children and young people in foster placements, the average annual cost to DSD was $41,563 and that for children in residential placements the average annual cost was $76,724.

The average annual cost to CYF for children and young people in s141 placements was $15,103., The average annual cost to CYF for children and young people in out-of-home placements under s101, s110, or s101 and s110 was $29,269.

Extreme caution needs to be exercised in interpreting this data.

Children first

We considered the appropriateness of having the 'disability provisions' (sections 140-149) in the CYPF Act, given the views we heard about the main purpose of the Act and the core business of CYF. We concluded that these provisions should remain in the CYPF Act and that CYF should continue to be involved with this group of children and young people, for the following reasons:

- To locate the care arrangements for children and young people with disabilities in the same regime as for other children
- To keep the focus on the children and young people rather than on their disability – they are children first

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[2] That is, those who meet the prevailing Ministry of Health definition of disability for the purposes of the Health and Disability Act.

- To reinforce CYF’s role as the agency through which the State supports and, when necessary, assumes the role of parents whenever circumstances require this
- Informal arrangements made by families and administrative arrangements managed by the appropriate government departments would not be robust enough for the long-term care arrangements involved.

Establishing clear principles

The policy framework for care and protection is underpinned by a clear and robust set of principles. This is contained in a variety of documents, among them:

- The United Nations Convention of the Rights of Children (UNCROC)
- The Children, Young Persons and their Families Act 1989, and
- The Care of Children Act 2004.

The Care of Children Act emphasises that “the welfare and best interests of the child must be the first and paramount consideration, in the administration and application of this Act … and in any other proceedings involving the guardianship of, or the role of providing day-to-day care for, or contact with, a child”.

In practice however, the framework for children and young people does not tend to inform wider government policy and operational practice. Also, CYF appears to apply the framework less rigorously with respect to children and young people with disabilities. DSD does not have a principles framework for children and young people with disabilities.

The Memorandum of Understanding between CYF and DSD is a useful vehicle for the agencies to express their commitment to a shared set of principles. The new MoU includes the following:

Principles

- That the rights of children are recognised and that they are not diminished by the presence of a disability
- That the best interests of the child are our primary concern
- That the child lives with or is regularly cared for by his or her own family or, when this is no longer possible, by (in order of preference) members of his or her own family, another family, or in a residential setting that is as family-like as possible
- That the care provisions of section 139 and/or section 140 will be used and every effort made to strengthen the capacity of the family to resume full-time or regular care of the child, before an out-of-home placement under section 141 is considered
- That at least as much support is made available to maintain the child with its family as would be provided for an out-of-home placement
- That an out-of-home placement under section 141 will be a last resort
- That no child under the age of seven years will be placed under section 141

- That when an out-of-home placement is being considered, the child will have an independent voice in the process and the child's interests will be recognised
- That when an out-of-home placement is being arranged, the child's involvement in education and other aspects of community life will be maintained with as little disruption as possible
- That the unique and complex support needs of this particular population are recognised by a response that takes a whole-of-life perspective, protects and strengthens natural resources, and uses available resources flexibly to develop individually tailored support packages.

Establishing a shared understanding between the agencies

There is a conspicuous lack of understanding about what lies behind the need for an out-of-home placement. Some see these children in terms of their deficits and regard them as too difficult to care for within a family, while others characterise the families seeking out-of-home placements as being not sufficiently committed to their children's best interests.

A shared understanding is required that is not unduly influenced by particular stakeholder interests or ideological positions. It needs to be non-judgemental. It needs to take account of the complexity of individual family situations, while providing a 'way in' to making an appropriate response.

The most helpful way to define the problem that we are endeavouring to address is to view it as an imbalance between the resources available to a family and the resources they require to function successfully.

A focus on the adequacy of the family's resources recognises that:

- The resources of a family need to match the demands it faces
- Family, extended family, community and government can help in many ways
- We can protect and strengthen the family's resources
- We can endeavour to manage the demands on the family's resources
- We can supplement the family's resources so that they are sufficient for the demands that the family faces
- We should try to ensure that any gap between the available resources and the demands on the family is not unsustainable
- We need to provide a safety net when the gap between the resources available to the family and the demands on them becomes unsustainable.

Clarifying the funding responsibilities of agencies

It is often unclear to CYF and DSD staff which agency should pay when a child or young person has a disability. In spite of the description of funding responsibilities in the 1999 Memorandum of Understanding, an expectation has developed that:

- If the out-of-home placement is caused by a child's or young person's disability support needs, then DSD will pay the full placement costs, or

- If the out-of-home placement is primarily caused by a child's or young person's care and protection needs, or if there is no intention for the child to return home, then CYF will pay the full placement costs.

This way of thinking about the situation encourages each agency to 'off-load the problem', and leads to protracted arguments about the cause of the out-of-home placement, and about funding responsibility.

Similar issues arise, usually for CYF, in relation to costs that schools or the Ministry of Education, or the funders of transport assistance would normally pay.

Policy on the roles and funding responsibilities of CYF and DSD is unambiguous, and is set out clearly in the 1999 Memorandum of Understanding:

- CYF is responsible for paying for services and supports related to care or protection, whether or not a child has a disability
- DSD is responsible for paying for services and supports related to disability, whether or not a child is involved with CYF or any other agency.

In other words, there is already agreement between CYF and DSD on their respective responsibilities and this agreement needs to find its way into practice.

Currently DSD pays basic living costs for children with disabilities in out-of-home placements under sections 141 and 142 (ie, food, shelter and clothing) and this seems an anomaly. The funding pathways for children and young people with disabilities should be normalised, that is to say, they should be no different from those for non-disabled children and young people. Accordingly, it is our view that:

- Families should be expected to contribute financially to the cost of the day-to-day care of their child (food, shelter, clothing) when this is within their means
- Any State contribution to the costs of day-to-day care should be provided by Work and Income, via the benefit system.

Integrating and strengthening the CYPF Act pathways

Part Two of the CYPF Act, which deals with care and protection, sets out two distinct pathways; the main 'care and protection pathway' and a separate 'disability pathway'.

Once a child or young person with a disability becomes involved with CYF, a judgement has to be made over which pathway is the more appropriate. Over time, this has become a major sticking point between CYF and DSD, and between their respective agents.

A raft of issues related to the two pathways and the differences between them has been identified. These issues have led some people to conclude that the best option is to remove the disability pathway altogether, to treat all requests for a full-time out-of-home placement as abandonment, and to deal with them under the care and protection pathway.

In our view, integrating the 'care and protection' and 'disability' pathways is a better way to improve consistency of approach and to ensure that the child's best interests are considered, all the options are explored and out-of-home placement is not a foregone conclusion. The integrated pathway would also mean that an out-of-home placement can be arranged without subjecting the family to a Court process.

The common pathway we are proposing will involve:

- Children and young people with disabilities who would previously have entered the system via a section 145 referral, now entering via a section 15 referral to CYF.
- Determining whether a formal investigation under section 17 is appropriate (ie, to ascertain whether the child or young person has been abused or neglected or is in imminent risk of abuse or neglect). Disability-specific indicators and/or a disability-specific approach will need to be developed.
- All FGCs being held under section 20 and the section 145 process no longer being used. The FGCs under section 20 will need to develop plans and strategies that explore a wider range of options than currently occurs under either pathway.
- Strengthening the section 20 FGC process for children and young people with disabilities through the participation of the section 141 certifier. We propose a change to the role of the section 141 certifier, so that they can meet the child or young person, their family and any proposed caregivers, and participate in the FGC *before any decisions are made.*
- Placements under section 139 continuing to be used for responding to crises.
- More frequent use of out-of-home placements under section 140. These are of shorter duration than some other options, and should be used earlier and more proactively while a sustainable care arrangement is developed with the family.
- Strengthening the section 141 process so that it is more closely aligned with the processes under section 101, which it is intended to mirror. This entails:
  - Regarding the section 141 placement as lasting until the child or young person turns 17
  - Ruling out section 141 placements for children under seven
  - A fully inclusive and thorough FGC process
  - A degree of advocacy through the involvement of the section 141 certifier
  - A reduction in the interval between formal reviews from two years to a maximum of one year, as for arrangements under section 101
  - A change to the section 141 agreement, so that it cannot be terminated on seven days notice. The FGC should be reconvened to consider the merits of any proposed change in custody, and to develop a plan for appropriately managing any transition in the best interests of the child or young person.
- Placements no longer being made under section 142.

Strengthening processes within and between agencies

During our consultation it became evident that where processes work well there is a common denominator — people with specialist interest or expertise in this area are known by their counterparts in the other organisation, and they meet regularly. Often these arrangements were relatively informal and had evolved over time as the staff involved with children and young people with disabilities and their families got to know each other. A more systematic approach is called for, to ensure there are good intersectoral relationships and processes everywhere and that they contribute to good outcomes. The necessary components include:

- An explicit commitment to working together to achieve a common goal
- Designated staff with authority to make decisions
- Regular contact
- Escalation pathways
- Joint and ongoing training
- Complementary data capture systems
- Mechanisms for monitoring and evaluating performance against the MoU and outcomes.

The new MoU comments on each of these.

Improving access to required services

Key informants and focus group participants identified a number of concerns about the availability of disability support services for children and young people with disabilities and their families, among them:

- Only a limited range of services is available
- There are critical service gaps, such as community support and specialist caregivers
- There is a lack of transparency and consistency in what is funded and for whom.

DSD should be developing disability support services that can be readily accessed by clients of CYF who meet the general eligibility criteria.

DSD has a considerable programme of work underway, to strengthen systems and processes and to improve services. Little of this work is targeted at children and young people with disabilities, however, and none of it focuses on the group at the centre of this review, whose support needs tend to be high and complex and lie outside the normal range. At present this group is seriously disadvantaged, and will continue to be so unless it becomes the focus of ongoing work, and gains a higher profile in other work being done by DSD.

Our review has highlighted a number of priority areas for further development. These are:

- A policy framework to inform and unify DSD’s approach on children and young people with disabilities and their families
- Use of individualised funding for this group of children and young people
- Wider application of Intensive Service Co-ordination
- Purchasing of a community support worker function
- The development of specialist caregivers
- Greater use of family caregivers.

In addition, more consistency among Needs Assessment and Service Coordination services (NASCs) and greater transparency about eligibility is required. People appreciate that resources are limited, and that access needs to be prioritised.

Consistency among NASCs would be improved by:

- A strategic framework
- Strong direction and national leadership
- Common service specifications and objectives
- A requirement to offer a range of flexible support services
- A focus on achieving desired outcomes
- Standardised assessment tools and processes
- Common training on the above.

Implementation

We have outlined the major components of the implementation task as we see them, although any comments that we make can only be conditional. The major elements of the task are:

- The agencies' response to the report
- Managing the implementation task
- Implementing the new MoU
- The new role of the section 141 certifiers
- Implementing the monitoring and evaluation strategy
- Legislative changes.

We have also identified activities that will require additional funding.

Conclusion

The solutions we have proposed will, we believe, address the concerns that gave rise to this review. In our view, improvements at the interface between CYF and DSD will not be difficult to achieve, but a commitment on the part of the agencies is required.

Progress depends on a commitment from CYF and DSD, to:

- Keeping a focus on this group of children and young people with disabilities. The first step is to assign responsibility for this group to specific people in their organisations, with the appropriate resources and capacity
- Recognising that the proposals are interdependent and implementing them as an integrated package
- Tackling the bigger issues, like access to alternate caregivers, which in practice have significant consequences for children and young people with disabilities and their families.

Recommendations

Establishing a shared understanding between the agencies

1. Establish a shared understanding between the agencies that is not unduly influenced by stakeholder interests or ideological positions, and that takes account of the complexity of individual family situations, including:
    - A problem definition that focuses on the imbalance between the resources available to a family and the resources they need to function successfully *(see sections 5.5, 5.6, 5.7)*
    - Normalisation of agency roles and responsibilities to ensure that children and young people with disabilities who are the subject of a process under Part Two the CYPF Act, or who are receiving care and other services in terms of Part Two of the CYPF Act are treated the same as other children and young people to the fullest extent possible *(see sections 6.3, 6.4)*
    - Recognising that the primary cause of an out-of-home placement is not a relevant consideration in determining agency roles and responsibilities. *(see section 6.2.1, 6.3)*

Strengthening the 'disability provisions' in the CYPF Act

2. Acknowledge that CYF is the agency through which the State takes care of children and young people with disabilities when their parents are no longer willing or able to be responsible for their day to day care. *(see section 3)*

3. Retain the 'disability provisions' in the CYPF Act, with the modifications outlined below.
(see section 3.7)

4. Integrate the 'care and protection' and 'disability' pathways in the CYPF Act, in order to improve consistency of approach, to ensure that the child's best interests are considered, that all the options are explored, and an out-of-home placement is not a foregone conclusion, by:
    - Using a section 15 referral to CYF as the entry point for children and young people with disabilities who would previously have entered the system via a section 145 referral.
    - Undertaking a formal care and protection investigation when this is indicated.
    - Using the process under section 20 for all FGCs and discontinuing the use of section 145 FGCs
    - Using section 20 FGCs to develop plans and strategies for children and young people with disabilities that explore a wider range of options than currently occurs under either pathway. *(see section 7.4)*

5. Strengthen the section 20 FGC process for children and young people with disabilities through the participation of the section 141 certifier, with modifications to the role, including:
    - Meeting the child or young person, their family and any proposed caregivers

- Ensuring that the child's views are considered in the FGC
- Ensuring that the principles set out in the MOU, and agreed processes, have been adhered to before an out-of-home placement is considered
- Providing independent advice about what is required to meet the child's best interests. *(see section 7.4.4)*

6. Continue to use section 139 placements for responding to crises involving children and young people with disabilities. *(see section 7.4.4)*

7. Use section 140 earlier and more proactively, while a sustainable care arrangement is developed in order to return the child to their family. *(see section 7.4.4)*

8. Restrict the use of section 141 to children aged 7 years and over only, with those under 7 years going through usual care and protection processes if an out-of-home placement or other form of care and protection is required. *(see section 7.4.4)*

9. Use section 141 as a last resort for full-time out-of-home placements, when day-to-day care is unlikely to be resumed by the family. *(see section 7.4.4)*

10. Reduce the interval between FGCs and review the suitability of section 141 placements annually, as occurs for arrangements under section 101. *(see section 7.4.4)*

11. Make termination of a section 141 placement subject to FGC agreement, rather than on 7 days' notice, in order to promote stable care arrangements and managed transitions. *(see section 7.4.4)*

12. Stop using the provisions of section 142 for out-of-home placements for children and young people with disabilities. *(see section 7.4.4)*

Clarifying agency funding responsibilities

13. Normalise funding pathways for children and young people with disabilities so that:
    - Families contribute financially to the cost of the day-to-day care of their child (food, shelter, clothing) when this is within their means.
    - Any State contribution to the costs of day-to-day care is provided by Work and Income, via the benefit system.
      (see section 6.4.1, and proposed MoU)

14. Agree that CYF is responsible for paying for services and supports related to care or protection, whether or not a child has a disability. *(see section 6.4.1, and proposed MoU)*

15. Agree that DSD is responsible for paying for services and supports related to disability, whether or not a child or young person is the subject of a process, or is receiving care and other services, under Part Two of the CYPF Act. *(see section 6.4.1, and proposed MoU)*

16. Undertake further work on the funding of transport assistance where children and young people are involved with multiple agencies. *(see section 6.4.2)*

17. Develop a policy on the funding of modifications to dwellings that are home to children and young people with disabilities. *(see section 6.2.4)*

18. Ensure that transitional planning occurs as follows:
    - Local CYF and NASC staff will meet to develop a transition plan for each child who is involved with the NASC and CYF
    - Transition planning will commence before the child turns 16
    - Transition planning will be completed *at least* six months before the child turns 17. *(see section 6.4.3)*

Improving access to required disability support services

The Disability Services Directorate should:

19. Designate at least one full-time position to be responsible for ensuring that the needs of children and young people with disabilities and their families, and in particular those with high and complex support needs:
    - Have a specialist focus within DSD.
    - Are properly considered and adequately addressed in mainstream work programmes within DSD, the health and disability sector, and wider contexts. *(see section 11.7)*

20. Develop a policy framework to inform DSD's approach on children and young people with disabilities and their families that is consistent with the wider care of children framework and principles set out in the proposed MoU. *(see section 10.4.1)*

21. Develop risk indicators to facilitate monitoring of need and timely access to early intervention, community support worker services, Intensive Service Co-ordination and individualised service packages and funding to ensure that 'at risk' families are supported to function successfully. *(see section 10.4.5)*

22. Incorporate access to Intensive Service Coordination as a requirement in the new MoU. *(see section 10.4.4)*

23. Develop and use an appropriate funding model for the purchase of residential support services for children and young people placed under section 141 of the CYPF Act, to ensure that assessed disability support needs are met. *(see section 10.4.3)*

24. Develop a service specification for a community support worker role, purchase these services in several locations, and evaluate the services with a view to a national roll-out. *(see sections 10.2.2, 10.3.3)*

25. Develop a multifaceted strategy for enhancing access to alternate caregivers that:
    - Preserves the current workforce by providing a good level of practical support, and adequate remuneration
    - Makes more efficient use of current caregiver capacity by managing the allocation of caregivers to families who can best use their skills
    - Increases the numbers of specialist caregivers available by using community development strategies to identify potential caregivers
    - Reduces demand for out-of-family care by supporting other family members to provide required care
    - Reduces demand for the out-of-family care by supporting families better through monitoring of risk indicators, responding promptly to emerging

need, mobilisation of natural and community supports, and timely access to appropriate services.
(see sections 10.3.4, 10.4.5)

26. Improve consistency among NASCs by providing strong direction and national leadership, developing common service specifications and objectives, developing standardised assessment tools and processes, and developing and providing a national training programme for NASCs. *(see sections 10.2.3, 10.2.4)*

27. Increase consistency, transparency and accountability by making publicly available reliable information about DSD's eligibility criteria, processes, and the services and supports it funds. *(see sections 10.3.5, 10.4.6)*

Replacing the current Memorandum of Understanding

28. Replace the 1999 draft Memorandum of Understanding with a new Memorandum of understanding that incorporates:
    - An explicit commitment to work together collaboratively
    - An set of principles to underpin operation of the MoU
    - Processes for timely consultation, coordination and joint decision making
    - A requirement for formal transition planning to occur
    - Clear guidance on funding responsibilities

    as set out in Appendix Three to this report, and subject to such modifications as the DSD and CYF may agree on. *(see Appendix 3)*

Other recommendations

29. DSD and CYF should develop a simple approach for recording meaningful disability information within CYFs database system (CYRAS), in order to identify all children and young people with disabilities who are clients of CYF for the purposes of monitoring and evaluation. *(see section 9.3.1)*

30. DSD and CYF should develop a simple approach for recording meaningful care and protection information within the NASC/DSD database system, in order to identify all children and young people with disabilities who are clients of CYF and/or are in out-of-home placements, for the purposes of monitoring and evaluation. *(see section 9.3.2)*

31. DSD and CYF, in collaboration with government and community stakeholders, should develop a set of outcome measures that reflect the principles set out in the care of children and DSD frameworks. *(see section 9.4.3)*

1 Introduction

1.1 Terms of Reference

The Baseline Review of the Department of Child, Youth and Family was undertaken by the Ministry of Social Development, CYF and the Treasury and was completed in September 2003. The Blueprint Investment Strategy is the Department's response to the Review and this project is one of the work-streams making up CYF's Blueprint Investment Strategy.

1.1.1 Two components of the task

The Baseline Review identified service access and inter-agency collaboration as problems in the provision of services for children with disabilities and their families. CYF and the Ministry of Health were directed to work together to develop solutions and in response to this directive, and they obtained Cabinet approval and funding to undertake (CAB Min (04) 12/6 refers):

- A first principles review and analysis of the legislative and policy frameworks for children with disabilities and
- A review of the operational agency interface between CYF and the Disability Services Directorate (DSD) of the Ministry of Health, based on the Memorandum of Understanding co-signed in 1999.

1.1.2 Purpose

The purpose of this work was to:

- Explore the policy, legislation and operational practice related to children and young people with disabilities and their families who are involved with CYF and DSD
- Identify the causes of the problems at the interface between the agencies
- Recommend changes that would clarify the principles, policy and operational practice

in order to promote access to timely and appropriate support services.

1.1.3 The desired outcomes

CYF and DSD indicated that the outcome they were seeking was a clear policy and operational framework which would support inter-agency collaboration and service delivery for children with disabilities and their families. The specific outcomes they sought included agreement on:

- A common understanding of disability between the agencies
- A common understanding of what constitutes an out-of-home placement
- A common understanding of the differences between care and protection issues and disability support needs, so that children with disabilities will only come under the auspices of CYPF Act when it is appropriate
- Clarification of agency responsibilities
- The design and delivery of quality support services within Child, Youth and Family for children with disabilities and their families

- Consistent interpretation of the CYPF Act across agency staff, including clarification of the intent of the legislation and CYF statutory processes for section 141 agreements for children with disabilities
- Methods for identifying and addressing issues in an appropriate and timely manner
- Increased intersectoral collaboration and co-operation.

1.2 Method

1.2.1 General approach

There are a number of complex and inconsistent legislative, policy and operational interfaces involving the support of children and young people with disabilities and their families, and out-of-home care arrangements. We considered that the best approach was to focus on the processes described in sections 139 to 145 of the CYPF Act, related legislation and policy, and the roles of CYF, DSD and contracted organisations before, during, and following out-of-home placements. This would involve a detailed drill-down to expose the underlying drivers of the issues, which have wider application to the interfaces between CYF and DSD.

We gathered information from May to October 2005, and completed a draft report in January 2006. Agency feedback was considered and the draft finalised in April 2006.

1.2.2 Components of the review

The main components of our review were:

A review of departmental papers

Both CYF and DSD – as well as some of the service providers – had already done a considerable amount of work to document the issues and to identify the cause of problems at the interface between CYF and DSD. We reviewed departmental briefing papers and analyses of the issues, as well as the exchanges between front-line and National Office staff in CYF, DSD and the NASCs about particular cases.

A data-gathering exercise

We undertook a data-gathering exercise, involving CYF, DSD and the section 141 certifiers, in an attempt to establish the number of children in out-of-home placements and the number of new out-of-home placements each year, and to determine the cost of the services.

Key informant interviews

We met *key informants* from government agencies. As well as National Office staff at CYF, DSD and the Ministry of Education, we met representatives of the Ministry of Social Development, the Ministry of Youth Development, the Office of Disability Issues, the Office of the Children’s Commissioner, the Families Commission and the Ministry of Health. We also met Judge Peter Boshier, the Principal Family Court Judge. We met representatives of national organisations, including for example, IHC/Idea Services, CCS, and Carers New Zealand among others. Details of those consulted are included in Appendix Six.

Focus groups

We held *focus groups and interviews in regional centres*, which were selected for the following reasons:

- Dunedin (and Invercargill), have widely dispersed and relatively small catchment populations. The range of out-of-home placement options is not well developed. There is very limited use of foster placements in Dunedin or Invercargill.
- Christchurch is reported to have relatively good levels of intersectoral collaboration and some innovative services. Until recently, the levels of disability support services provided in the region have exceeded national averages by a considerable margin.
- Hamilton has a relatively well-developed range of disability support services overall, with pockets of innovation.
- Auckland is the major urban population centre, and is the most demographically diverse. There has also been a cluster of controversial issues there in recent times. We had been told that there are strongly-held positions that would provide valuable input to the project.

In most of these regional centres we met with NGOs, with CYF staff (Social Workers and Care and Protection Co-ordinators), with the NASCs, with child development staff at District Health Boards, and with Group Special Education staff. The purpose of these meetings was to explore local experience, to give us an insight into the perspectives of the different sectors and the different players in the process, and to give us a sense of the national picture. We were interested in finding out about processes that worked well in each area, and innovative solutions that had been developed. We also wanted to get a sense of what mattered most to families and providers and what might work well to improve the system.

We also held a focus group with *section 141 certifiers*. The certifiers have a unique overview of placement processes and issues, and several had recently expressed concern over aspects of the processes for supporting children with disabilities, their families and service providers.

As far as possible, we sought a *Maori perspective* on services for children with disabilities and out-of-home placements. Some key informants were Maori and/or commented specifically on Maori perspectives. We met Ngati Kapo in Hastings and the CCS Community Support Co-ordinators at Papakura and we consulted Roger Jolley, DSD’s Manager, Maori Development. None of the agencies could refer us to a Maori reference group on disability issues. Also, we were told that none of DSD’s contracted Maori providers of disability support services provided out-of-home placements for Maori children and young people under section 141 of the CYPF Act.

We did not target *parents* for consultation as part of this review because of earlier work that had been done. Some of the people we met with in other capacities were in fact parents of children with disabilities. *Just Surviving* (Carpinter et al, 2000) and other reports provide a comprehensive account of parents’ and families’ experience with children with high and complex disability support needs, and their experience in dealing with the agencies in the disability, health, education and other sectors. In the light of this earlier work, we decided not to impose on the good will of parents by consulting again on the same issues. There was no reference group of *children and young people with disabilities* that we could consult for their perspective, so we have relied on secondary sources that report on the views of children and young people with disabilities.

Details of the people we consulted are set out in Appendix Six.

Review of other jurisdictions

We reviewed the New Zealand and overseas literature and took, as a starting point, Australia, Canada and Britain for the period from 1998 to 2005. We focused on services for children and young people with disabilities and their families and inter-sectoral strategies and collaboration related to care and protection and children and young people with disabilities. We also reviewed the literature on inter-agency collaboration more generally, with a focus on successful models of collaboration.

Appendix Seven provides an overview of what we found. A selected bibliography is included as Appendix Eight.

1.3 Related work

We were aware from the outset that there was a substantial amount of work going on that had a bearing on our project. This included:

- *The Interagency Needs Assessment and Service Coordination (INASC) trials*, led by DSD and being run during 2005 in Rotorua, Wellington and Christchurch. The aim of the trials was to improve intersectoral collaboration in needs assessment and service co-ordination for disabled people under 65 years of age.
- *The roll-out of intensive service co-ordination* (ISC) by DSD. The objective of intensive service co-ordination is "to provide co-ordination of supports, be they natural resources and/or formal paid services, for the small number of people within the NASC client population who have high and complex needs, usually requiring the involvement of multiple providers and ongoing problem-solving." ISC also involves an ongoing relationship between the co-ordinator and the person, their family/whanau, and carers where relevant, for the period that intensive service co-ordination is needed.
- *A pilot of intensive/flexible family support services*, led by Family and Community Services of MSD, and CCS.
- *Autistic Spectrum Disorder workforce development*, led by DSD.
- *Autistic Spectrum Disorder, severe anti-social behaviour project*, led by DSD.
- *A home-based support workforce training project* being undertaken by DSD.
- Policy work on *payments for family caregivers* by the Office of Disability Issues.
- A *review of long-term disability support* services by the Office of Disability Issues.
- Service development work on an *advocate for disabled children and young people*, being undertaken by CYF.

- *The development of the Differential Response Model* by CYF. Changes to the CYPF Act 1989 will introduce a differential response model, intended to promote more effective and timely service for CYF clients by enabling the Department to respond more flexibly to different types of notifications. "The changes should signal a move towards more support for children, young people and families in situations of low risk but high need. Having multiple explicit options for responding at intake should help CYF to respond more appropriately to different kinds of notifications than it can at present. The new 'preliminary assessment' process being introduced should identify some notifications that need investigating, others that need a family support response, and others again that need both (or some other response)."[3]
- *Changes to the role of CYF* and the transfer of some responsibilities to MSD. For example, the Family Start programme transferred from CYF to Family and Community Services of MSD from 1 July 2005.[4]
- *The restructuring of CYF.* This meant that some of the organisational structure and new roles had not been finalised.
- Policy work by CYF and DSD on *compulsory care of young people with intellectual disabilities who offend* (IDCC).

Some of this work has the potential to improve services for the children and young people with high and complex disability support needs and might reduce the need for out-of-home placements. Little of it is specifically focused on the issues at the interface between CYF and DSD, and few of the projects focus specifically on children and young people with disabilities.

1.4 This report

1.4.1 Reliability of the findings

This report brings together a diverse and complex range of issues. Input was sought from many different perspectives. Much of the information was subjective and anecdotal. The themes arising were highly consistent though, suggesting that we have obtained a reliable impression of the current situation. We have made our best endeavour to capture detail as accurately as possible. People in key positions sometimes provided contradictory advice as to current policy and practice. We were not always able to clarify these matters to our satisfaction. A draft report was provided to DSD and CYF, seeking the identification of any errors or omissions. It is likely because of the scope and level of complexity that some errors remain. None-the-less we are confident that the picture we have presented is fair and that the conclusions we have reached are sound.

1.4.2 Focus of the report

Although our review involved a significant amount of research and consultation, the focus of our report is on discussing the underlying issues and setting out our proposals for addressing them. Extensive appendices are included to ensure that the research and thinking underpinning the recommendations are captured. A glossary is also included.

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[3] Waldegrave et al, 2005.

[4] Prior to the conclusion of this report it was announced that CYF would be incorporated into the Ministry of Social Development.

2 Background: Identifying the group of children and young people

2.1 Description of the children and their situations

The review focuses on children and young people with disabilities under the age of 17 who are, or ought to be, involved with both CYF and DSD. Sometimes the disability is incidental to a care and protection issue. Sometimes it is the needs of family members rather than the needs of the child or young person with disabilities that are most pressing. Sometimes the disability may be a critical factor, especially where the disability support needs are high and/or complex. Typical scenarios include:

- A boy aged 12 years with severe autism. He becomes extremely distressed by even the smallest changes in routine or environment. His distress is expressed through violent outbursts, often directed at his 6 year old brother. His father finds it increasingly difficult to manage his son's outbursts without violence.
- A girl aged 9 years, with severe intellectual and physical disabilities. She sleeps poorly and receives fluids via a feeding tube directly to her stomach. She is dependent on others for all her needs. She has an 11 year old sister who the mother relies on heavily. The mother is depressed and father has moved to Australia.
- A girl aged 14 who is blind and has a moderate intellectual disability. She is overweight, and has poor muscle tone and co-ordination. She needs physical assistance with most tasks. Her mother is her primary care-giver, and she has permanently injured her back.
- A boy aged 15 with a moderate intellectual disability and Attention Deficit Disorder. He has a history of antisocial behaviour that has not responded to behaviour management programmes. He has recently been accused of exposing himself to boys and girls at his school. He is cared for by his mother and her new partner. There are four younger siblings, two of whom have been the subject of care and protection notifications in the past for being left at home without adult supervision.

In each of the scenarios there are disability and care and protection components that need to be explored before an appropriate response can be determined. Many response options may be possible, such as increased respite and/or the mobilisation of an intensive short-term strategy under the auspices of the High and Complex Needs (HCN) unit.[5] Any of these scenarios however, could potentially require an out-of-home placement of one sort or another, depending on factors such as safety, the family's resilience, whether friends and relatives can increase their support and assistance, whether appropriate support services are available and so on.

An out-of-home placement may be required:

- In the child's or young person's best interests, where adequate care is not being provided

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[5] See Glossary.

- Where the family cannot continue to provide adequate care, and a placement needs to be found that supports the best interests of the family.

2.2 Defining the group

Previous attempts to define the group of children and young people with disabilities who are involved with both CYF and DSD have focused on cause (ie, whether their need for an out-of-home placement is primarily caused by their disability or by care and protection concerns in the family situation) but this has not proved helpful. There are indicators such as the severity or type of disability, whether the family is a single-parent family and how many children are in the family, which might suggest that a family may be at risk but these indicators have no predictive reliability. In fact, the group is defined by the involvement of both CYF and DSD. Accordingly, we have developed the following working definition.

> *"Children and young people with disabilities*[6] *who are the subject of a process under Part Two the CYPF Act, or who are receiving care and other services in terms of Part Two of the CYPF Act."*

2.3 The numbers involved

Based on data supplied by CYF, DSD and current section 141 Certifiers, we estimate the number of children and young people in this group, as at 1 July 2005, to be in the vicinity of:

- 140 children and young people with disabilities in out-of-home placements under section 141
- 350 children and young people with disabilities under other care and protection arrangements.

The number requiring high levels of input at any given point in time is only a small proportion of this total. We estimate there are likely to be no more than 50 section 141 placements a year, nationwide, and possibly 100 placements of children and young people with disabilities under other care and protection arrangements.

2.4 Costs[7] of services

We were not able to get a good grasp on the cost of services for this group of children and young people. Confounding factors included:

- Data collection systems not having the fields that would permit identification of our client group (ie, CYF has poor capture of data on disability, and DSD captures no data on CYF status)
- DSD and CYF both funding some of the costs for many of the children and young people with a disability in this group
- Inconsistent charging of expenditure to budgets, so that funding data is hard to interpret
- Multiple systems for recording expenditure within DSD, among them the client claims payment system (CCPS) and the contract management system (CMS) for bulk funding of NASCs and providers, making it difficult to get a

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[6] That is, those who meet the prevailing Ministry of Health definition of disability for the purposes of the Health and Disability Act.

[7] All costs reported are approximate, and GST exclusive.

picture of total expenditure. In addition, NASCs may allocate discretionary funding to meet the costs of services in some situations
- Other sources of funds may be accessed, including personal funds, funds from Charitable Trusts, Education funding, DHB funding etc
- Poor record keeping, affecting the reliability of all the information related to this group.[8]

The data reported below is by no means complete or comprehensive and can only give an *indication* of the costs of services.

2.4.1 DSD data

NASCs identified 74 children and young people with disabilities (out of a possible 140) who were in out-of-home placements under section 141 as at 1 July 2005. Ministry of Health national records contained information on the payments for 66 of these 74, and these payments accounted for $4.04 million of DSD expenditure on an annualised basis.

Thirty two percent of this expenditure, or $1.21 million, was spent on the 29 children and young people with disabilities in foster placements:

- The minimum annual cost was $22,485 per child
- The average annual cost was $41,563 per child
- The maximum annual cost was $141,859 per child.

Sixty eight percent of the total placement expenditure, or $2.84 million, was spent on the 37 children and young people with disabilities in residential placements:

- The minimum annual cost was $28,606 per child
- The average annual cost was $76,724 per child
- The maximum annual cost was $233,533 per child.

Based on this data, residential placements are, on average, 1.8 times more expensive than foster placements. This is probably a stronger reflection on contract arrangements than a distinction in the level of support need required by those in foster care and those in residential care. That is to say, the higher premium for residential care is not necessarily caused by the children and young people in residential care having higher disability support needs than those typically in foster care. In Auckland for example, the dominant provider only offers residential care, so foster care options are not available to the majority of children and young people with disabilities, whatever their needs may be.

2.4.2 CYF data

The best source of information on CYF payments relates to payments against national contracts. This does not include payments made in relation to regional contracts and payments to CYF contracted caregivers, for which reliable data could not be readily obtained within our timeframe.

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[8] See section 1, which comments on improving data capture for monitoring and evaluation purposes.

Fifteen children and young people in out-of-home placements under s141, are funded by CYF via national contracts. The following data relates to projected expenditure, totalling $205,814 for the period 1 July 2005 to 30 June 2006 for these 15 s141 placements.

- The minimum annual cost was $2,265 per child or young person
- The average annual cost was $14,701 per child or young person
- The maximum annual cost was $38,584 per child or young person.

In addition these s141 placements attracted at total of $5,630 (average $402 each) to cover items of expenditure such as travel to school, and clothing grants.

Data on some, but not all, s101, s110, and s101/110 combined placements of children and young people with disabilities were available. Data was available for 64 children and young people, and total placement expenditure was $1.649 million.

- The minimum annual cost was $2084 per child or young person[9]
- The average annual cost was $25,761 per child or young person
- The maximum annual cost was $165,484 per child or young person.

In addition these s101 and/or s110 placements attracted at total of $224,528 (average $3,508 each) to cover items of expenditure such as travel to school, school support, clothing, and health expenses.

2.5 Numbers and significance

Extreme caution must be exercised in interpreting the data presented here, given that it is not comprehensive or particularly robust. A major project would be required to achieve a comprehensive picture of the expenditure on children and young people with disabilities in out-of-home placements.

It is clear though, that the population of children and young people with disabilities who are involved with CYF is relatively small, and this may be why they have rarely been under the spotlight for policy and service development.

This group represents however, some of the most disadvantaged members of our society:

- Children and young people with disabilities are particularly vulnerable to abuse.
- They are often unable to communicate, and cannot advocate effectively for themselves.
- Many, but not all, will have high and complex disability support needs, which will often be compounded by other factors such as poor health, poverty and geography.
- They live in a society where, until recently, such children were segregated and where discrimination against people with disabilities is still common.
- Services to meet the needs of the children and young people with disabilities and their families are under-developed.

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[9] Of these children and young people 9 were only placed under s101 and/or s110 for only part of the financial year.

Children and young people with disabilities in this group are, almost by definition, exceptions to the rule. Their situations are unusual, sometimes unique, and the ordinary ‘solutions’ tend not to work for them. Ultimately, this places them at risk of being separated from their families – an outcome that is highly undesirable.

A considerable investment may be required to achieve the outcomes we aspire to for each of these children and young people and, in this respect; their small number may be an advantage.

3 Children First: The relationship between care and disability

3.1 Introduction

This section outlines the issues that were raised with us about the ‘disability provisions’ in the CYPF Act and about the involvement of CYF with this group of children and young people with disabilities. It also places the discussion of the CYF/DSD interface in the context of the UN Convention on the Rights of the Child and New Zealand law on children and young people. It concludes that the (modified) ‘disability provisions’ should remain in the CYPF Act and that CYF has a central role to play. See Appendix Two, *A Framework for the care of children with disabilities*, for more detail on the international and domestic law related to this issue.

3.2 The ‘disability provisions’ in the CYPF Act

Quite early in our review, several people questioned the appropriateness of using the CYPF Act as the mechanism for arranging out-of-home placements for children and young people with disabilities. They suggested that the main purpose of the CYPF Act was to deal with the most serious care and protection and youth justice issues – situations that often involved using the coercive powers of the State to over-ride the normal responsibilities of families and to remove children and young people from home. The circumstances of children and young people with disabilities, when these concerns do not arise, were seen to be of a very different order from the main business of the Act (and of CYF) and it seemed inappropriate to include them in the regime dealing with care and protection and youth justice.

As well, we were told that the families of children and young people with disabilities who needed an out-of-home placement often felt they were stigmatised by having to go through a CYF process to arrange the placement. This was particularly hard for the families who had done their very best to care for their disabled children but who could no longer manage. It was suggested that if the process was not so closely linked to CYF and the care and protection process, it would be much easier for the families of children and young people with disabilities.

3.3 The Baseline Review and CYF core business

We were also briefed on the Baseline Review of CYF, and the position that the Review had taken on the role of CYF. We were told of the functions that were transferring to the Ministry of Social Development, and of CYF’s intention to focus on its “core business”. Again, it was suggested that CYF’s core business might not include an involvement with children and young people with disabilities except where there was a serious care and protection or youth justice issue.

3.4 Arranging care: the family’s role, with support from the State

The position outlined in New Zealand law is that, if a child or young person needs care or support which the family is not able to provide itself, the parents, in the first instance, are encouraged to make their own arrangements:

- They need to identify someone to provide the care.

- They need to provide or secure funding for that care. For example, funding is available through Work and Income for a family caregiver in certain circumstances.

The presumption is that parents will act in the best interests of their child, and the State will intervene only when:

- Parents are not acting in the best interests of the child
- Parents need assistance with the cost of an out-of-home placement (managing access to public funds)
- Parents need help to arrange an appropriate care placement (ensuring quality and safety).

When a family is in crisis, the parents may find it difficult to weigh up the best interests of their child against the family's needs. Where children and young people with disabilities are involved, and especially where they have high and complex support needs, it may be difficult for the family to find a suitable out-of-home placement for their child, and to pay for it.

One informant suggested that the CYPF Act has two important functions; to support families to care for and protect their children, and to provide and fund services of an adequate standard to care for and protect children and young people when their parents cannot.[10]

3.5 The roles of CYF and DSD – distinct but complementary

3.5.1 CYF's role

CYF is the government's agent for ensuring the care and protection of children and young people when families cannot do so. In order to fulfil this role, CYF has expertise in matters such as family ecology and functioning, attachment and permanency, as well as statutory powers under the CYPF Act. In addition, CYF contracts with providers of child and family support services, to purchase alternative care arrangements such as foster care, when a child or young person can no longer live with their family.

The fact that a child or young person has a disability is incidental to CYF's responsibility to ensure the care and protection of children and young people. The disability is significant, however, because it may increase the child's vulnerability to abuse and neglect and/or place a strain on family functioning. As with any particular population group, providing responsive and appropriate services may require the *generic approach* to be modified.

3.5.2 DSD's role

DSD's role, on the other hand, focuses on assessing disability support needs and arranging access to disability supports and services, which may include the provision of funding. DSD works with individuals in the context of their families, but addresses

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[10] Personal communication, Judge Peter Boshier, Principal Family Court Judge, 21 September, 2005.

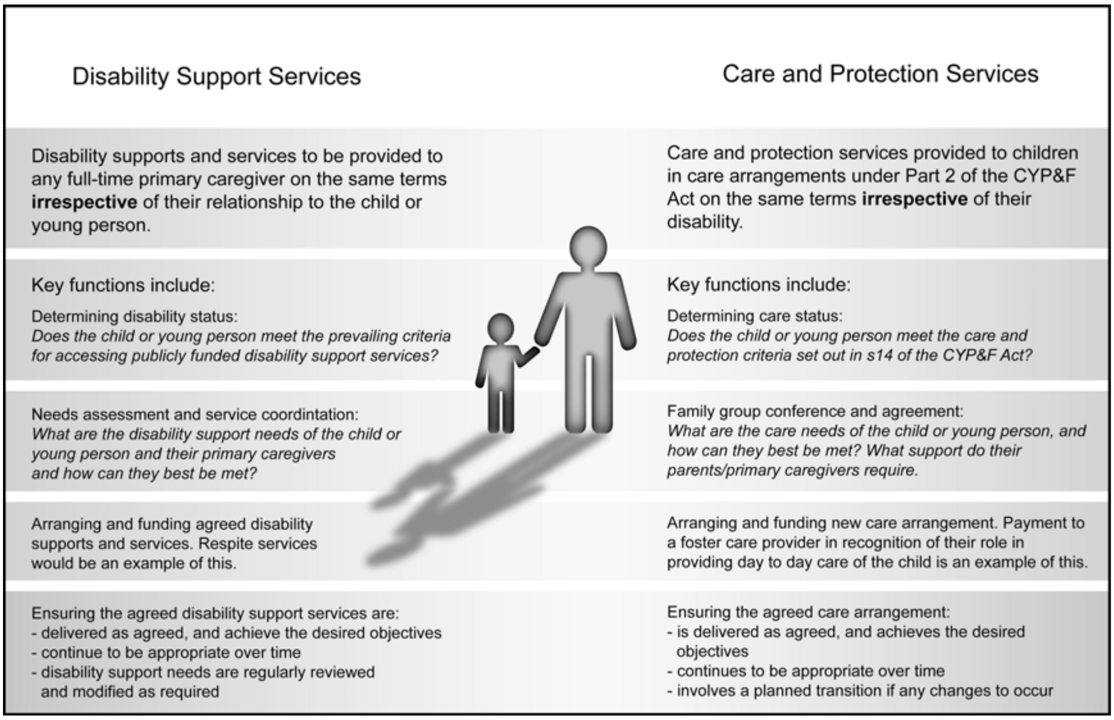
only the child's disability support needs and not those of the family unit, or its support networks, or supports in the community more generally.

The care arrangement for the child or young person with a disability is incidental to DSD's responsibility for disability support services. DSD may need to adjust the level and type of support provided in the event that there is a change in a care arrangement, but *assessed needs* should determine what disability supports and services are arranged rather than the child's relationship to their primary caregiver. The care arrangement itself is not a disability support service.

3.5.3 Relationship between the roles of CYF and DSD

While there are similarities between them, the roles of CYF and DSD do not overlap. Figure 1 below illustrates the differences in responsibilities between the two agencies with respect to children and young people with disabilities and their families.

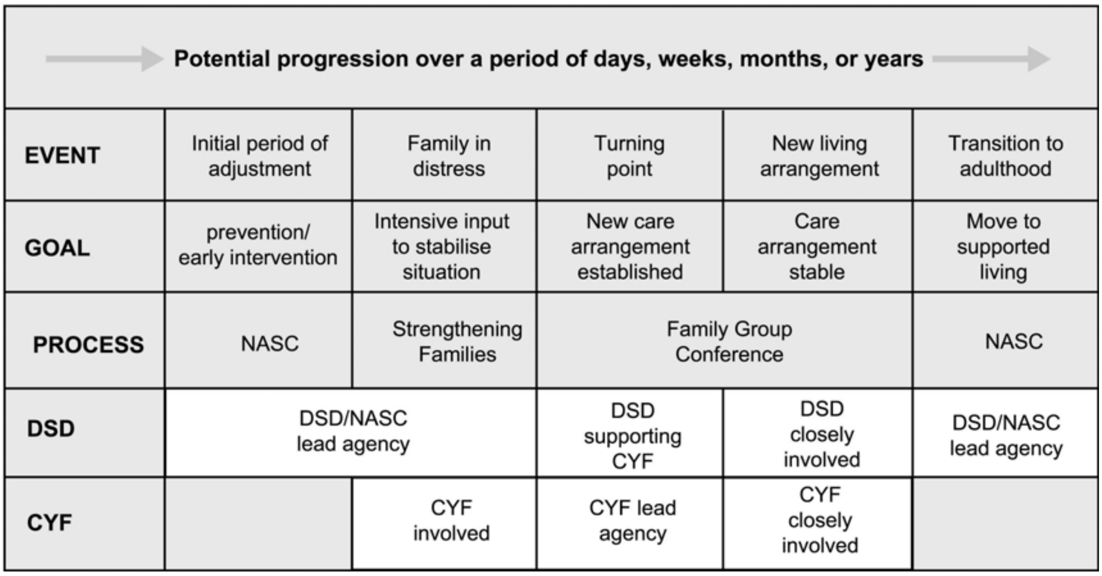
Figure 1: The Roles of CYF and DSD Compared



Disability Support Services	Care and Protection Services
Disability supports and services to be provided to any full-time primary caregiver on the same terms **irrespective** of their relationship to the child or young person.	Care and protection services provided to children in care arrangements under Part 2 of the CYP&F Act on the same terms **irrespective** of their disability.
Key functions include: Determining disability status: *Does the child or young person meet the prevailing criteria for accessing publicly funded disability support services?*	Key functions include: Determining care status: *Does the child or young person meet the care and protection criteria set out in s14 of the CYP&F Act?*
Needs assessment and service coordintation: *What are the disability support needs of the child or young person and their primary caregivers and how can they best be met?*	Family group conference and agreement: *What are the care needs of the child or young person, and how can they best be met? What support do their parents/primary caregivers require.*
Arranging and funding agreed disability supports and services. Respite services would be an example of this.	Arranging and funding new care arrangement. Payment to a foster care provider in recognition of their role in providing day to day care of the child is an example of this.
Ensuring the agreed disability support services are: - delivered as agreed, and achieve the desired objectives - continue to be appropriate over time - disability support needs are regularly reviewed and modified as required	Ensuring the agreed care arrangement: - is delivered as agreed, and achieves the desired objectives - continues to be appropriate over time - involves a planned transition if any changes to occur

CYF has a greater role to play when a family is at risk, and when alternate care arrangements are made. DSD's involvement begins before this and continues afterwards, potentially from the time the child or young person is identified as having a disability until they transition into services for older people in their later years.

Table 1: Changes in Roles over Time



Potential progression over a period of days, weeks, months, or years					
EVENT	Initial period of adjustment	Family in distress	Turning point	New living arrangement	Transition to adulthood
GOAL	prevention/ early intervention	Intensive input to stabilise situation	New care arrangement established	Care arrangement stable	Move to supported living
PROCESS	NASC	Strengthening Families	Family Group Conference		NASC
DSD	DSD/NASC lead agency		DSD supporting CYF	DSD closely involved	DSD/NASC lead agency
CYF		CYF involved	CYF lead agency	CYF closely involved	

3.6 Alternatives to the CYPF Act mechanism - requirements to be met

There is a range of alternatives to the CYPF Act mechanism for arranging care for children and young people with disabilities, including:

- Informal arrangements between families and others, made by families themselves or through a process such as Strengthening Families
- Administrative arrangements, managed by the appropriate government departments
- A regime based in legislation.

Whatever alternative was used, however, it would need to:

- Ensure a robust and enduring arrangement for the children and young people whose lives are changed by an out-of-home placement
- Reinforce the child’s or young person’s connection to their family
- Promote lasting arrangements, to ensure permanency
- Provide a solid basis for reaching agreements between families and carers
- Provide good processes and clear accountabilities for the agencies involved
- Provide clear responsibilities for guardianship and custody
- Provide a review mechanism to ensure the arrangements are in the child’s best interests
- Ensure that agreements for the care of children and young people in out-of-home placements are recognised by the State through all of the agencies that have contact with the child and the person who is responsible for them – ie, schools, health and disability services, Work and Income (W&I), the Inland Revenue Department (IRD) and others
- Interface smoothly with Court processes should these be required at a later point in time.

3.6.1 Informal and administrative arrangements

We were not convinced that, for the long-term out-of-home placements currently being arranged under section 141 of the CYPF Act, informal or even administrative arrangements managed by the appropriate departments would be robust and enduring enough. They would not meet all of the requirements outlined above.

3.7 Retaining the current provisions in the CYPF Act

In our view it is clear that a legislative regime is required and we could find little to commend any other option except retaining the current regime in the CYPF Act. Moreover, the arguments for locating the regime in the CYPF Act rather than anywhere else were compelling, as discussed below.

3.7.1 Children and young people with disabilities are children first

Government is committed to ensuring that all children and young people are well cared for and protected from harm. To support this, it has established a strong legislative framework under the CYPF Act and Care of Children Act. Section 13 of the CYPF Act sets out the principles specific to the care and protection of children and young people.

The principles that underpin the legislation do not distinguish children and young people with disabilities from other children, recognising that they are *children first*. Their disability does not define them. The consequences of a disability, in many cases, have a significant impact on a child's or young person's ability to achieve the goals for their stage of life, but that does not render the goals irrelevant. The pursuit of these specific goals, and not a lesser or different set of goals, is the reason for providing disability support services to children and young people and their families.

The CYPF Act clearly meets the requirements outlined above. Furthermore, the Differential Response Model, being introduced through an amendment to the CYPF Act, should allow CYF to engage with high-risk families in ways that are more supportive and less intimidating than those used in cases of abuse and neglect. The introduction of the Differential Response Model will, to some extent, address the concern that involving CYF is too heavy-handed a response for some families who can no longer provide the day-to-day care for a child or young person with a disability.

3.7.2 Other considerations

Maintaining the focus on children and young people, rather than the disability, is sufficient reason to continue to use the CYPF Act for making care arrangements for children and young people with disabilities. There are also other considerations that strengthen the argument:

- It has proved counter-productive, and sometimes it is not possible, to establish the main cause of an out-of-home placement. We contend that the attempt to do so is conceptually flawed. The imperative to establish the cause of an out-of-home placement would be even greater if there were a separate legislative regime for children and young people with disabilities.
- If a separate legislative regime were to be established for children and young people with disabilities, it would involve replicating both the regime in the

CYPF Act and CYF infrastructure – staff and expertise – and this would be costly, in terms of both specialist workforce capacity and funding
- DSD, which might seem an obvious choice for what are currently s141 and s142 placements under the CYPF Act, has no framework for children and young people with disabilities
- The Health and Disability legislation is not the appropriate location for the care and protection functions, and the health and disability sector does not have comparable responsibilities
- The workforce of both CYF and DSD has been subject to frequent review and restructuring and further change would be disruptive. Morale is low. Experience and expertise has been lost as staff have left to work in other areas. Our recommendations favour clarifying current roles and responsibilities by aligning practices more closely with existing policy intent.

3.8 Conclusion

It has been assumed that there is overlap between the roles of CYF and DSD, and that care arrangements for children and young people with disabilities who are not being abused or neglected might sit better with DSD. We do not consider there to be any overlap. Rather, the roles are complementary and interdependent.

The CYPF Act, together with the Care of Children Act, provides a very solid framework for ensuring that children and young people are well cared for and protected from harm, even when their families can no longer provide their day-to-day care.

Sometimes the best interests of children and young people with disabilities are eclipsed by the difficulties agencies face in responding to those needs, and as a result inferior outcomes are tolerated. This is not acceptable, but nor is it a good reason for dismissing the CYPF Act as the appropriate legislative regime.

We have identified considerable scope for strengthening the administrative processes under the CYPF Act so that children and young people with disabilities and their families are better served. More effective working relationships between CYF and DSD, that recognise their complementary and interdependent roles, will also do much to improve outcomes for children and young people with disabilities. Our proposals for this are outlined later in the report.

4 Establish Clear Principles

4.1 Current frameworks

There is a strong framework of policy around the care and protection needs of children and young people, underpinned by a clear and robust set of principles. This is contained in a variety of documents, among them:

- The United Nations Convention of the Rights of Children (UNCROC)
- The Children, Young Persons and their Families Act 1989[11], and
- The Care of Children Act 2004.

The Care of Children Act emphasises that “the welfare and best interests of the child must be the first and paramount consideration, in the administration and application of this Act … and in any other proceedings involving the guardianship of, or the role of providing day-to-day care for, or contact with, a child”.[12]

In practice however, the framework for children and young people does not tend to inform wider government policy and operational practice. Also, CYF appears to apply the framework less rigorously with respect to children and young people with disabilities. Tolerance of the placement of children and young people with disabilities in adult services is one example of this. Making a placement under the ‘softer’ section 141 option where a Court order would offer more appropriate safeguards for care and protection is another.

DSD appears to have no specific framework for dealing with children and young people with disabilities, or for those who are the focus of this review. In the absence of a framework, confusion is manifest, resulting in inconsistent and sometimes quite inappropriate treatment and outcomes. Requiring that a family relinquish custody under section 141 in preference to providing more than three days of out-of-home care per week is an example of a highly inappropriate practice that has developed in the absence of any clear framework.[13]

Disputes between the agencies have major repercussions for the families of children and young people with disabilities, who have access to support services delayed, or limited or in some cases denied. In these circumstances, families suffer additional stress and this can lead to a further reduction in their capacity to function effectively.

4.2 The need for complementary frameworks

Application of the care and protection framework to children and young people with disabilities would be strengthened if practice was informed by a complementary disability framework. In the absence of a shared framework, people make assumptions that are not well-founded. One example of this is a belief that children and young people with high and complex disability support needs can only be cared for in a

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[11] Mention of the CYP&F Act should always be taken to include any amendments to the Act unless specified to the contrary.

[12] Care of Children Act 2005, section 4(1)(b).

[13] It should be noted that this is **not** current DSD policy, and never has been, despite some people providing advice and making decisions based on this misconception.

specialist facility – a position that might be reasonably inferred from the wording of section 141 of the CYPF Act, although this is not the case.

Development of a disability framework for children and young people should, in turn, be informed by, and be consistent with, the care and protection framework. While of broader application, any framework developed will need to encompass the principles proposed for the MoU.

4.3 Proposed principles

4.3.1 Principles set out in the MoU

The principles set out below, and in the Memorandum of Understanding in Appendix Three, are not new: they are drawn from UNCROC and current legislation, and make an explicit link to the children and young people with disabilities who are involved with both CYF and DSD. The purpose of stating them is to highlight the key points of the principles in the law as they relate to this group, and to show the commitment of CYF and DSD to giving effect to these principles.

4.3.2 Proposed principles

- The rights of children are recognised and that they are not diminished by the presence of a disability
- The best interests of the child are our primary concern
- The unique and complex support needs of this particular population are recognised by a response that takes a whole-of-life perspective, protects and strengthens natural resources, and uses available resources flexibly to develop individually tailored support packages
- The child lives with or is regularly cared for by its own family for as much of the time as possible
- At least as much support is made available to maintain the child with its family as would be provided for an out-of-home placement
- The care provisions of section 139 and/or section 140 will be used and every effort made to strengthen the capacity of the family to resume full-time or regular care of the child, before an out-of-home placement under section 141 is considered
- When an out-of-home placement is being considered, the child will have an independent voice in the process and the child’s interests will be recognised
- When an out-of-home placement is being arranged, the child’s involvement in education and other aspects of community life will be maintained with as little disruption as possible
- When an out-of-home placement is required, care should be provided by (in order of preference) members of its own family, another family, or in a residential setting that is as family-like as possible
- An out-of-home placement under section 141 will be a last resort
- No child under the age of seven years will be placed under section 141.

5 Develop shared understanding - definitions

5.1 Introduction

All agencies working with children and young people with disabilities need to appreciate that the relationship between disability and support needs is highly contextual – there is no simple causal link, or even a direct correlation between any particular disability or level of disability and the support needs a person or their carers will experience. Each situation is unique and needs to be considered on its own merits.

This section sets out the definitions of disability and care and protection and clarifies the terms used to describe various types of care provided for children and young people with disabilities away from their home. It then proposes a problem definition, focusing on the imbalance between the resources available to a family and the resources they require to function successfully when they have a child or a young person with a disability. While this frames the issue in terms of the needs of the family, it also informs the way we think about the role that government plays in supporting the family.

5.2 Definition of disability

The 1999 Memorandum of Understanding makes it clear that the population it is intended to cover are those who are eligible for disability support services funded by the Ministry of Health via contracted needs assessment and service co-ordination providers (NASCs). The Government's definition of disability [CAB (94) M 3/5(1a) refers] determines who is eligible, and states that:

> *"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 the reduction of independent function to the extent that ongoing support is required."*

But eligibility is not static. Since 1994, when this definition was formulated, there have been some significant changes. Clients with a physical, intellectual or sensory disability (or a combination of these) now constitute DSD's main client group because disability support funding for people with psychiatric disabilities and age-related disabilities has been devolved to district health boards (DHBs). Eligibility criteria continue to be modified, and it is the role of the NASCs to determine eligibility in individual cases.

Also, the boundaries between related areas of need within the health sector, including disability, personal health and mental health, are not clear-cut and are constantly being adjusted. For instance, DSD will fund disability support services for:

- People with certain neurological conditions that result in permanent disabilities
- Certain developmental disabilities in children and young people

- Physical, intellectual or sensory disabilities that co-exist with a health condition and/or injury.

A NASC can clarify eligibility in these situations by contacting its DSD Service Manager.

Many families and people working in related areas have difficulty with what seem to be ambiguous boundaries. The different treatment of children and young people with similar disability support needs, and equal merit in terms of priority, seems inequitable and is very hard to understand. They are also given conflicting advice by health sector personnel about where they should go to have their needs assessed and responded to. Sometimes it can appear that people are arbitrarily defined as not having a disability, so that the NASC can avoid getting involved, especially when another agency has a role.

5.3 Definition of care and protection

Section 14 of the CYPF Act defines a child or young person in need of care and protection. For the purposes of this report several grounds are particularly relevant and include, in summary, a child or young person who:

- Is being, or is likely to be, harmed
- Is being, or is likely to be, neglected
- Is, or is likely to be, harming themselves or others
- Has parents or carers who are unwilling or unable to fulfil their parental role
- Has been abandoned
- Has their wellbeing impaired by the discord between their carers
- Does not have sufficient continuity of care.

Care and protection measures provide CYF with powers to intervene on behalf of a child or young person to protect them from harm. The State will only intervene where it is deemed necessary. A range of responses is possible but the full powers provided, which include removing the child from their family and the Court appointing a guardian, are reserved for the most serious circumstances.

5.4 Different kinds of out-of-home placement

Most of the issues identified in the project terms of reference concern out-of-home placements. There are many different kinds of out-of-home placement, and some confusion about the distinctions between them. Informal out-of-home care provided by family members or friends is not included here as it is not a funded disability support service or a care and protection service.[14] Parents can make any private arrangement they wish, so long as the child's welfare is not compromised.

Respite care: Occasional short periods of out-of-home care. Respite care may be provided by another family, or in a residential facility that is staffed and provides out-of-home care for more than one child or young person at a time. The purpose of

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[14] Family caregivers may be entitled to financial support from Work and Income (W&I) under certain conditions.

respite care is to relieve the family of responsibility from time to time so that they can 're-energise'[15].

Shared care: Part-time out-of-home care that is usually more regular than respite care and involves, as the name suggests, another family caring for a child or young person. A typical arrangement might be 2-3 days every week, or alternate weeks. The purpose of shared care is to develop a support system that is as much like an extended family as possible, so that the child or young person and the family sharing the responsibility for care can form an attachment. Shared care is organised where a family needs, or will need, regular breaks in order to continue to care for the child or young person with a disability.

Where needs are high, respite care and shared care may serve a similar function. Sometimes shared care cannot be arranged, or is not an appropriate option for the family.

Temporary care: An out-of-home placement with either a foster family or in a residential setting. Its purpose is to provide care to a child or young person during a family crisis, vesting custody outside the family for the duration of the arrangement. It is provided on an as-required basis but not regularly or frequently. Temporary care tends to be for 2 to 8 weeks in total. Section 139 of the CYPF Act is used to fund temporary care arrangements.

Extended care: Full-time out-of-home placement when a family cannot provide the day-to-day care their child requires for an extended period of time. It can be a foster placement or a residential placement, and is typically of 6 months to one year's duration, depending on the age of the child or young person. It can be for longer periods, or even ongoing. Often, but not always, it is expected that the child or young person will return to the care of their family as soon as possible. An out-of-home placement of this nature must be arranged under the provisions of the CYPF Act – eg sections 141, or 142. A custody order under s101 also provides for extended care arrangements, however it can be imposed by the Court and remains in place until the child or young person turns 17 unless there is an application to the Court and it decides that the order may be discharged earlier.

These types of out-of-home care are not equally available choices for families. Difficulties in finding carers and respite places, for instance, mean that families sometimes have quite limited options available to them. There are many examples of the difficult access to short-term and part-time options resulting in full-time out-of-home placements. See further comments in section eight below.

Wardship: The Family Court may be appointed as guardian under the Care of Children Act. This order expires when the young person turns 17 years. The Chief Executive of CYF may be appointed sole guardian, which suspends the rights of all other guardians. This order ends when the young person turns 20.

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[15] In the mental health context, respite is also used to describe breaks provided to a person with mental health concerns, to relieve stress and reduce the likelihood of serious ill-health. This does not apply to children and young people with disabilities.

Other: There are a few other care arrangements that have varying conditions. A notable example is that of Hohepa. Current Ministry of Health policy is to require children entering Hohepa to do so under section 141 in order to attract a residential support subsidy, but it is expected that the child's family will resume care for the child during school holidays. This is not an expectation for other children in s141 placements, and creates difficulties if the family are unable to provide care during this interval. More importantly, it can be extremely disruptive for the child or young person and have an adverse effect on their wellbeing and progress.

5.5 Understanding the problem

There is a conspicuous lack of understanding about what underpins the need for an out-of-home placement. Rather, there are a multitude of individual and often conflicting perceptions. For example, some see children with disabilities in terms of their deficits and regard them as 'too difficult' to care for within a family, while others characterise the families seeking out-of-home placements as being not sufficiently committed to their children's best interests. There is a need to provide clear direction to ensure that those implementing policies do so in a manner that is consistent with the clearly expressed intent of those policies.

5.6 The need for a common problem definition

A problem definition is required that is not unduly influenced by particular stakeholder interests, or ideological positions. It needs to be non-judgemental. It needs to take account of the complexity of the situation, while providing a 'way in' to making an appropriate response.

5.7 Proposed problem definition

The most helpful way to define the problem that we are endeavouring to address is to view it as an imbalance between the resources available to a family and the resources they require to function successfully.

In this context the term 'resources' includes the family's:

- Financial resources – income, savings, credit
- Material resources – house, car, phone, equipment
- Personal resources – skills, experience, attitudes, knowledge
- Social resources – family and community networks and support
- Mental/physical resources – health, strength, energy
- Logistical resources – time, proximity to supports and services.

Adequate resources in one area may compensate for shortfalls in another but, overall, each of the individual resource components needs to be reasonably strong. A family that has a strong financial and material base will have some advantages, but will not survive without adequate personal and social resources, and vice versa.

A focus on the adequacy of the family's resources recognises that:

- The resources of the family need to match the demands it faces
- Family, extended family, community and government can help in many ways

- We can protect and strengthen the family’s resources
- We can endeavour to manage the demands on the family’s resources
- We can supplement the family’s resources so that they are sufficient for the demands that the family faces
- We should try to ensure that adequate resources are available to the family
- We need to provide a safety net when the gap between the resources available to the family and the demands on them becomes unsustainable.

6 Clarify the Funding Responsibilities of Agencies

6.1 Introduction

This section outlines the issues related to boundaries and agency funding responsibilities that arise in connection with children and young people with disabilities. While our focus is mainly on the CYF / DSD interface, there are significant issues involving the Education sector and the agencies that fund transport assistance. Another area we comment on is the transition planning that needs to occur before CYF, Education and various health services cease their involvement with young people with disabilities.

6.2 Current blurring of boundaries

6.2.1 Disability vs. care and protection

There is some dispute between CYF and DSD about who should pay when a child or young person has a disability. In spite of the description of funding responsibilities in the 1999 Memorandum of Understanding, an expectation has developed that:

- If the out-of-home placement is caused by a child or young person's disability support needs, then DSD will pay the full placement costs, and
- If the out-of-home placement is primarily caused by a child's or young person's care and protection needs, or if there is no intention for the child to return home, then CYF will pay the full placement costs.

This way of thinking about the situation encourages each agency to 'off-load the problem', and leads to protracted arguments about the cause of the out-of-home placement, and about funding responsibility. The 1999 MoU, which puts a lot of emphasis on establishing the cause of the out-of-home placement, contributes directly to this. For example, the practice guidelines that are part of the MoU comment that:

> "*It can be difficult to distinguish between disability issues and care and protection issues for some children or young persons presenting to Child, Youth and Family. Nevertheless, this distinction is the critical first step to all further decision-making and involvement*[16]*.*"

The 1999 MoU recognises that there will be times when cause is difficult to establish, and suggests apportioning costs on a 50/50 basis in these cases. In practice, costs are rarely shared like this and there can be considerable delays in reaching agreement, making decisions and providing an appropriate package of services for the child and family.

6.2.2 Education costs

We were told that CYF has sometimes felt pressured into picking up special education costs in order to keep children with disabilities (who are CYF clients) at school. For example, some schools have adopted the position that unless a child or young person with a disability brings certain resources, such as supervision during breaks and lunch intervals; they will not be permitted to attend the school. This stance is at odds with the child's right to an education in the public school system.

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[16] See the practice guidelines at p26 of the 1999 MoU.

On the same grounds, CYF also pays for additional teacher aide hours during class time, for some children and young people. This can lead to the situation where children with similar needs receive different levels of support, because some will receive only the support that is available through the school and others will receive support from CYF. This seems inequitable, and suggests that cost shifting from the school's Special Education Grant (SEG) funding, to CYF may be occurring.

6.2.3 Transport costs

Transport costs are another significant interface issue. Many agencies have a role in funding and providing transport assistance, and funding responsibilities are not well defined.[17] The agencies include:

- DSD (for car modifications)
- DHBs (transport to attend specialist health and disability support services)
- Education (transport to and from school)
- Local authorities (public transport services including the Total Mobility Scheme)

Transport assistance is also funded on an ad hoc basis by CYF, NASCs, Charitable Trusts, and NGOs among others.

We were told about cut-backs in transport assistance, which led to cost shifting and/or erosion of access. In addition, there is limited availability of disability-accessible taxis and vans, and funders are competing for the available capacity at peak times. There is a perception that ACC has first call on the transport that is available because it pays more.

Children and young people with disabilities may be subject to a variety of different regimes in their capacities as children, students, people with disabilities, patients etc. As is often the case, the children and young people with disabilities involved in the DSD/CYF interface have complex circumstances and can 'fall through the cracks' in current service delivery. For example, decisions that affect where a child lives, on either a part-time or a full-time basis, can have important transport/resource implications. Strict application of education sector eligibility criteria can result in a child receiving assistance with transport to get to and from school for the days they are at home, but no assistance when they are in alternative care at a different address. Ad hoc arrangements are required to ensure continuity of the affected children's schooling, but setting these up is difficult.

6.2.4 Housing modifications / Environmental Support Services

At the time of writing there was no clear policy regarding eligibility for assistance with environmental modifications to dwellings in which children with disabilities reside. DSD perceives a risk that the family may not continue to live in the dwelling for a sufficient period to justify the considerable financial outlay that is usually

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[17] A major exercise was recently undertaken to develop a robust policy framework to underpin access to and operation of the Total Mobility Scheme. As a result of this review, children were formally recognised as eligible to access the scheme, subject to certain qualifications. See Ministry of Transport, *Total Mobility Scheme Review,* August 2005, Wellington, New Zealand for further information.

entailed, and this appears to have resulted in an widespread reluctance to provide this support.

The risk of a relatively short stay at a particular address is particularly high in the case of people in rental property. Given the compounding effect of low income and presence of disability it would seem desirable to find a way to provide families in rental accommodation with the opportunity to live in a suitably modified dwelling. Similarly, where a child is in a foster care placement there is a risk that it may be short-term. A s141 placement, under the proposals outlined in this report, would be likely however to be a fairly enduring placement, and appropriate modifications to the homes of such carers should not be precluded from consideration.

It is clear to us that environmental modifications can be a very effective way to support some families to cope, especially given the current lack of suitable alternate carers and other service options, and that policies need to be developed that manage the perceived risk.

6.2.5 Payments by DSD for basic living costs

When a child or young person with a disability is in a full-time out-of-home placement, the payment made by DSD covers the costs of disability support services, as well as the child's or young person's living costs (i.e., food, shelter and clothing). The expectation that the Disability Services Directorate should fund the basic or extraordinary living costs because a child or young person happens to have a disability appears to:

- Be a policy anomaly
- Create a separate arrangement for children with disabilities
- Introduce unnecessary complexity to decision-making
- Create an opportunity for CYF and DSD to cost shift
- Encourage a competitive rather than collaborative working relationship
- Encourage cost shifting behaviour in other areas.

One response to this may be to say that there is no argument about the different roles the State plays as funder of income support and funder of disability support services, but that the administration is more straightforward if there is only one payment (rather than two) for a contracted service. There is an implicit understanding, in these situations, that DSD is paying both components of the State's contribution. However, this approach is not used with people in other age-groups, where the person's income support entitlement is paid to the provider of the residential services by Work and Income, and DSD pays only the balance related to the disability support services.

6.2.6 Payments by CYF for basic living costs

CYFs board payments are considered by some to cover ordinary living costs like food, shelter and clothing, although the amount of the board and double board payments is extremely modest. Again, one might reasonably ask why is W&I not meeting these costs through income support. If W&I were to do so, and CYF to focus solely on the Care and Protection costs including a fee for service to alternate caregivers (foster parents), funding responsibilities would be much clearer.

6.2.7 The transition to adulthood: managing the exit of CYF and other agencies

CYF's involvement with a young person usually ceases on their 17th birthday. Other agencies such as DSD and Group Special Education, as well as provider organisations like residential facilities and schools, can find access to resources ending abruptly, and this can put at risk the existing arrangements for the child's care and schooling.[18] It is uncommon for transition planning involving CYF, Education and DSD, to occur and often there is a last-minute rush to set up new arrangements because current funding and services are about to cease. Sometimes a young person with a disability will lose contact with all of the services they have been involved with (such as hospital paediatric services, school, GSE, CYF and their caregivers).

6.3 Basis for clarification

Current policy on the roles and funding responsibilities of CYF and DSD is unambiguous, and is set out clearly in the existing Memorandum of Understanding:

- CYF is responsible for paying for services and supports related to care or protection, such as the cost of a foster carer, whether or not a child has a disability
- DSD is responsible for paying for services and supports related to disability, such as the cost of respite care for a foster family, whether or not a child is involved with CYF or any other agency.

This agreement on the respective responsibilities of CYF and DSD needs to find its way into practice. This would be helped if the agencies ceased trying to determine the main cause for the out-of-home placement and, instead, asked the following questions:

- Is there a care and protection concern? If CYF considers that there is, then CYF must be involved and will be responsible for any services that are required to address the care and protection concern.
- Does the child or young person have a disability? If the NASC assesses that the child or young person has a disability, then the NASC must be involved and will be responsible for any services that are required to address the disability support needs.

CYF and DSD will both be involved with the children and young people with disabilities who are at the interface between the agencies. In our view, the main purpose of the new Memorandum of Understanding is to give CYF and DSD a way of working together on these complex cases.

6.4 Proposed roles and responsibilities

6.4.1 Allocation of roles and responsibilities

There should be much stricter adherence to CYF and DSD funding responsibilities, in line with their respective and complementary roles, to avoid argument and cost-shifting. Accordingly:

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[18] There are exceptions where CYF involvement may be maintained until a child or young person turns 20, such as where the child is subject to a guardianship order under the CYPF Act.

- CYF should *always* pay for the care and protection components of a service package, including the costs of an alternative caregiver, even where the child or young person is under a section 141 agreement. This includes the ordinary costs of a caregiver, and recognition of any challenges that exceed the norm which the caregiver may have to manage
- DSD should *always* pay for the disability support services care components of a service package, including any specialist caregiver component over the normal caregiving function. irrespective of the child's living arrangements[19], even when a child is subject to and order under section 101

Conversely:

- CYF should *never* pay for the disability support services or special education components of a service package, even where the child or young person is subject to and order under section 101
- DSD should *never* pay for the living cost, care and protection or special education components of a service package, even where children are under a section 141 agreement.

The funding pathways for children and young people with disabilities should be normalised. That is to say, they should be no different from those for non-disabled children and young people. Accordingly, we recommend that:

- Families should be expected to contribute financially to the cost of the day-to-day care of their child (food, shelter, clothing) when this is within their means
- Any State contribution to day-to-day costs such as food, shelter and clothing, should be provided by W&I, via the income support system.[20]

Current and proposed arrangements are outlined in Table 2 below.

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[19] Even in the case of housing modifications, the same eligibility criteria are likely to apply. Policy in this area had yet to be clarified at the time of writing this report.

[20] Failing this it should be paid by CYF, acting as the proxy for the parents, rather than by DSD, which should only ever pay for the specialist disability support services component.

Table 2: Outline of Current and Proposed Agency Funding Contributions for Children, Young People and Adults in Various Living Arrangements

Item of Expenditure	Living Arrangement				
	Family or other privately arranged caregiver	Family caregiver arranged under CYPF Act	Non-family caregiver arranged under CYPF Act	Care provided in residential disability service arranged under CYPF Act	Adults
Disability support services	DSD. Government policy appears to be clear on this -. DSD determines eligibility for access to available disability support resources. In practice there is a view among some DSD personnel that the disability support needs of CYF clients are the responsibility of CYF.				
CYF care and protection services	CYF. There is little dispute about the costs of care and protection services, although there is some concern around the abrupt cessation of support from CYF when care and protection concerns are deemed to have been addressed.				N/A
Substitute parental care	Family can make private arrangements. No need to involve CYF or to use s141. Privately arranged alternate carers, even if they are family members, *may* be eligible to an unsupported child allowance from Work and Income.	By one account CYF currently recognises this service through its so-called Board payments, but particularly through double board payments, which recognise particularly challenging foster care situations, with or without a disability component. Others consider that the double-board payment is intended to cover costs of disability and/or disability support services. We are strongly of the view that substitute parental care should be explicitly purchased, by CYF, irrespective of the type of out-of-home care arrangement.			N/A
Additional costs of disability[21]	The family normally picks up the bulk of these costs. Families with a child who has been assessed by a paediatrician as having a disability are entitled to the Child Disability Allowance (CDA) from Work and Income (W&I). This is a standard payment, currently at $72 per fortnight, which is often represented as a non-asset tested *contribution* toward the costs of disability. In some instances, a Disability Allowance (DA) may also be claimed on behalf of a child with a disability with respect to additional costs of disability. Under a social model of disability, it would be appropriate for the CDA, and possibly other forms of income support, to follow a child with a disability and be paid directly to them to maximise the accountability to the person for whom it is intended.				Self +/- W&I
Food, clothing and shelter[22]	Under normal circumstances the family meets these costs. Where the family has insufficient income Work and Income provides both universal and targeted income support. At present CYF may pick up these costs via Board payments to foster care providers. DSD may pick up these costs, via the Residential Care Subsidy for some children. In our view the family and/or W&I should be responsible for meeting these costs even when a child has have been formally placed in out-of-family care. Under this scenario, CYF should be able to supplement these sources, at its discretion where there are				Self +/- W&I

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[21] This includes the cost of additional heating, extra wear and tear on clothing etc. Work and Income makes a contribution to these costs for eligible people via the Child Disability Allowance, and the Disability Allowance. CYF may contribute to these costs for children under its care, at its discretion.

[22] These are not disability related costs. Families with limited means may receive assistance from Work and Income via the benefit system, which includes benefits such as the Unsupported Child Allowance among others.

	extenuating circumstances.	

6.4.2 Transport assistance

Long-term resolution of the issues around transport assistance is beyond the scope of this review. A coherent cross-agency policy on the provision of transport assistance to children with disabilities should be developed, to minimise gaps and duplication in coverage, expedite access to assistance, and to facilitate more efficient use of available resources.

Until a long-term solution is developed, agencies should use the Strengthening Families and Family Group Conference processes to clarify how transport assistance costs are to be met in particular cases. Data on the allocation of costs should be collected to inform any future policy review.

6.4.3 Transition planning

Transition planning is required whenever there are major changes in circumstance, including transfers from one area to another, when the lead agency changes, but most particularly when the young person makes the transition to adult services or independent living.

As a matter of priority, we recommend that CYF and DSD undertake to ensure that transitional planning occurs as follows:

- Local CYF and NASC staff will meet to develop a transition plan for each child who is involved with the NASC and CYF
- Transition planning will commence before the child turns 16
- Transition planning will be completed *at least* six months before the child turns 17.

7 Integrate and Strengthen CYPF Act Pathways

7.1 Introduction

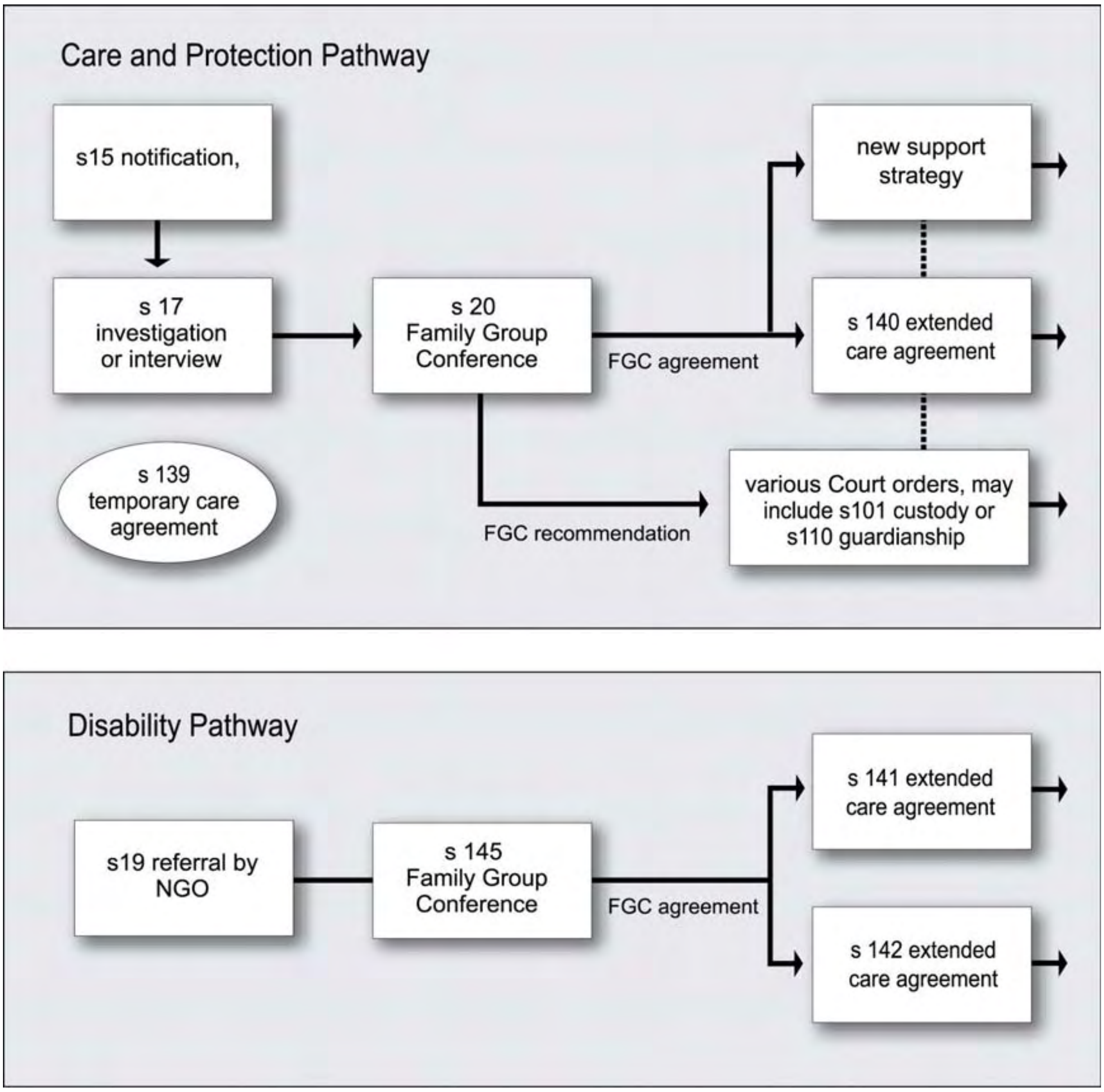
Issues with the current pathways under the CYPF Act, their processes, and the support options available via each pathway lie at the heart of this review. The arrangements and related issues are complex. Without detailing every aspect of the care and protection system, this section explains the key issues affecting children and young people with disabilities and it identifies ways they may be addressed.

7.2 Current CYPF Act pathways

7.2.1 Two CYPF Act pathways

Part Two of the CYPF Act, which deals with care and protection, sets out two distinct pathways; the main ‘care and protection pathway’ and a separate ‘disability pathway’ as illustrated in Figure 2 below.

Figure 2: Current CYPF Pathways into Care



Choosing the right pathway

Once a child or young person with a disability becomes involved with CYF, a judgement has to be made over which pathway is the more appropriate. Over time this has become a major sticking point between CYF and DSD, and between their respective agents.

CYF staff tend to ask: *"Would there be a care and protection issue if the child or young person didn't have a disability?"* If the answer to this question is no (ie, any care and protection issues are "caused by" the disability), then they are likely to conclude that it is a disability support issue and not a care and protection issue, and that the 'disability pathway' is the more appropriate route.

DSD staff tend to ask: *"Is there a care and protection issue here?"* If the answer is yes (ie, the family is unable or unwilling to care for the child or young person) then they are likely to conclude that it is a care and protection issue rather than a disability support issue, and that the care and protection pathway is the more appropriate route. DSD staff also regard the issue as care and protection if there are no plans for the child or young person to be reunited with their family.

The pathway that is finally taken has different funding and workload implications for each of the agencies. It seems to service providers and families that decisions are driven by the agencies' interests as much as the best interests of the child or young person.

The pathways compared

Each pathway involves different processes and leads to different support options as summarised in Table 3 below.

Table 3: Comparison of Current Placement Options

Current Measures	CYP&F Act Placement Options				
	s101	s139	s140	s141	s142
entry pathway	C & P	C & P	C & P	Disab.	Disab.
requires investigation	yes	yes (see below*)	no	no	no
requires FGC	yes	no	yes	yes	yes
requires Court order (see below**)	yes	no	n/a	n/a	n/a
conditional on resuming care	n/a	yes	yes	no	No
conditional on maintaining contact while in care	n/a	no	yes	yes	yes
duration if < 7 years	set by Court	28 days	6mths	2 years	1 year
duration if 7 years or older	set by Court	28 days	1 year	2 years	1 year
reviewed via Court report	yes	no	n/a	n/a	n/a
reviewed via FGC	n/a	n/a	n/a	yes	yes
frequency of review	6 mos/ 1 year	once	n/a	2 yearly	yearly
renewable	n/a	once	no	until 17	until 17
maximum length of care	17 years	56 days	6 mos/ 1 year	17 years	17 years

* Section 139 provides for a timely response in a crisis, and therefore does not require an FGC prior to placement. CYF need to authorise the placement, but this capacity may be delegated to another organisation, such as Barnados and the Open Home Foundation, if it is authorised to carry out an appropriate investigation.

** Child will be represented by a barrister or solicitor in any Court proceedings (s159), and have a lay advocate appear in their support (s163).

7.2.2 Entering the system

The care and protection pathway

Children and young people usually access the care and protection pathway following a report of suspected child abuse under section 15, section 18 or section 19 of the CYPF Act. Notifications are screened, and those that appear to be significant are prioritised and assigned to a CYF social worker for investigation under section 17. If, following an investigation, concerns about the child's care and protection remain, the social worker will usually refer the case to a Care and Protection Co-ordinator, who will convene a Family Group Conference (FGC) under section 20 of the CYPF Act.

The care and protection pathway is intended to cover children with disabilities when there are care and protection issues, but there is a perception that children and young people with disabilities are less likely to be able to access the care and protection processes. For instance, neglect or even abuse is sometimes seen as "understandable", given the child's disability. Disability may not be recognised by CYF Social Workers as a risk factor when they are prioritising referrals, despite the fact that research indicates children and young people with disabilities are more likely to be abused or neglected that their non-disabled peers and siblings.

Paradoxically, a child or young person may be considered not to be in need of care and protection *because* they have a disability.[23] They may not be accepted into the CYF system at all, or may be referred to a Care and Protection Co-ordinator for a section 145 Family Group Conference with a view to an out-of-home placement under section 141. This denies those concerned their right to an investigation and/or care and protection.

Conversely, a small number of children and young people with disabilities seem to be subject to care and protection mechanisms, which involve a formal investigation and may require a Court order to be implemented, when a less intrusive process such as a section 141 placement would be the more appropriate pathway to take. This is most likely to occur when an inexperienced CYF Social Worker refers the matter to an FGC or the Family Court as a care and protection issue.

The disability pathway

The 'disability pathway' is intended for children and young people with disabilities whose parents can no longer meet the needs of the child or young person within the family situation. The disability pathway recognises that while community care is preferable to institutionalisation, that care will not always be able to be provided by the family of origin. The disability pathway involves a simpler and less formal process than the care and protection pathway.

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[23] An assumption is made that the problem is best addressed with disability support services.

Access to the ‘disability pathway’ is by referral to a CYF Care and Protection Co-ordinator for a section 145 FGC. Anyone can potentially contact a CYF Care and Protection Co-ordinator for this purpose. The purpose of the FGC is to make an agreement about an out-of-home placement. There is a requirement under the 1999 MoU to establish, before an FGC is convened under section 145, that there is a provider who is willing and able to accept the placement and that the NASC has approved funding of such a placement. There is no investigation under section 17, so care and protection issues may be overlooked. The child or young person is not considered to be on the CYF caseload. CYF’s role is simply to conduct the section 145 FGC process and manage the related administration.

Temporary care arrangements under section 139

Section 139 placements do not require a formal investigation, an FGC or a Court hearing. Section 139 is part of the care and protection pathway, and provides for voluntary temporary care arrangements to be made where a caregiver *‘is temporarily unable or unwilling to care for a child or young person’*. While it is not disability-specific, section 139 is used frequently to place children and young people with disabilities into temporary care in times of family crisis. An example of this might be where a family feels unable to have a child or young person return home after a period of residential respite. Section 139 provides an opportunity to assess a situation and/or take some action that resolves the matter. Although the intent of section 139 is to allow for prompt action and a short-term placement, it is also used as an interim measure while a longer-term placement is arranged.

Care under section 139 must be delivered by providers approved under section 396 of the CYPF Act. The providers fall into three categories:

- Iwi Social Services
- Cultural Social Services
- Child and Family Support Services.

Placements may be entered into directly by some section 396 organisations (eg Open Home Foundation and Barnardos) and with the approval of CYF for other organisations. A section 139 placement can be made for up to 28 days, and may be renewed only once, providing a maximum of 56 days temporary care.

To ensure that temporary care can be arranged quickly, a placement can occur prior to an investigation of the care and protection concerns. The costs of the section 139 placement are picked up by CYF. The cost of a residential placement for a child or young person with a disability can be much higher than the standard rates that CYF pays, because of the child’s disability support needs. Sometimes this places a strain on the CYF budget. On other occasions, to avoid the high cost of a disability support service, a less desirable or inappropriate placement may be made with a CYF provider.

Sometimes, a section 139 placement is not accompanied by an adequate plan to help the family resume the care of the child or young person. This can result in the child ‘drifting’ into a longer term care arrangement.

7.2.3 Family Group Conferences (FGCs)

Involvement with CYF is seen as stigmatising by some, and a heavy-handed mechanism for problem solving. On the other hand, people observed that, compared to the Strengthening Families process for instance, FGCs provide a mechanism with the weight of the law behind it that people take seriously. They are more likely to attend and participate constructively, and follow through on any agreements that are reached at an FGC.

Care and protection FGCs

In the care and protection pathway, a Family Group Conference (FGC) is convened in accordance with section 20ff of the CYPF Act. It is used to explore options for enhancing the care and protection of the child or young person and to develop an agreed plan for doing so. The Act specifies in detail how FGCs are to be run, including:

- The need to consult with family, whanau, and the family group
- Who is entitled to attend
- The need to seek the views of those unable to participate, and
- That all relevant information and advice is available to participants.

The function of an FGC is to:

- Consider care and protection issues
- Make decisions and recommendations and formulate plans, and
- From time to time, review the decisions and their implementation.

A section 20 FGC will usually result in one or more of the following outcomes:[24]

- A new plan or strategy that does not involve an out-of-home placement or require a Court order
- An extended care agreement under section 140
- An application to the Court for a declaration that the child or young person is in need of care and protection, leading to a range of orders, most commonly:
  A support order
  A services order
  A custody order under section 101
  A guardianship order under section 110.

While a section 20 FGC tends to be an effective mechanism, there can be a failure, where children and young people with disabilities are involved, to:

- Obtain and circulate relevant information to FGC participants on disability support needs and their implications
- Invite NASC participation so that disability implications can be considered, and disability support services can be built in to any plan that is developed

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[24] Other outcomes are possible including, for example, a restraining order, but are not sufficiently pertinent to discuss in this report.

- Invite Group Special Education participation so that educational implications can be considered, and special education services can be built in to any plan that is developed.

'Disability' FGCs

The requirements in the Act related to section 145 FGCs are essentially the same as for FGCs under section 20. In practice, they are quite a different process:

- The outcome sought from a section 145 FGC is an out-of-home placement
- The process does not usually explore all the possible options for resolving a situation
- Far fewer people are invited to participate in the FGC.

A section 145 FGC will usually result in either:

- An extended care agreement under section 141
- An extended care agreement under section 142.

One study found that:

> *"…referrals under section 145 of the Act were responded to differently than the cases referred under the care and protection provisions of the Act (sections 15 or 19). The review found that there was significantly less involvement of family in the decision-making area and there were few cases where there was any investigation of family options for the child. There appeared to have been little attempt to ensure that all options to maintain the child within their family had been explored… In these FGCs convened under section 145, it was common practice for only the parents of the child to be invited and to attend… Frequently the (FGCs covered by the review) were also rubber-stamping exercises with few family members in attendance… In no case was there evidence of the child attending the FGC… FGC plans were sometimes very sketchy, in some instances merely recording that it had been agreed to enter into a section 141 agreement. Plans often failed to specify the nature of the family contact to be undertaken… (None of the FGC plans reviewed) contained creative plans for the involvement of family members in the overall care of the child. An option such as shared or respite care with family members, with provision for training and support for the family member to assist them to learn about caring for the child, was never included in the plans reviewed. Overall, FGC plans were inadequate, with a few notable exceptions that provided excellent detail about all aspects of the child's care."*[25]

A section 145 FGC is likely to be abandoned where agreement cannot be reached regarding the out-of-home placement, for example, when the parent is not willing to agree to a placement with the proposed provider. An alternative arrangement that does not involve a full-time ongoing out-of-home placement may (or may not) then be negotiated outside the FGC.

7.2.4 The outcomes of Family Group Conferences

New plans and strategies

A section 20 FGC does not necessarily result in a referral to the Family Court. Section 73 of the CYPF Act suggests that implementing any decision, recommendation or plan made or formulated by an FGC where appropriate or practicable, is preferable to seeking a formal declaration from the Court that a child or young person is in need of

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[25] Green P, and Wilcox D, *Review of Children and Young Persons in IHC Care,* June 2000

care and protection. FGCs are expected to find creative ways of addressing identified concerns, if possible, without escalating matters to the Court.

Services orders

Section 86 of the CYPF Act empowers the Court to make a services order directing the Chief Executive of CYF or any other person or organisation to provide the services and assistance specified in the order to the child or young person or their parent, guardian or other caregiver. Those directed to provide services under section 86 are entitled to be given notice, and can be heard by the Court before the order is made.[26] Counsel for the child sometimes requests that a services order is made to ensure that the services the child requires are funded. A services order can be an effective way of ensuring significant contributions from multiple agencies.[27]

Support orders

A support order can be made by the Court under section 91 of the CYPF Act, directing the Chief Executive of CYF or any other person or organisation to provide support as specified in the order to the child or young person for up to 12 months. In this context support includes:

- Monitoring the standard of care, protection and control being provided
- Providing or co-ordinating the provision of services and resources to ensure the appropriate care, protection and control are provided.

Support orders are not always required. They may be used to enable CYF monitoring where it is anticipated that a child or young person will be discharged from CYF custody, or to provide some continuity of care during the transition to new care arrangements or independence.

Custody orders under section 101

A custody order places responsibility for the day-to-day care of a child or young person, for the period specified in the order, with one of the following:

- The Chief Executive of CYF
- An Iwi Social Service
- A Cultural Social Service
- The Director of a Child and Family Support Service
- Any other person (eg, an individual foster care provider).

A custody order empowers the above to make decisions and act on behalf of the child or young person with respect to their day-to-day care. This includes, for example, placing them with a foster family or in a residential facility, consenting to medical treatment, agreeing to the child's participation in recreational activities and so on. The parents' custodial rights and responsibilities are suspended, although a Court order may stipulate the retention of certain rights and responsibilities. The parents will retain their guardianship role, however, unless this is affected by another Court order such as a section 110 guardianship order (see below). It is important to note that a

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[26] The Court can make a services order to the Chief Executive of CYF even without their consent if the Court is not satisfied that providing the service is impractical or inappropriate.

[27] Personal communication, Judge Peter Boshier, Principal Family Court Judge, 21 September, 2005.

placement under sections 139, 140, 141, and 142 confers *the same powers and responsibilities as if that person had been placed in the custody of that person pursuant to an order under section 101*.

The arrangements for out-of-home placements under section 101 are often less than ideal when a child or young person has a disability. This is because the custody order under section 101 is part of the 'care and protection pathway' and often there is not a good link between the CYF staff and the NASC in these cases. Examples of this include a foster caregiver who is willing to care for children and young people with disabilities being allocated several children with disabilities, thereby undermining their capacity to meet the individual needs of those children and to provide a family-like environment. Again, CYF may not recognise or be willing to pay for the disability support services the child or young person needs and may make an inappropriate placement.[28]

At other times children and young people with disabilities are placed with available foster carers who are not well-equipped or well-supported to meet the needs of a child or young person with a disability. Furthermore, a foster family may not receive any recognition of the additional work involved in providing such care, and may not have access the same type and level of support that a natural caregiver may be able to access. (For example, foster carers are often the employees of organisations like IHC/Idea Services. The organisations' contracts with DSD for providing foster placements are intended to cover any respite and other support the carers may need, so the individual foster carer is not able to access respite and other support directly, via the NASC.)

Placement difficulties arise partly because CYF lacks expertise in disability support but primarily because there are very few carers who are willing and able to care for children and young people with disabilities and especially to care for those with high and complex needs. There is considerable competition to obtain skilled and experienced carers, and those who are available are in high demand. CYF is not well-placed to access them because it is neither a specialist disability agency, nor able to offer the same level of remuneration as the Accident Compensation Corporation for example. There is concern also, when CYF does manage to access skilled and experienced carers, that if the match is not appropriate, scarce carer capacity may not be used in the best way.

Guardianship orders under section 110

Guardianship involves contributing to the child's or young person's intellectual, emotional, physical, social, cultural and other personal development, and helping the child or young person with important decisions that affect them. The latter may include issues of where they live, their schooling, religion and cultural attachments, among others.

The Court can appoint guardians in addition to the natural guardians, for a specific purpose, or as sole guardians. A sole guardianship order suspends the rights of other guardians.

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[28] In our view DSD should assessment the need for and meet the costs of any disability support services, but this is not the current operational understanding.

Permanency

Where it has been decided that the child or young person is best placed permanently with their caregiver, it may be appropriate that the caregiver be granted orders in their favour to reflect the permanent nature of the care arrangements. This recognises the attachment of the caregiver to the child, and is consistent with the principles under the CYPF Act.

Orders considered appropriate may include: custody and additional guardianship under the CYPF Act, a parenting order and guardianship under the Care of Children Act, and/or a services order for financial and other assistance.

For caregivers of children and young people with disabilities who may have high support needs, change of custodial status in particular, can reduce the level of support and household income quite significantly. Because of the desirability of permanence, CYF and DSD have worked together to neutralise the financial impact of assuming guardianship by continuing to pay the caregiver and provide other support.

We were told that, in order to remove the disincentive for the prospective guardian, CYF is increasingly paying a ‘top-up’ that bridges the difference between the standard income support entitlements and what the guardian would have received as a paid caregiver, and that this has had a significant cost impact on CYF.

In addition, service providers are deciding that the caregiver is not eligible for ongoing support, and there are several factors which contribute to this. One is a narrow interpretation of DSD’s policy on not paying family caregivers.[29] The other is that the service provider has less influence over a guardian who is effectively the child’s parent than over a caregiver who is an employee. As the service provider may still have some responsibility for the quality of care, but little leverage with the caregiver, they are reluctant to have a continuing role. A third factor that can come into play is whether the caregiver fosters other children. Some disability organisations have a policy of only supporting families fostering a single child or young person with a disability. These policies are giving rise to interesting situations. For instance, in one case it was suggested that a child should be removed from a successful foster placement and placed with a new carer in order to comply with the service provider’s operational policy — an outcome that would most certainly not have been in the best interests of the young person concerned.

Extended care agreements under section 140

An extended care agreement under section 140 is part of the care and protection pathway. It provides for an out-of-home placement of up to 6 months for a child under the age of 7 years, and for up to 1 year for a child or young person 7 years or older and up to their 17th birthday.

Section 140 offers a larger window of opportunity than a section 139 temporary care agreement to implement some form of intervention or to put services in place that address the concerns identified. It could enable a parent to receive health care or to take an extended break to recuperate, for example. Section 140 placements are strictly

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[29] That is, the paid caregiver has now become a guardian, which counts as a family member, and thereby renders them ineligible to receive payment as a caregiver.

conditional on the family resuming day-to-day care at the end of the placement. The placements are non-renewable, reflecting that 6 months and 1 year are long periods of time from the perspective of a child or young person.

Because it is part of the care and protection pathway, extended care under section 140 is not always considered for those using the disability pathway. This deprives them of the opportunity to have any care and protection concerns identified, and addressed and followed by the resumption of care by the family at the appropriate time.

Extended care agreements under section 141

A section 145 FGC most commonly agrees to an out-of-home placement under section 141. The Act stipulates that section 141 placements are appropriate when "*the child or young person is so mentally or physically disabled that suitable care for that child can be provided only if that child or young person is placed in the care of an organisation or body approved under s396 to provide care for such a child or young person".*[30]

A major criticism of this provision is that it is at odds with contemporary philosophy and practice. People with profound disabilities are no longer institutionalised and many live successfully with their families when sufficient and appropriate resources and support are available to them.

An out-of-home placement under section 141 can be for up to two years initially, and may be renewed with the agreement of an FGC. Section 141 placements are subject to less frequent review than the out-of-home placements arranged via the care and protection pathway, and some see no good reason for this.

The legislation specifies (in section 147[2]) that the family must be willing to maintain contact with the child or young person during the placement. The Act specifically states that family reunification need not be a goal under a section 141 placement. This is seen as inequitable by many critics of the process under section 141.

Other criticisms include that:

- No test of 'severity' of disability is applied when considering the appropriateness of a section 141 placement
- Parents may be pressured to agree to a section 141 placement in order to access the level of services and support their child requires – and that were not available to the child or young person while they were with their family
- Section 141 may be used where the care and protection pathway would be a more appropriate option
- No consideration is given to the age of a child, with shorter placements for those under the age of 7 years, as there is under the care and protection provisions, even though the developmental age of children and young people with disabilities may be significantly below that of their chronological age
- Care under a section 141 placement cannot be provided by a family member, and this seems at odds with the principles underpinning the CYPF Act

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[30] See section 141(1) of the CYPF Act.

- A two year placement erodes family involvement and makes the child's return to the family less likely than after a shorter placement
- There is no requirement that the child or young person return to the care of their family, and placements can be renewed repeatedly until the child turns 17 without providing for permanency
- A section 141 placement is sometimes a case of abandonment or may lead to abandonment, but a placement under section 101 is rarely pursued
- Section 141 agreements can be terminated by either party on 7 days' notice, and this means there is little assurance of stability in the placement, or opportunity for transition planning. If there are care and protection concerns, these can place the child or young person in jeopardy
- Although children and young people placed under section 141 may be some of the most vulnerable and least able to self-advocate, there is no provision for independent advocacy as there is through the Court for placements under section 101.

There is also a view that the existence of the section 141 placement option creates demand by presuming that families will not be able to cope. It is also regarded by some as a service option rather than a last resort, which masks poor access to required disability support services.

The section 141 certifier role

Section 141 placements differ from care and protection placements in that no agreement can be made unless a section 141 certifier confirms that:

- The proposed caregiver has appropriate facilities and adequate staffing to care for that particular child, or
- That the proposed caregiver has appropriate facilities and adequate staffing to supervise the placement and ensure the child or young person is well cared for.

The focus for the certifier is on the needs of the particular child they have received a referral about. Accordingly, they make an independent evaluation of the organisation each time a placement is made with that organisation.

The current certification process is widely criticised on the grounds that:

- It adds little value to existing processes, and wastes precious time and resources.
- It appears to duplicate the quality assurance processes in existing approvals, licensing and contracting regimes, as well as the quality assurance processes of the provider organisations.
- It often takes place long after a child is placed, and has no influence on the placement decision.
- Without meeting the child or the day-to-day caregiver, or viewing the new living arrangements, the certifier cannot make an informed judgement as to whether the child's or young person's needs are well met in the placement.
- Sometimes certifiers decline to certify a placement but this is not followed up — the child's care arrangements are neither reviewed nor modified.

- There are no organisational systems or processes around the role of the certifier in terms of person specification, job description, training, guidelines, record keeping, peer review, professional supervision, line management, operational or legal accountabilities.
- Many placements occur without any certification due to the lack of knowledge among CYF and DSD staff about the requirements of the CYPF Act and the 1999 MoU, or because of a lack of confidence in the process, or difficulty identifying and contacting approved certifiers.
- Certifiers may have a conflict of interest through their involvement with disability support services or care and protection organisations.

Extended care agreements under section 142

The disability pathway also has the option of a placement under section 142. This permits a placement with an organisation that is not approved under section 396 as a child and family service, but which has been approved as a provider of residential disability care, under the Disabled Persons' Community Welfare Act 1975 (the DPCW Act). These organisations manage residences for adults with disabilities.

Placements under section 142 can be made for up to one year at a time, but are renewable until the child or young person turns 17 years of age. As with section 140 and section 141, the family is required to maintain contact during the placement.

The definition of disability in the DPCW Act is a broad one:

> *"Disabled person means any person who suffers from physical or mental disablement to such a degree that he is seriously limited in the extent to which he can engage in the activities, pursuits, and processes of everyday life."*[31]

The 1999 MoU describes a section 142 placement as being for children with 'moderate' disability, presumably reflecting this definition.

In practice, placements are rarely made under section 142, and only when a service provider approved under section 396 of the CYPF Act is not available. Occasionally section 142 has been used to place children with disabilities in rest homes for older people.

The criticisms levelled at section 142 placements are similar to those about section 141 placements and relate to the age appropriateness of the placement, the low expectation of the child returning to their family and the lack of advocacy for the child. But there are also strong concerns that:

- There is no certification requirement, even though the provider is less likely than an organisation approved under section 396 to be providing care suitable for a child or young person
- Placement of a child in an adult facility is not good practice and is inconsistent with the principles underpinning legislation and policy related to the care of children

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[31] See section 2 of the DPCW Act, 1975.

- The capacity to make such placements removes any incentive to develop alternative, age-appropriate, care options
- There is no equivalent ‘loophole’ permitting placement of non-disabled children and young people in adult services. For example, the placement of non-disabled children in adult services such as rest homes, or child offenders in adult prisons, would not be acceptable.

7.2.5 Advocacy

Children – especially those with high and complex disability support needs – cannot advocate for themselves in the processes we are describing. Many people fulfil an advocacy role to some extent – including parents, siblings, other family members and whanau, officials involved in the care and protection system, and the providers involved with the family. Each of these people however, are stakeholders in the process in one way or another, and cannot always represent the best interests of the child or young person.

In holding the best interests of the child or young person paramount, the CYPF Act requires that in any Court proceeding, the child or young person have an independent advocate, who may be a legal advocate (see section 159) and/or a lay advocate (see section 163).). In the ‘care and protection pathway’ this would apply whenever an out-of-home placement of more than 6 months for a child of 6 years or younger, or 12 months for a child or young person aged 7 to 17 years was being considered. In the disability pathway a Court process is not entailed so there is no provision for an independent advocate. As a result the child’s best interests are not always reflected in FGC processes or outcomes.

While some would say that the appointment of an independent advocate might make participants behave defensively, in practice an independent advocate often facilitates a strong focus on the individual needs of the particular child or young person that can lead to innovative solutions.[32]

7.3 Building on the strengths of the existing system

The raft of issues that has been identified has led some people to conclude that the best option is to remove the disability pathway altogether, to treat all requests for a full-time out-of-home placement as abandonment, and to deal with the issue under the care and protection pathway. In our view, integrating the ‘care and protection’ and ‘disability’ pathways is a better way to improve consistency of approach and to ensure that the child’s best interests are considered, all the options are explored and out-of-home placement is not a foregone conclusion. The integrated pathway would also mean that an out-of-home placement can be arranged without subjecting the family to a Court process.

There are in fact many strengths in the current system, among them:

- The principles in the CYPF Act, which provide an excellent framework
- The provision of a safety net through the CYPF Act, when families cannot provide the care and protection that their children and young people require

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[32] Personal communication, Judge Peter Boshier, Principal Family Court Judge, 21 September, 2005.

- A competent workforce committed to supporting children and young people with disabilities and their families
- Some good processes for working together to ensure the care and protection of children and young people.

We need to build on these strengths to ensure that:

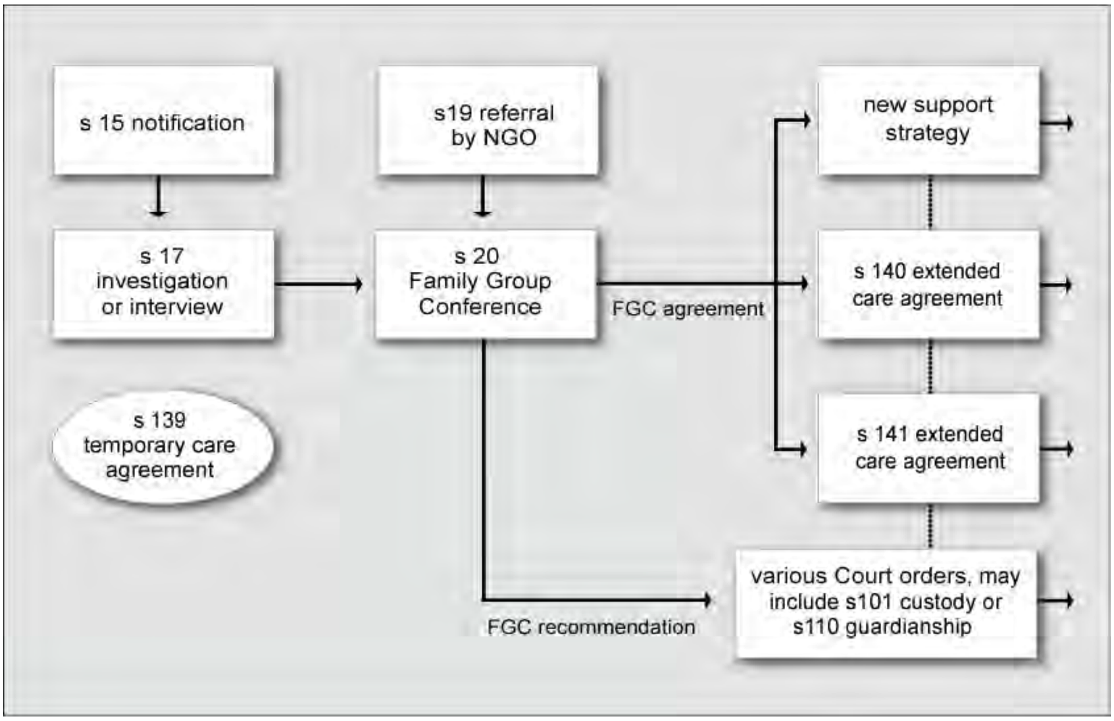
- All processes and decisions are *consistent with the principles* set out in the CYPF Act.
- The *best interests* of children and young people with disabilities determine the processes we use and the decisions we make.
- Children and young people with disabilities have *access to the same level of care and protection* as their non-disabled peers.
- The processes used are constructive, and have *minimum adverse impact* on children and young people with disabilities and their families.
- *Incentives work in favour of outcomes* that are in the best interests of children and young people with disabilities.
- The *workforce is supported* to facilitate the best possible outcomes for children and young people with disabilities and their families.
- The interests of the particular child or young person are appropriately *represented* in all processes.
- Outcomes are not determined before all options are thoroughly considered.
- The implementation of plans and decisions is *monitored* in an appropriate and timely way to ensure the desired outcomes are achieved.
- Plans and decisions are *regularly reviewed* to ensure that the best interests of the children and young people with disabilities continue to be pursued.

7.4 Proposed changes

7.4.1 Overview

There are many opportunities for improving the current system so that it better serves the interests of children and young people with disabilities and their families. The proposed integrated pathway is illustrated in Figure 3 below.

Figure 3: Proposed Integrated CYPF Act Pathway into Care



Proposed changes to current placement options are summarised in Table 4 below

Table 4: Comparison of Proposed Placement Options

Proposed Measures	CYP&F Act Placement Options				
	s101	s139	s140	s141	s142
entry pathway	C & P	C & P	C & P	C & P	no longer to be used
requires investigation *(see below)*	yes	no[33]	yes	yes	
requires FGC	s20	no	s20	s20	
requires Court order	yes	no	no	no	
conditional on resuming care	no	yes	yes	no	
conditional on maintaining contact while in care	no	no	yes	yes	
duration if < 7 years	set by Court	28 days	6mths	none	
duration if 7 years or older	set by Court	28 days	1 year	ongoing	
reviewed via Court report	yes	no	no	no	
reviewed via FGC	no	no	no	yes	
frequency of review	6 mths/ 1 year	28 days	n/a	yearly	
renewable	n/a	once	no	n/a	
maximum length of care	to 17 years old	56 days	6 mths/ 1 year	to 17 years old	

These and other proposed changes are set out in more detail in the text that follows.

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[33] Section 139 provides for a timely response in a crisis, and therefore does not require an FGC. CYF need to authorise the placement, but this authority may be delegated to another organisation, such as Barnados and the Open Home Foundation.

7.4.2 Entering the system

In the integrated pathway we propose that children and young people with disabilities who would previously have entered the system via a section 145 referral now enter via a section 15 notification to CYF. This would require two things:

- The best interests of children and young people with disabilities for whom an out-of-home placement is proposed are taken into account, but that
- A formal investigation is only carried out when indicated, and not as a matter of course.

The first of these should be fairly straightforward, requiring an appropriate amendment to current practice guidelines and training in their application.

With respect to the second, the 1999 MoU already suggests that situations of low urgency where no abuse or neglect is alleged and the parent or caregiver is actively pursuing the well-being of the child or young person, an exploratory interview should be undertaken rather than a full investigation in the first instance.[34] Such an approach would be consistent with the Differential Response Model (DRM) that is currently being developed by CYF.[35]

To determine whether a formal investigation under section 17 is appropriate (ie, to ascertain whether the child or young person has been abused or neglected or is in imminent risk of abuse or neglect), disability-specific indicators, and/or a disability-specific approach, will need to be developed.

7.4.3 Family Group Conferences

Section 145 FGCs appear to be less rigorous than FGCs conducted under section 20. In our view there should be no distinction, hence the recommendation that all FGCs are held under section 20 and that section 145 is no longer used. A single FGC process would overcome the marginalisation of children and young people with disabilities in the care and protection system, and avoid the presumption that the FGC will result in an out-of-home placement. A section 20 FGC would consider a wider range of options, including options for supporting the family so that it does not need to relinquish custody. It would compare the appropriateness of a section 141 placement to a section 101 placement. It should also be able to agree on the option that is most closely aligned with the best interests of the child or young person.

The section 20 FGC process would be strengthened with respect to children and young people with disabilities by the participation of the section 141 certifier. A new role for the certifier is described below.

A new role for the section 141 certifier

As mentioned above, other perspectives may limit the ability of stakeholders in the process to be objective about the best interests of the child. We propose that the current section 141 certifier arrangements are changed, so that the certifier can meet the child or young person, their family and any proposed caregivers, and participate in the FGC *before any decisions are made.*

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[34] See 1999 MOU, p9 for further detail.

[35] See comments in section 1.3, on work related to this review.

The certifier would not replicate the work of NASC assessors, CYF social workers or others, but would review processes and decisions to ensure that:

- The principles of the CYPF Act have informed the process and decision-making
- Agency processes and policies have been followed in accordance with best practice guidelines
- All the options have been explored before an out-of-home placement is arranged
- The proposed out-of-home placement is in the best interests of the child or young person.

Under our proposal, a certifier could decline to certify a placement if they are not satisfied that all of the options have been considered, or that the proposed placement is in the best interests of the child. In this instance the certifier's report and the FGC's proposal for an out-of-home placement would need to be referred to a higher authority for approval – ie, for approval to depart from agreed best practice on this occasion. The process described in the new Memorandum of Understanding is the recommended process in these circumstances.

The certifier's function would be more proactive, focusing on good process rather than certifying after the event. Certifiers will become experts in this specialist area and will develop a regional and national overview of out-of-home placements and successful alternatives. As a result, their participation in FGCs is likely to provide useful support to DSD and CYF staff and other stakeholders, just as the Plan Advisors do in the HCN application process.

The "licensing" functions carried out by the section 141 certifiers should be incorporated into the work of the Quality Assurance team in CYF.

7.4.4 Response options: Temporary care and the outcomes of FGCs

Temporary care agreements under section 139

Section 139 placements should continue to be used for responding to crises. In addition, they should be used more proactively, to establish sustainable care arrangements with the family, rather than as a holding pattern until the crisis 'blows over'.

Costs should not fall exclusively on CYF as they do at present. DSD should pay for the disability support services component of care.

The management of section 139 placements might be one of the processes that certifiers would review in assessing the appropriateness of an extended care agreement under section 140 or section 141 for a child with a disability. Failure to use section 139 effectively might indicate that staff training or some other action to address the issue is required.

New plans and strategies

The section 20 FGC provides the opportunity to explore a wider range of options than currently occurs in a section 145 FGC. One of the options is the development of plans and strategies that could limit the need for further CYF involvement. This will often be a new approach to the delivery of support to the child or young person and their family, including informal or private arrangements or different service configurations that have not been considered in the context of earlier Strengthening Families meetings.

Extended care agreements under section 140

Under an integrated pathway, section 140 out-of-home placements, of shorter duration than some of the other options, would be used more frequently in order to develop a sustainable care arrangement with the family. This type of agreement might involve the implementation of therapeutic programmes to reduce support need levels, and/or the reconfiguration of supports and services to better serve the child or young person and their family.

We would expect that, where the gap between the child or young person's disability support needs and the capacity of the family to meet those needs has widened over time, section 140 will have been used to full effect before a full-time out-of-home placement under section 141 is considered.

Again, failure to use the options under section 140 effectively would be identified by certifiers and might serve as an indicator that staff training or some other action to address the issue is required.

Extended care agreements under section 141

We are strongly of the view that section 141 should be retained as an out-of-home placement option. Its main point of difference is that it permits an out-of-home placement to be arranged without subjecting the child and young person and their family to a Court process. It recognises that the family is doing its best for their child, that there is no issue of abuse, neglect or abandonment, but that the family is unable to provide the day-to-day care themselves.

The section 141 process does, however, need to be strengthened so that it is more closely aligned with the principles underpinning the CYPF Act and the processes provided under section 101, which it is intended to mirror. In our view, section 141 placements should:

- Be regarded as lasting until the child or young person turns 17, although a return to the family should not be ruled out
- Not be considered for children under seven
- Be agreed following a inclusive and thorough FGC process, that considers the full range of options
- Involve a section 141 certifier in a new role, to provide a degree of process advocacy and quality assurance.

Other changes should include:

- Reducing the interval between formal reviews from two years to a maximum of one year, as for arrangements under section 101

- A change to the agreements under section 141, so that they cannot be terminated on 7 days notice. The FGC should be reconvened to consider the merits of any proposed change in custody, and to develop a plan for appropriately managing any transition in the best interests of the child or young person.

Extended care agreements under section 142

In our view:

- All out-of-home placements should be subject to the same processes and safeguards
- No child should be placed in a facility that is not operated by an approved child and family service provider.

The need to use non-approved facilities is a reflection on poor service development, and the opportunity to place children, inappropriately in our view, mitigates against rectifying the problem. Accordingly, we recommend that section 142 is no longer used for the placement of children and young people with disabilities.

Discontinuing use of section 142 will have limited impact on the system, as it is not often used at present. But it will be significant for the small number of children who have been placed in unsuitable environments, such as rest homes.

Ultimately the CYPF Act should be revised and the option of a section 142 placement removed.[36]

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[36] Most of the provisions of the 1975 DPCW Act, under which section 142 providers must currently be approved, have already been repealed.

8 Strengthen Processes Within and Between Agencies

8.1 Introduction

We recommend that CYF and DSD continue to have a Memorandum of Understanding about the arrangements for children and young people with disabilities. This section describes the processes to support collaboration and decision-making that will need to be set out in the proposed MoU and comments on the involvement of other agencies, in particular the Ministry of Education.

8.2 The 1999 MoU

In 1999 a draft MoU was introduced and feedback was sought from those using it, in the expectation that some revisions would be necessary. We were told that initial feedback was positive and no changes were expected to be made to the MoU in light of this feedback.[37] Over time, the level of satisfaction has diminished considerably. This can be attributed to the fact that most people who now use the MoU have had no training about it or related matters, and often have little contact with their counterparts in the other agency. It also reflects the perception – in both agencies – that section 141 placements are primarily the responsibility of the other agency.

8.2.1 Processes set out in the 1999 MoU

The 1999 MoU was designed to facilitate joint agency decision-making related to FGCs convened under section 145, and to reduce the scope for disputes about the responsibilities of each agency. There is a need to strengthen the processes set out, and in particular to:

- Stop focussing on the primary cause of the out-of-home placement as the basis for determining agency responsibilities that is a central feature of the 1999 MoU. Earlier sections of this report have commented at length on this issue. *(see also sections 2.2, 3.7.2, 6.2.1 and 6.3)*
- Develop an effective dispute resolution process. Experience shows that the positions staff adopt (with the best of intentions) can lead to stalemates and lengthy delays requiring ad hoc processes to work out solutions.

8.3 Important process components

During our consultation it became evident that where processes work well there was a common denominator — people with specialist interest or expertise in this area are known by their counterparts in other organisations, and they meet regularly. Often these arrangements were relatively informal and had evolved over time as staff involved got to know each other. A more systematic approach is called for, to ensure that there are good intersectoral relationships and processes everywhere and that they contribute to good outcomes. The necessary process components include:

- An explicit commitment to working together to achieve the common goal
- Designated staff in CYF, the NASCs and DSD with authority to make decisions
- Regular contact
- Clear escalation pathways

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[37] No steps were taken to re-issue the MOU with the word ‘draft’ removed.

- Joint and ongoing training

8.4 Processes proposed for the 2006 MoU

8.4.1 A commitment to working to achieve a common goal

The proposed MoU includes an explicit commitment on the part of CYF and DSD to work together to develop an integrated package of services for:

- Each child and young person with disabilities in need of care and protection, and
- Each child and young person with disabilities for whom a full-time out-of-home placement is being considered.

The new MoU also proposes a set of principles to guide the endeavours of both agencies towards the common goal, which is a safe and stable living arrangement in which the child's or young person's care and protection and disability support needs are well met.

8.4.2 Lead agency responsibilities

A lead agency should be identified in every case, to expedite communication and co-ordination. The appropriate lead agency may change from time to time, as indicated in Table 1, on page 13.

The draft 2006 MoU proposes that:

- Whenever both CYF and DSD are funding or providing services for a child, they will agree which of them will take the lead agency role
- CYF has the lead agency role whenever care and/or protection issues are under investigation and in all cases where care and/or protection matters remain unresolved.

The NASC should be responsible for co-ordinating the input of any other health and disability sector involvement, for instance, from child development teams, mental health services, paediatricians and other health specialists.

GSE should take the lead in co-ordinating education sector involvement.

8.4.3 Timeframes

The proposed MoU specifies timeframes for responding to identified need, just as the 1999 MoU did. It includes timeframes for:

- DSD to respond to a request for a needs assessment in urgent cases
- DSD to respond to a request for a needs assessment in less urgent cases – ie, where there is no risk of immediate harm
- CYF to respond to a referral/notification by a NASC or any other person in urgent cases
- CYF to respond to a referral/notification by a NASC or any other person in less urgent cases

These timeframes provide a clear statement of expectations, and should be published, as well as incorporated in contracts.

8.4.4 Transition plans

Transition planning is not routinely undertaken for this group at present. *(see also sections 6.2.5 and 6.4.3)* The proposed MOU requires that transition planning occurs as follows:

- Local CYF and NASC staff will meet to develop a transition plan for each child who is involved with the NASC and CYF
- Transition planning will commence before the child turns 16
- Transition planning will be completed at least six months before the child turns 17, or is otherwise expected to leave CYF care.

Given the importance of transition planning, and the current lack of it, it is suggested that data is routinely collected on the transition planning undertaken in a given period. *(see section 9.4.2)*

8.4.5 Shared knowledge and expertise

The children and young people with disabilities and their families who are involved with both CYF and DSD will have high and/or complex needs. It will be necessary for each agency to seek advice from the other regarding the disability and the care and protection status. This is not to clarify service and funding responsibilities, as these are already quite distinct. Rather, the focus is on ensuring that each agency's support for the child or young person and their family is optimised.

Specifically:

- CYF should seek advice from the local NASC whenever it considers that a child may have a disability so that the NASC can determine the significance of the disability issue (ie, whether the child meets DSD disability criteria)
- Each NASC should seek the advice of CYF whenever it considers that there may be care and/or protection concerns for any child with whom it has contact, and assist CYF to assess the level of risk. CYF will determine the significance of the care and/or protection concern.

Except where urgent action is required to protect a child from harm, CYF and the NASCs will collaborate in developing a complementary package of services to meet the needs of each child and young person with disabilities and their family. This will include:

- Assessing disability support and care and protection needs, and jointly considering these
- Determining whether an out-of-home placement is appropriate, and if so
  - Identifying and establishing a suitable placement
  - Ensuring that the child or young person with a disability receives the support services they require
  - Ensuring that the caregiver receives the support services they require.

Group Special Education (GSE) will always need to be involved in this planning process so that:

- The potential impacts of changes of caregiver / residence on the child's schooling can be taken into account when decisions are being made
- A strategy for maintaining continuity of the child's schooling is developed
- A strategy for supporting the child and family through any changes can be developed
- GSE has the opportunity to work with CYF, the NASC and the schools to manage any resource implications arising from any transition.

8.4.6 Designated staff

To facilitate communication and collaboration between the two agencies, the proposed MoU refers to designated positions in each agency with decision-making authority. This provides for:

- Experience and specialist training to be focused on a person at each level of the organisation who will become the agency's 'expert' on children and young people with disabilities who may be in need of care and protection or for whom an out-of-home placement is being considered.
- A person to become the known point of contact in each agency.
- An expectation that the designated staff in DSD/NASCs and CYF will develop effective and collaborative working relationships.

While each NASC will need to have a designated staff member, there are, in our view, too few children and young people with disabilities involved with CYF to warrant a designated position in each CYF office. We suggest that, in the larger centres, a single office should develop a specialty focus on this group of children and young people with disabilities, and deal with all of the cases that arise in the area. We understand that this is already the practice in Christchurch.

8.4.7 Regular and purposeful contact, and escalation pathways

Feedback during the consultation process indicated that regular contact between the agencies is important but that meetings needed to be quite focused. The new MoU proposes regular meetings at local, regional and national levels, for the following purposes:

- At the local level, CYF and NASC staff should set up a regular meeting process to confer about children and young people with disabilities with whom both agencies are involved, to develop a co-ordinated approach for each situation and to reach agreement on each agency's contribution
- In each region, designated CYF and DSD staff should meet regularly (and at least once a month) to ensure that the exchange of information and the resolution of issues is occurring at the local level and to deal with any issues that cannot be resolved locally. Minutes of these meetings should be kept to enable continuity through staff changes.
- At National Office, designated staff will meet as required to make decisions on cases where local and regional processes have not reached agreement. They will also meet periodically to address policy and inter-agency issues raised by staff, by the reporting process, and by other agencies. This will

provide a mechanism for early recognition and appropriate action on systemic problems.

This should facilitate the development of strategies involving CYF, DSD and GSE that will be acceptable, affordable and sustainable for each agency.

8.4.8 Joint and ongoing training, and best practice guidelines

Joint and ongoing training is required to develop and maintain expertise and shared understanding, and to support effective working relationships between the agencies. The training will have to be developed nationally to ensure that the content and key messages are consistent throughout the country.

The new MoU proposes that:

- All operational staff in CYF receive training in disability awareness
- All DSD staff working with children receive awareness training in family ecology and care and protection
- All DSD and CYF staff working with children have access to a copy of the MoU. An electronic copy of the MoU should also be publicly available via the CYF and MOH websites
- All designated staff in CYF, NASCs and DSD receive on-going training related to the MoU. There should be a common training programme that is jointly attended by both CYF and DSD/NASC staff (and other agencies as appropriate).

Policy and operations manuals will need to be revised so that they are aligned with the MoU, and to set out how each agency plans to give effect to the principles and processes specified in the MoU.

- CYF and DSD will need to update their operations manuals so that information is readily available to all operational staff.

9 Establish a Monitoring and Evaluation Framework

9.1 Introduction

As mentioned above, we could not obtain the information we sought on the numbers of children and young people with disabilities involved with both CYF and DSD, or about the cost of providing services to these children and young people and their families.

No monitoring or evaluation takes place for this group, despite their being one of the most vulnerable groups in our society, the Government having a clear policy on the care of children, and this group of children accessing relatively high levels of public funding via CYF, DSD and Education.

There is a need to strengthen the data systems in both agencies, so that they capture information about the involvement of CYF and DSD, and of other agencies playing a significant role.

Strategies need to be developed and appropriately resourced to:

- Support operational activity, such as routine follow-up and review of service suitability and effectiveness
- Routinely monitor and evaluate access to, and the quality of, services against policy and funding objectives
- Monitor and evaluate the impact of improved processes and changed outcomes, including implementation of the recommendations from this report.

This section provides some guidance on improving monitoring and evaluation but further work, with appropriate specialist input, is required to develop appropriate systems and specify the units of data to be collected.

9.2 National data collection

9.2.1 Current CYF and MoH data capture systems

CYF collates national data on an electronic database, which usually contains a client ID number, which permits data to be pulled together for a particular individual. The database contains a field for capturing data on whether a child or young person has a disability and to rate the disability as mild, moderate or severe. There are no guidelines for making a judgement about this, and CYF personnel rarely have expertise in disability. The ratings are therefore not useful and the field cannot be meaningfully analysed. Furthermore, the disability field is optional, and is often left blank.

The Ministry of Health (MoH) collects data on disability support services expenditure. The systems appear have been designed to monitor expenditure against particular budget items, using several separate systems depending on the budget from which the funding derives. Ministry of Health data usually contains a National Health Index (NHI) number, which permits individual data to be pulled together from the different systems within health. Information on CYF status (ie, whether a child or young person is a CYF client) is not systematically collected.

9.2.2 Data matching

Being able to match data between the two systems would be useful under *current* conditions, where there is considerable overlap in what is funded by each agency, and some inconsistency in what is funded by whom in a particular situation. However, if the service and funding boundaries are clarified in the ways we have suggested *(see section 6.4)*, and the information systems are strengthened, there will be less value in matching data from the two systems.

Data matching between agencies is generally not recommended in the interests of individual privacy. There is currently no way for data from the two agencies to be matched, nor is this desirable. A more complete picture of the total services that are being accessed by common clients would be possible if each of the systems was strengthened. Ways of strengthening the systems are outlined below.

9.3 Strengthening the data systems

9.3.1 CYF to collect better disability data

CYF staff need to routinely *ask* whether a child or young person has a disability.[38] Furthermore, if the answer is yes, they may need to ascertain whether the child or young person meets the prevailing disability criteria. It is the NASCs who make this determination. With the family's consent, the local NASC should be contacted by CYF – they may already have determined the child or young person's disability status and, if not, may wish to undertake a needs assessment so that the family can access any publicly funded disability support services to which they may be eligible.

CYF should formally record, for all the children and young people it is involved with:

- Whether they identify themselves as having a disability (self-report)
- Whether they meet the prevailing disability criteria (from the NASC)
- Their primary disability (from the NASC)
- Their overall support needs level (from the NASC).

CYF staff should not make any determination of disability status or any assessment of a person's primary disability type or support needs level. This information should be provided by the local NASC, and recorded as "not disclosed" when the family declines permission to confer with the NASC.

A simple approach for describing the type and level of disability support needs to be developed in conjunction with DSD.

9.3.2 DSD to collect better care and protection status data

NASC staff need to routinely *ask* whether a child or young person is involved with CYF, prompting the respondent to answer yes, no, or don't know, or decline to answer.

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[38] Asking is important – as with ethnicity, status may not be obvious and appearances may be deceptive.

The NASC should formally record, for all children and young people it is involved with:

- Whether they are involved with CYF (self-report)
- The name and address of the child's or young person's parent or guardian, and their relationship to the child or young person (self report)
- The name and address of the child's or young person's day-to-day caregiver and their relationship to the child or young person (self report)
- Whether they reside with their immediate family, with alternate caregivers, or in a residential support service.

As NASCs only record information with appropriate informed consent[39], and this information is required for the NASC to undertake a needs assessment, there should be no new privacy concerns to be addressed.

A simple approach for describing the items specified above needs to be developed in conjunction with CYF.

9.4 Major development components

9.4.1 Establish a population baseline

There is no baseline population data other than the data that was gathered for this report, and this is incomplete. The first step will be to devise a system for capturing quantifiable information, including:

- The total population of children and young people with disabilities who are involved with CYF
- Where they live
- Their age, gender and ethnicity
- Their broad disability type (from the NASC)
- A summary of assessed need (from the NASC)
- An indication of support need level (ie severity/complexity of need)
- Full details concerning the supports and services in place
- Full details on the costs of the above
- Information on children exiting the system during the period (see below).

9.4.2 Collect operational data

While baseline data would be a quantum improvement over the current situation, it would be highly desirable to capture quantitative and qualitative operational data. Measures might include the number of:

- Section 15 notifications for children and young people with disabilities received over a standard time period (eg, 3 months)
- Agency case conferences held (ie, to discuss how best to respond to shared clients)
- Strengthening Families meetings initiated

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[39] From a client or guardian in the case of a minor.

- Strengthening Families meetings attended
- HCN referrals made, accepted and declined
- First time FGCs attended
- Review FGCs attended
- Number and type of out-of-family placements made for children or young people with disabilities
- Children and young people with disabilities expected to exit the system within 6, 12, and 18 months and, for each of these groups, the number for whom transition planning meetings have not been held and the number for whom transition plans have not been finalised.

And, for each FGC that results in a section 141 placement, a report to National Office covering:

- A brief summary of circumstances
- Outline of the disability support services funded prior to the FGC
- Outline of the disability support services funded after the FGC
- CYPF Act outcomes agreed
- Detail on new care arrangements (eg, who to provide what type of care)
- A copy of the certifier’s process report and expert opinion
- A schedule of future reviews and transition planning to be undertaken
- An explanation of any deviation from the MoU or agreed best practice.

9.4.3 Provisional outcome measures

The need to identify and measure outcomes was emphasised during consultation. Trends need to be monitored as we would expect to see the desired changes occurring over a period of several years. Crude measures such as a reduction in the number of children and young people with disabilities going into full-time care are not particularly useful. (It was observed this could be achieved overnight without necessarily improving the situation of the children and young people with disabilities or their families.)

The following tentative outcome measures are drawn from comments made to us and the principles set out in the care of children and DSD frameworks, and are a good starting position. A major piece of work is required, involving government and community stakeholders, to develop a robust and feasible set of outcome measures.

Process measures might include:

- Increased use of (and participation in) Strengthening Families processes to support families
- Increased use of section 139 temporary care arrangements to put in place intensive support strategies to stabilise a situation (this should not be confused with respite)
- Increased use of s140 extended care arrangements, with changes in support provided, and a return to family
- Decreased use of s141 placements as a result of families being better supported

- Increased transfer from s141 to s101 where the family is no longer involved.

Outcome measures on *entry* to the CYF system might include:

- Assessed level of disability support need rising very gradually over time as access to early intervention and other appropriate supports improves
- Age at entry increasing gradually as families are better supported to care for their children at home for longer
- Placements with family members increasing as current funding issues are resolved by normalising access to funding for children and young people with disabilities
- Increasing placement of children and young people with known caregivers, in preference to placement with strangers or in residential services
- Reduced distances between placement and family as caregiver workforce capacity is developed across the country
- Changes to children's schooling arrangements becoming less common as children are placed closer to home and greater consideration is given to continuity of support.

Outcome measures *during* involvement in the CYF system might include:

- The number of placement changes, and whether these occur with short notice to remove the child or young person from an unsuitable situation (crisis) or are planned transitions from a suitable situation to a better one.

Outcome measures on *exit* from the system might include the numbers of children and young people:

- Returned to parental care
- Returned to a family caregiver
- With guardianship transferred to a foster caregiver
- Transferring to supported independent living in the community on reaching age 17.

9.4.4 Stakeholder satisfaction

No-one (including family members, advocates, NGOs, government agencies or clinicians) reported a high level of satisfaction with the existing system and many people were able to articulate very clearly their reasons for this. Their personal experience of the system was the basis of most commentators' criticisms. Accordingly, one of the best measures of any changes is whether people have a more positive experience of the system in future.

We recommend a qualitative approach to this. While feedback would be based largely on subjective impressions, this is a rich source of information that can be readily accessed. A small cohort of key informants could be identified and followed up regularly by questionnaire and/or interview about what changes appear to have occurred 'at the coal face'. It would also provide a useful vehicle for identifying success factors and barriers to change.

9.5 Reporting processes

Data collection is resource-intensive and is not an end in itself. It is imperative that the data collected is monitored and evaluated and used for ongoing quality improvement. Data collection needs to be:

- Selective rather than comprehensive
- Driven by end user requirements
- Collected routinely and to a high standard
- Regularly summarised and forwarded for national collation
- National centres need to aggregate the data and report back national, regional and local profiles to inform local service delivery and development
- There needs to be specialist monitoring and evaluation of data at regular intervals (eg, 3 monthly) to monitor performance against expectations, to identify areas requiring additional support, and to identify any systemic issues that need to be addressed, and to be able to report progress against specified outcomes to Ministers.

The new MOU proposes that designated staff at CYF and within NASCs report quarterly, via regional offices, to the staff designated to co-ordinate this work at a national level. Agencies may wish to use shared administrative capacity in order to manage the information efficiently.

9.6 Conclusion

We have recommended a practical rather than an academic approach, that builds on existing systems. If resources are limited the focus should be on gathering sound information for all *new entrants* to the system rather than on retrospectively trying to identify those already in the system and gather the data suggested.

10 Improve Access to Required Services

10.1 Introduction

The preceding sections have focused on clarifying the roles of the agencies and improving interagency processes as a means of ensuring timely and appropriate access to services. This section explores the services that are required by children and young people with disabilities and their families. The focus is on disability support services and NASCs as the organisations responsible for managing access to these services. We also make suggestions about improving access to an appropriate continuum of supports and services. We comment on these issues because early intervention and appropriate disability support services will, in many cases, prevent or at least delay the need for an out-of-home placement.

10.2 The current situation

Key informants and focus group participants identified a number of concerns about the availability of services, among them:

- Only a limited range of services is available
- There are critical service gaps, such as community support and specialist caregivers
- There is a lack of transparency and consistency in what is funded and for whom.

10.2.1 Limited range of services provided

At present there is a limited range of services specifically targeted to meeting the needs of children and young people with disabilities and their families with respect to supporting family functioning. They include:

- Home help
- Carer support
- Community respite / shared care
- Residential respite.

Many key informants and focus group participants described the NASCs' provision of access to these services as 'reactive'. Sometimes the service only becomes available once a crisis has developed. A much greater focus on supporting families from an early point was called for. People were strongly of the opinion that doing so would achieve the kinds of outcomes that are sought (ie, children being cared for successfully within their own families wherever possible), as well as being a more effective way to deploy available resources.

Some NASCs were criticised for having a minimalist approach, which was characterised by the assessment of clients' eligibility for a stock range of services in standard increments and doing little else to find a solution that would work for a particular family. Other NASCs were very responsive. One NASC, for example, funded an airfare so that a child could have a holiday with family members in another part of New Zealand, in preference to funding a residential respite option that would have been less than ideal for the child.

Sometimes families meet the criteria for access to services but still cannot get the help they need. This happens frequently with community respite, where families often find that there are no suitable caregivers available at any price. Residential respite can also be difficult to access, with the number of respite days strictly limited, and long waiting lists in some places.

10.2.2 Critical service gaps

Intensive service co-ordination

Children and young people with disabilities with high and complex needs tend to access a high level of support and services from diverse sources, including family and friends, government departments, DHBs, general practitioners, NGOs, schools and community groups. Managing these relationships can be an overwhelming task for the parents. There is a risk that resources will be wasted through duplication, or that a family may miss out because providers all assume that someone else will meet a particular need.

Intensive service co-ordination is required in these circumstances to set up the best arrangement of services for the family, especially when major events such as a change of care arrangement need to be managed. We were told, however, that the children and young people who are the focus of this report often do not access intensive service co-ordination.

Community support workers

A theme that came up frequently when we talked to organisations representing parents was the need for ‘someone to walk alongside me’. Many community-based service providers affirmed this and called for some sort of community support role to be funded - preferably within existing disability support agencies. Functions suggested for this role included someone to:

- Form a long-term relationship with the family
- Help the family to get information
- Mobilise the family’s personal resources and engage their natural and community support networks.
- Listen and, at the appropriate time, to prompt and support the family to seek additional help
- Help the family to work with the various agencies.

Both parents and providers observed that this role was more common in the past, when agencies like CCS and IHC were ‘bulk funded’. The purchasing of specific ‘outputs’, such as bed-nights or hours of caregiver support, has reduced the flexibility that provider organisations have and it has reduced their capacity to provide services that are not explicitly funded by DSD. Nevertheless, some provider organisations continue to employ community support workers, using their own income[40], because they are convinced that this is an essential component of their service. It was clear however, that only a few organisations or branches had the funding to do this.

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[40] Such as income derived from Trust Funds, bequests, donations and other fund raising.

The support worker role is seen to be particularly important for Maori and Pacific Islands families. These populations are under-represented as users of mainstream disability support services, and lack of confidence and a lack of fit with cultural practices were strong barriers to participation. Some providers are frustrated that, despite there being a clear need, they cannot obtain a contract with DSD to provide access to community support workers.

Specialist caregivers

Specialist caregivers are people who are well-equipped to provide the day-to-day care of children and young people with disabilities.

The shortage of specialist caregivers is not a new issue and has been described as the single most important area for service development for more than a decade.[41] Our consultation found that this was still the case. Lack of specialist caregivers affects the quality of care that children and young people receive, the ability of families to get the respite or other support they require, and the ability of agencies to meet the needs of their clients.

The reasons given to explain the lack of specialist caregivers include:

- Lack of sector leadership
- Lack of investment in appropriate recruitment and retention strategies
- Inadequate preparation, training and in-service support
- Low pay
- Poor working conditions related to the casualised workforce, such as lack of paid leave, supervision, special pay, training opportunities, or a career pathway.

These factors are all the more important because the work entails a steep learning curve for every new relationship. It involves a high level of responsibility and it is physically, mentally and emotionally demanding.

We consider that DSD is responsible for the specialist caregiver workforce development and related areas (ie, strategies to enhance recruitment, training, support and retention).

10.2.3 Lack of transparency and consistency

Access to services is constrained by the range and quantity of services available, and the funding available to purchase them. Other factors also come into play, as outlined below.

Lack of transparency

People we spoke to often reported that they could not seem to get a straight answer from NASCs or DSD about what support and service options were possible, and what the eligibility criteria were for accessing these services. In one city the DSD service manager was reported to have refused to give this information to providers to prevent them from ‘coaching’ parents.

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[41] See Judge Mick Brown’s report and *Just Surviving,* for example.

Of equal concern to us was the amount of misinformation about services, eligibility rules and so on. For example, in some locations it is claimed that if a family wants four or more days of respite care per week, they must enter into a full-time care agreement under section 141 of the CYPF Act and relinquish custody of their child. This is neither a legal requirement, nor a reflection of government or DSD policy. Nonetheless, some parents have been pressured into this, with devastating consequences.

Lack of consistency

Lack of consistency is a strong feature of the current disability support system. People recounted many examples of unequal treatment within and between NASCs. Providers working with children and young people with disabilities and their families say that some differences in treatment seem arbitrary. Several observed that attractive and articulate families seem to get a relatively good deal. Being persistent and 'stroppy' was also an effective strategy for gaining access in the long term, but sometimes at a high personal cost.

NASCs appear to have quite divergent philosophies. For example, some consider that early intervention is not part of their role. Others resist supporting families as far as possible in the belief that it undermines their resilience, and some do not support or fund residential respite services on principle.

10.2.4 Recognition of NASC difficulties

While NASCs were frequently criticised during our consultation, there was also some sympathy for their position. It is recognised that they do not have an easy task as holders of the purse-strings in a disability support system in which:

- There is no principles framework underpinning the approach to supporting children and young people with disabilities
- There is a lack of clear direction
- Parts of the system, even within the health and disability sector, are not well co-ordinated
- Demands on scarce resources are high
- Some needs are extremely difficult to meet
- Access to support services is a critical issue for those who need them
- Staff have heavy caseloads, sometimes exceeding 400 clients
- NASCs are under funded to deliver on what is expected from them.[42]

We had the impression that some NASCs have little opportunity to develop the networks and relationships that they require to function successfully within the communities they serve.

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[42] We were advised by DSD regional staff that funding averages out at around $100 per assessment, and this was confirmed by DSD representatives on the Project Steering Group.

10.3 Greater choice and flexibility

10.3.1 Developing and maintaining a full continuum of service options

During the consultation some people argued that families should *never* find themselves in a situation where they can no longer provide day-to-day care for their children, suggesting that with appropriate support all out-of-home placements could be avoided. Others argued that the availability of shared care, respite and out-of-home placements actually created the demand, and without them families would find better ways of managing. Some said that it was these very services that enabled families to keep going, and that, for many families, relinquishing day-to-day-care was resisted well beyond the point when it would be a reasonable course to take. Some feel that residential services are never an acceptable option, while others felt that particular children would have the best possible quality of life in an appropriate residential setting.

All of these things are true, some of the time, for some families. This is the particular challenge of the disability support sector; people are complex and what is right for one person may be wrong for the next. Also, disability support services are dealing not with individuals but with social units made up of a diversity of individuals, family and whanau groups, and communities. Choice and flexibility are vital.

As well as individually targeted disability support services there needs to be a continuum of service options that includes:

- Community development
- Family support (community support workers, home help, environmental supports and house modifications)
- Shared care
- Respite care
- Out-of-home placements.

There needs to be a mix of services available so that there is real choice. In Auckland for example, a great deal of residential care has been purchased and very little foster care. Parents there have limited choices. A stronger investment in service development is required.

10.3.2 Individualised service packages and funding

As discussed earlier, children and young people with disabilities placed in full-time out-of-family care under section 141 of the CYPF Act are likely to have exceptional disability support needs. The normal solutions do not work for this group. It is a major concern that many people involved in the DSD/CYF interface:

- Receive little if any support because what is available is not appropriate or helpful
- Are allocated a standard package of support that is not appropriate or adequate
- May be encouraged to consider an out-of-home placement in order to manage the cost of providing the services they need

- Are funded under mechanisms such as the Residential Support Subsidy (RSS), at a standard rate but cannot get the package of supports a particular child requires.

10.3.3 Intensive service co-ordination and community support work

The objective of Intensive Service Coordination (ISC) is to provide co-ordination of supports for “the small number of people within the NASC client population who have high and complex needs… ISC will involve an ongoing relationship between the person, their whanau, aiga, carers where relevant, and the co-ordinator for the period that the ISC is needed.”[43] ISC is distinguished from service co-ordination by its level of intensity rather than the nature of the role or core functions. ISC is not yet fully funded and rolled out throughout the country, and in some places where it has been rolled out access is reported to be poor.

Community support work is more in the nature of a direct support to families than ISC provided by NASCs. A close working relationship is required, and there is an element of social support that cannot be provided by NASCs directly, given their role as budget holder.

There are many examples of successful community support workers already operating, albeit on a small scale. We were given many examples of how community support workers, if appropriately deployed, provide very high value in terms of achieving some of the critical but more difficult outcomes we seek, among them building resilience, monitoring progress, and finding alternate caregivers within the family’s immediate community.

Community support work is not a service that DSD currently purchases although there is a strongly held view that it should be a core disability support service. The report of the recent FACS[44]/CCS pilot (2005) would seem to confirm this view. We consider that while community support work might be considered to fit well under the early intervention mandate of the Ministry of Social Development, the need for a specialist disability focus implies a key role for DSD. As a matter of priority, specialist support worker capacity should be purchased from a range of providers so that families can access community support from an agency that they are comfortable with.

10.3.4 Supporting alternate caregivers

Specialist caregivers

Recruitment, training and retention of caregivers is one of the highest priorities. There will be no quick fix, and a long term strategy is required. There are many difficulties to be overcome, but also many avenues worth pursuing, such as using community support workers to identify potential carers via informal networking within local communities.

We use the term specialist caregivers to describe carers who have capacity to care for those children and young people with disabilities who require support that is outside

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[43] Draft NASC policy, procedure and information reporting guidelines, September 2005.

[44] Family and Community Services, Ministry of Social Development

the normal range.[45] They require a good parenting skills and a reasonable level of disability awareness, Other skills such as behaviour management or medical support will often be specific to the needs of the child or young person, and training may be necessary. It would seem wiser to invest in capacity to train and support specialist caregivers as required, than to expect individual caregivers to develop a broad base of skills and be ‘on call’ to care for any child or young person whatever their needs might be. Again, this kind of support role does not tend to be favoured within existing approaches to contracting.

DSD should take a strong leadership role in this area, with respect to:

- Workforce planning
- Recruitment
- Training, and
- Supervision and support.

Access to publicly funded carer support should be carefully managed, especially given the scarcity of caregivers and the dependence on respite caregivers to enable some families to remain intact.

In our view, DSD should take responsibility for managing the development and utilisation of specialist caregivers, given that specialist caregivers:

- Are used in a part-time capacity as providers of shared care
- Will ideally be available to assume a full-time caregiver role to provide continuity should a full-time out-of-home placement be sought.

In addition:

- DSD is responsible for developing disability support services
- DSD already contracts with organisations that have the infrastructure to support specialist caregivers.

We acknowledge that there are significant issues over the specialist caregiver workforce given that there are several government agencies that are purchasing these services. Nevertheless, it is our view that CYF and DSD should collaborate over the allocation of specialist caregivers to children and young people with disabilities.

Family caregivers

Greater use of family caregivers would reduce demand for specialist caregivers. DSD currently has a policy of not funding family caregivers. In practice this can mean that DSD will fund a placement with a stranger, or in a residential facility, in preference to funding a placement with a family member. This is clearly at odds with New Zealand’s care of children framework.

It is widely believed that funding family caregivers is not possible. But government has a mechanism for funding family caregivers via W&I, subject to processes that ensure a placement with family members is in the *best interests of the child*. If this mechanism were accessed for children and young people with disabilities, as it is for

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[45] Disability awareness training for non-specialist caregivers would be valuable however.

their non-disabled peers, the impediment to children and young people with disabilities being placed with family would not exist.

All caregivers

DSD should implement a policy of providing access to disability support services *irrespective* of the child's living arrangements. This would mean that family and specialist caregivers would be able to obtain similar access to respite and other support services that the family would receive under the same circumstances. What, if anything, they are being paid to provide the day-to-day care that any child requires, has no practical bearing on what disability support needs they may experience and warrant assistance with.

10.3.5 Consistency and transparency

Lack of consistency is a concern given the goal of fair and equitable access to services and supports. Consistency should not be confused with uniformity, because a flexible response is also necessary to meet the diverse needs and circumstances of people with disabilities. Without transparency there is no way for families to gauge whether they are missing out on support they could reasonably expect to receive, or whether they have had fair treatment.

10.4 Next steps in the development of disability support services

The review has identified a number of priority areas for further development.

10.4.1 A policy framework to inform DSDs approach

There is no clear policy framework within the health and disability sector for responding to the needs of children and young people with disabilities and their families. A framework will need to incorporate several key components to inform the development and operation of disability support services.

DSD's children's framework will need to be consistent with the children's framework established under the CYPF Act and Care of Children Act, identifying as priorities:

- Keeping families intact
- Enabling parents to maintain their day-to-day caregiving and custodial roles to the fullest extent possible
- An out-of-home placement will be a last resort
- Where an out-of-home placement is required, it will preferably be with other family members as per the hierarchy set out in the CYPF Act

Practical elements of a framework would include:

- Support for shared care and respite care. This might sometimes involve the child spending more than 90% of the time with an alternate primary caregiver, provided that the child's parents remain closely involved and no detrimental effects to the child or young person are evident
- A mandate for early intervention to help build resilience and support families, in the interests of keeping families intact
- A mandate for intensive service co-ordination and relatively high levels of resources where required to keep families intact

- Clarifying that the purpose of an out-of-home placement is *not* to make service co-ordination, funding or service delivery easier but to meet the needs of the child or young person and their family, where their needs cannot be met while the child or young person lives at home
- Ensuring that caregiver access to disability support services is not dependent on the relationship of the full-time carer to the child, even where that caregiver is a family member[46]
- An understanding of how involvement with other parts of the health sector will be co-ordinated with disability support services, and with the wider range of agencies that may be closely involved with a family.

10.4.2 Use of individualised service packages and funding

At present there is a strong tendency for families to be offered a 'stock menu' of possible supports, and some NASC personnel report that the discretion required to be responsive to individual circumstances is diminishing. Individualised service packages and funding should be used more often with 'at risk' families to purchase disability support services that are outside the 'normal' range.

10.4.3 Development of an appropriate funding model for residential care

Every child or young person with a disability who is placed in full-time ongoing out-of-home care under section 141 of the CYPF Act should receive disability support services based on assessed need. A model for determining an appropriate level of funding has been introduced for two residential support service providers with some success, although the model has not been validated for use with children. It would be timely to revise this model in light of experience and develop a similar approach for use with all providers of full-time out-of-home placements of children and young people with disabilities under section 141.

10.4.4 Intensive service co-ordination and community support work

We believe that there needs to be a clear distinction between the function of ISC and the community support worker role, which entails much more intimate involvement with families and the communities in which they live than NASCs are currently resourced to deliver.

ISC would be helpful to many 'at risk' families, but would be invaluable to every family that is already involved with both DSD and CYF. It would help them find alternatives to full-time out-of-family care, or to establish support during the transition to a new living arrangement. Accordingly, we have specified access to ISC as a requirement in the new MoU.[47] NASC guidelines should be amended to reflect this requirement.

Community support work is of greatest value within the context of early intervention, especially with respect to mobilising the family's personal resources and engaging their natural and community support networks. Effective community support work

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[46] Note that we have assumed any fee for service payment for assuming *general* parental responsibilities, or reimbursement of *ordinary* living expenses is not a disability support service, and should ideally continue to be met by the family, with support from W&I or CYF if required.

[47] While we require that a family has 'access', this in no way precludes a family from exercising choice in deciding that they do not want to have Intensive Service Coordination.

will reduce demand for access to specialist caregivers, and has the potential to help identify suitable caregivers from within the community. A service description should be developed. Community support work could be explicitly purchased in several locations and the outcomes evaluated with a view to revising the service specification prior to a national roll-out.

10.4.5 Specialist caregivers

A multifaceted strategy for improving access to specialist caregivers is required, that:

- Preserves the current workforce by providing a good level of practical support, and adequate remuneration
- Makes more efficient use of current caregiver capacity by managing the allocation of caregivers to families who can best utilise their skills
- Increases the numbers of specialist caregivers available by using community development strategies to identify potential caregivers within local community networks
- Reduces demand for the out-of-family care by supporting other family members to provide required care
- Reduces demand for the out-of-family care by supporting families better through monitoring of risk indicators, responding promptly to emerging need, mobilisation of natural and community supports, and timely access to appropriate services.

10.4.6 Improving consistency and transparency

Performance monitoring needs to strike a better balance between compliance and more qualitative outcomes than at present.

The key to achieving better consistency among the NASCs is to have:

- A strategic framework
- Strong direction and national leadership
- Common service specifications and objectives
- A requirement to offer a range of disability support options
- A focus on achieving desired outcomes
- Standardised assessment tools and processes
- Common training on the above.

NASCs are agents of DSD and should be operating collaboratively and in a similar manner.[48] Consideration should be given to standardising NASC operations. A common assessment tool and process should be required, and all NASCs should be using evidence-based best practice.

Without transparency it is difficult to demonstrate consistency. Furthermore, transparency creates a need to operate consistently. We consider that the kinds of assistance that can be accessed, and the eligibility criteria for gaining access, should be widely known, to agencies, service providers and the wider public.

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[48] It has been suggested that having fewer NASCs might facilitate achieving these goals.

The W&I website is an excellent model in setting out assistance and eligibility criteria. It was established in response to concerns that are similar to those about access to disability support services. It recognises that there will be exceptions to the rule and it encourages people to contact one of its offices.

11 Implementation

11.1 Introduction

This section outlines the major components of the implementation task as we see them, although any comments that we make can only be indicative. The implementation work programme will be decided by CYF and DSD after they have considered our report, briefed their Ministers and made decisions about the resources and priorities.

We outline the major components of the implementation task under the following headings:

- The agencies' response to the report
- Implementing the new MoU
- The new role of the section 141 certifiers
- Implementing the monitoring and evaluation strategy
- Legislative changes
- Managing the implementation task.

In some instances, we outline the different options that might be considered. We also comment on the approach to the implementation task, through the appointment of a project manager, the establishment of a steering group and working group and the management of the implementation task as a set of related work-streams. We also recommend an end date of 31 December 2008 for the implementation project.

11.2 The agencies' response to the report

The first task, once we have delivered our report and briefed agencies, is for CYF and DSD to consider the report, brief senior staff, reach a shared view on the proposals and brief their Ministers. They will also need to make a decision about releasing the report (or a summary of it) and the information to accompany the report when it is released – about the response, the linkages between this work and related activities, the likely implementation timeframe and so on. This initial phase of the work also involves developing a detailed implementation work programme and deciding on the priority and the resources to be committed to the task.

11.3 Implementing the new MoU

As well as reviewing the draft MoU in the light of their position on the report, CYF and DSD will need to work up some of the operational detail to be included in the MoU, or to support its implementation. For instance, they will need to decide who will be the designated staff at local, regional and national levels, and develop the detail of the reporting and monitoring requirements. Similarly, they will need to decide on their approach to training related to the MoU and will need to develop a training seminar for CYF, NASC and DSD staff. A facilitator and expert staff will be needed to run the training workshops and responsibility will need to be assigned for managing ongoing joint training. The meeting and reporting processes outlined in the MoU will also need to be set up.

11.4 The new role of the section 141 certifiers

Assuming that the agencies agree with our recommendations on the new role for the section 141 certifier, the implementation task will involve reviewing the administrative arrangements for the certifiers and deciding whether to contract the role to a national organisation, or to strengthen the administrative and professional support for the certifiers provided by the Ministry of Health. If the work is to be contracted to a national organisation, a service specification will need to be developed, and a contract negotiated. The actual cost of the service will, of course, be subject to negotiations with the provider and to their assessment of the workload and costs involved.

11.5 A monitoring and evaluation strategy

Strategies need to be developed and appropriately resourced to:

- Support operational activity, such as routine follow-up and review of service suitability
- Routinely monitor and evaluate access to, and the quality of, services against policy and funding objectives
- Monitor and evaluate the impact of improved processes and changed outcomes, including implementation of the recommendations from this report.

Guidance on improving monitoring and evaluation is provided throughout section 9 of the report, but further work, with appropriate stakeholder and specialist input, is required to develop appropriate systems and specify the units of data to be collected.

11.6 Legislative changes

The proposals in the report involve the redrafting of section 141 and the repeal of sections 142 and 145 of the CYPF Act. CYF and DSD will need to consider which proposals can be implemented by changes in operational practice before the Act is amended and which proposals, if any, require the amendment of the Act before they can take effect. Consideration will need to be given to the priority and the options for amending the Act, and arranging policy and other approvals for the legislative changes.

11.7 Managing the implementation task

Keeping the focus on children and young people with high and complex disability support needs

There are several approaches the agencies could take to managing the implementation task. One would be to focus on the MoU and assimilate other components of the task in the work programmes of CYF, DSD and other departments. We advocate keeping the focus on children and young people with disabilities, as the report does, and managing the implementation task as a co-ordinated project that interfaces closely with other work-streams. This small but important group of children and young people with disabilities is consistently overlooked. A focus on the group of children and young people and their families provides a cross-cutting perspective on the issues and it will help to ensure that the implementation work programme achieves the gains that the report signals.

11.7.1 A steering group, a project manager and a joint working group

For leadership and co-ordination, we recommend setting up a CYF / DSD steering group and a working group. The steering group should fill the management role that the interagency BIS group has taken in the project to date, and should include the appropriate managers from CYF and DSD. The current working group should continue, with the addition of a representative from MSD. We recommend the appointment of a full-time project manager and a project team worker. In addition, project teams will need to be set up for each of the identified tasks, and we assume that the membership of these project teams will be broader than CYF and DSD. See further comments under Budget, below.

11.7.2 Budget

The implementation work programme will involve expenditure on the following items:

Training workshops related to the new MoU

We assume that workshops for CYF and NASC/DSD staff will be held in Dunedin, Christchurch, Wellington, Hawkes Bay, Rotorua/Bay of Plenty, Hamilton and Auckland. There will be costs for meeting rooms, refreshments, travel for Wellington-based staff and a daily rate for the facilitator.

Annual refresher training on the MoU processes

An annual round of refresher training and training for new staff will need to be arranged. This should involve a repeat of the training outlined above.

The section 141 certifier role

We estimate that certifiers will attend up to 50 FGCs per year. We estimate this will involve about 6 hours work per FGC as well as travel time and costs when a certifier needs to travel to another town.

In addition, in-service training for certifiers will need to be arranged (say, four training days per year).
Administrative and professional support will also be required. We estimate 0.3 FTE at National Office. One option for this function is a lead or principal certifier, who has responsibility for professional matters related to the certifier role.

Managing the implementation task

We assume that the project manager, the project team worker and the members of the working group will be staff from CYF, MSD and the Ministry of Health (DSD). If staff are seconded to the project manager and project team worker roles, and to the project working group, the agencies may wish to identify the salary and other costs involved in back-filling the positions of those who have been seconded.

We assume that the steering group would be made up of the appropriate managers from CYF and DSD, that the project manager and a project team worker would be appointed as a full-time positions until the end of 2008.

We estimate that working group members would have a commitment of 0.2 FTE to the project and that the workload and commitments of other staff who are contributing to project work-streams should be managed in the usual way.

In setting the budget, some consideration should be given to the consultation and travel that might be involved in the implementation phase.

11.7.3 Information materials for CYF, DSD and NASC staff, providers and families

There will be production and distribution costs for an information pamphlet for families about the review and about the likely changes in inter-agency collaboration and service delivery.

Agencies will need to decide whether to publish and distribute this report, or to produce a summary version for distribution. We would recommend a summary version. A covering letter, on the response to the report and the implementation work programme, will need to accompany the summary report. We would recommend distribution to the people and organisations we consulted during the review. CYF and DSD will have other contacts on their mailing lists.

Training materials, updated content for staff manuals and other documentation will also need to be developed. Some of this, such as the production of training materials, will be an implementation task. Other elements will be business-as-usual, when manuals and other documentation are updated.

Implementation timeframe and end date

As well as keeping the implementation work programme focused on the group of children and young people with disabilities, we believe it would also help to focus the work by setting an end date for the implementation project, by which time the major elements of the task should be completed and other work should be sufficiently well advanced that the longer term work can be integrated into the agencies work programmes. There is a risk that, if the implementation task is assimilated into departmental work programmes, and if the implementation timeframe is open-ended, the work will lose momentum and focus.

We recommend 31 December 2008 as the end date for the implementation project.

12 Conclusion

Our brief encouraged a principles-based approach to the review and this has enabled us to consider the legislation, policy and operational practice in a unified way. We have focused on the outcomes the system should be trying to achieve for the children and young people with disabilities who are involved with CYF and DSD. We have been able to redefine the ‘problem’ in a way that is normalising, and suggests a way forward.

Rather than proposing a substantially new approach, we have built on the strengths of the current system – specifically, the legislative framework and the principles they enshrine, current agency roles and specialisation, and, not least, the commitment of the staff of CYF, DSD, the NASCs and provider organisations to doing their best for these children and young people and their families – within the constraints of current policies and practice.

The solutions we have proposed will, we believe, address the concerns that gave rise to this review. In our view, improvements at the interface between CYF and DSD will not be difficult to achieve, but a commitment on the part of the agencies is required.

Progress depends on a commitment from CYF and DSD, to:

- Keeping a focus on this group of children and young people with disabilities. The first step is to assign responsibility for this group to specific people in their organisations, with the appropriate resources and capacity
- Recognising that the proposals are interdependent and implementing them as an integrated package
- Tackling the bigger issues, like access to alternate caregivers, which in practice have significant consequences for children and young people with disabilities and their families.

The most significant gains will come from improvements to the range of disability supports and services, and ensuring that ‘at risk’ families get timely access to them. An investment in planning and implementation will be required, as well as an investment in developing additional capacity and new services, and purchasing these supports and services as they come on-stream.

We believe that we have provided a robust and comprehensive platform for bringing about changes within a realistic period of time. There is already widespread recognition of our failure as a society to support families to meet the needs of children and young people with disabilities within the family setting. Now an undertaking to act is required, together with a commitment of necessary resources.

APPENDIX ONE: Glossary

Care of Children Act	The Care of Children Act 2004, which came into force on 1 July 2005. The purpose of the Act is “to promote children’s welfare and best interests, and facilitate their development, by helping to ensure that appropriate arrangements are in place for their guardianship and care; and to recognise certain rights of children”.
CCS	CCS New Zealand, service provider and advocacy organisation, formerly the Crippled Children’s Society
CYF	The Department of Child, Youth and Family Services
CYPF Act	The Children, Young Persons and their Families Act 1989. “An Act to reform the law relating to children and young persons who are in need of care or protection or who offend against the law and, in particular, (a) to advance the wellbeing of families and the wellbeing of children and young persons as members of families, whanau, hapu, iwi, and family groups; (b) to make provision for families, whanau, hapu, iwi, and family groups to receive assistance in caring for their children and young persons; (c) to make provision for matters relating to children and young persons who are in need of care or protection or who have offended against the law to be resolved, wherever possible, by their own family, whanau, hapu, iwi, or family group.”
DHBs	District Health Boards, the providers of hospital- and community-based services and the funders of some community-based health and disability services
DSD	The Disability Services Directorate of the Ministry of Health
W&I	Work and Income
Extended care	Full-time out-of-home placement when a family cannot provide the day-to-day care their child requires for an extended period of time. It can be a foster placement or a residential placement, and is typically of 6 months to one year’s duration, depending on the age of the child or young person. It can be for longer periods, or even ongoing. Often, but not always, it is expected that the child or young person will return to the care of their family as soon as possible. An out-of-home placement of this nature must be arranged under the provisions of the CYPF Act – sections 101, 141, or 142.
FGC	A Family Group Conference, convened by CYF under either section 20 or section 145 of the CYPF Act
GSE	Group Special Education, part of the Ministry of Education
HCN	The High and Complex Needs funding programme, managed by the High and Complex Needs Intersectoral Unit, based in CYF

IHC	IHC New Zealand, service provider and advocacy organisation, formerly the Intellectually Handicapped Children's Society. The operational branches of IHC are called Idea Services.
MoU	The Memorandum of Understanding signed in 1999 by CYF and the Health Funding Authority, whose role has since been absorbed into the Ministry of Health
NASCs	Needs Assessment and Service Co-ordination agencies, which undertake needs assessments and arrange services for people with disabilities, on behalf of DSD
NGOs	Non-governmental organisations, in this context usually the providers of disability support services and the advocates for people with particular types of disabilities
Respite care	Occasional short periods of out-of-home care. Respite care may be provided by another family, or in a residential facility that is staffed and provides out-of-home care for more than one child or young person at a time. The purpose of respite care is to relieve the family of responsibility from time to time so that they can 're-energise'.
Shared care	Part-time out-of-home care that is usually more regular than respite care and involves, as the name suggests, another family caring for a child or young person. A typical arrangement might be 2-3 days every week, or alternate weeks. The purpose of shared care is to develop a support system that is as much like an extended family as possible, so that the child or young person and the family sharing the responsibility for care can form an attachment. Shared care is organised where a family needs, or will need, regular breaks in order to continue to care for the child or young person with a disability.
Temporary care	An out-of-home placement with either a foster family or in a residential setting. Its purpose is to provide care to a child or young person during a family crisis. It is provided on an as-required basis but not regularly or frequently. Temporary care tends to be for 2 to 8 weeks in total. Section 139 of the CYPF Act is usually the basis for funding temporary care.
UNCROC	The UN Convention on the Rights of the Child, which New Zealand signed in April 1993

APPENDIX TWO:
A framework for the care of children with disabilities[49]

In this appendix we comment on the law related to the care and protection of children and young people with disabilities.[50]

International law

The current view is that international laws, including United Nations conventions, infuse domestic law and should be taken into account. International law can be used where domestic law is ambiguous or silent. Where two interpretations are possible, the interpretation most consistent with the international obligation should be adopted.

New Zealand ratified UNCROC on 6 April 1993.[51] New Zealand's ratification of UNCROC creates a commitment to implement its principles in domestic law. Article 2(1) says that "States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind." Article 3(2) of UNCROC obliges signatories to take "all appropriate legislative and administrative measures… to ensure the child such protection and care as is necessary for his or her well-being". Under Article 3(1) this applies to "all actions concerning children", clearly covering situations involving the out-of-home placement of a child with a disability. Further, this applies to both private and state agencies.[52]

A hierarchy of UN documents is suggested by *Tavita*, with some having little bearing, while others, and UNCROC was included in this latter category, were "so manifestly important" as to place a fetter on the discretion of administrative officials.

The *Tavita* case provides an example of the application of UNCROC to an immigration case, because it involved the potential separation of a child from its parents. An analogy could be drawn with a disability case involving the day-to-day care of a child, and therefore bringing in UNCROC principles, especially considering Article 3 of UNCROC. It also suggests that if a health law conflicted with a law relating to children, such as the CYPF Act, UNCROC principles might indicate that the CYPF Act, which is considered to align with UNCROC, should apply.

UNCROC creates an obligation on the government to implement domestic legislation that supports the aims of the Convention. While there is no single New Zealand family law framework, UNCROC, together with the NZ Bill of Rights Act, the CYPF Act and the Care of Children Act, create strong pointers as to applicable standards and principles when interventions are made in the lives of children. In cases of conflicting domestic law, an interpretation consistent with UNCROC is indicated.

Judicial interpretation supports a broad application of a principled approach when dealing with children, even when a statute is silent or focused on an area traditionally

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[49] Legal advice provided by Wendy Parker LLM, Family Law Specialist, October 2005.

[50] CYF roles with respect to young offenders with disabilities lies outside the scope of this review.

[51] The Convention was signed subject to 3 reservations. These relate to children unlawfully in NZ, the protection of children in employment and the mixing of young and adult prisoners.

[52] See Puli'uvea v Removal Review Authority [1996] NZLR 538

considered outside of the ambit of family law, such as immigration (and, by analogy, disability). Therefore it can be concluded that there is an obligation on state agencies to consider this broad UNCROC-infused legal framework even if their own legislation does not make specific reference to the interests of children.

Domestic law

The law relating to children has developed in a piecemeal fashion over time. Different messages and values about children and families appear in different statutes and reflect changing notions of children.

It is common in family law to find tensions between the need for society to protect children as a group of its more vulnerable members, and the desire to protect family autonomy and keep it from the reach of the state. The state has both paternalistic and bureaucratic interests in the lives of children.

Since the late 1980s, a number of key statutes have been passed relating to children. Naturally, these are products of their times, and promote a rights-based approach to children. The notion that each right has a corresponding responsibility is reflected in a legal focus on the responsibilities of families.

Mechanisms exist for the removal of children from families, as they have for a long time, but in addition, the law now creates state obligations to provide support for families.

The Care of Children Act 2004

The Care of Children Act came into force on 1 July 2005 and replaces the Guardianship Act. The Act is used, among other things, to determine custody and access (now called residence and contact), that is, the day-to-day care of children. Guardianship changes, including the appointment of additional guardians, are also possible under the Act. The Care of Children Act applies not only to proceedings under that Act, but to any proceedings involving the guardianship of, or the role of providing day-to-day care for, or contact with, a child.[53]

(1) The purpose of this Act is to—

> (a) promote children's welfare and best interests, and facilitate their development, by helping to ensure that appropriate arrangements are in place for their guardianship and care; and (b) recognise certain rights of children.

(2) To that end, this Act—

> (a) defines and regulates—
>
> (i) parents' duties, powers, rights, and responsibilities as guardians of their children
>
> (ii) parents' powers to appoint guardians
>
> (iii) Courts' powers in relation to the guardianship and care of children.

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[53] Care of Children Act 2005, section 4(1)(b).

Section 4 restates and expands the paramountcy principle to include both welfare and best interests:

Child's welfare and best interests to be paramount —

(1) The welfare and best interests of the child must be the first and paramount consideration—

> (a) in the administration and application of this Act, for example, in proceedings under this Act; and
>
> (b) in any other proceedings involving the guardianship of, or the role of providing day-to-day care for, or contact with, a child.

(2) The welfare and best interests of the particular child in his or her particular circumstances must be considered.

(3) A parent's conduct may be considered only to the extent (if any) that it is relevant to the child's welfare and best interests.

(5) In determining what best serves the child's welfare and best interests, a Court or a person must take into account—

> (a) the principle that decisions affecting the child should be made and implemented within a time frame that is appropriate to the child's sense of time; and
>
> (b) any of the principles specified in section 5 that are relevant to the welfare and best interests of the particular child in his or her particular circumstances.

Principles relevant to child's welfare and best interests—

The principles referred to in section 4(5)(b) are as follows:

> (a) the child's parents and guardians should have the primary responsibility, and should be encouraged to agree to their own arrangements, for the child's care, development, and upbringing:
>
> (b) there should be continuity in arrangements for the child's care, development, and upbringing, and the child's relationships with his or her family, family group, whanau, hapu, or iwi, should be stable and ongoing (in particular, the child should have continuing relationships with both of his or her parents):
>
> (c) the child's care, development, and upbringing should be facilitated by ongoing consultation and co-operation among and between the child's parents and guardians and all persons exercising the role of providing day-to-day care for, or entitled to have contact with, the child:
>
> (d) relationships between the child and members of his or her family, family group, whanau, hapu, or iwi should be preserved and strengthened, and those members should be encouraged to participate in the child's care, development, and upbringing:
>
> (e) the child's safety must be protected and, in particular, he or she must be protected from all forms of violence (whether by members of his or her family, family group, whanau, hapu, or iwi, or by other persons):
>
> (f) the child's identity (including, without limitation, his or her culture, language, and religious denomination and practice) should be preserved and strengthened.

The Children, Young Persons and their Families Act 1989

The CYPF Act was passed into law in 1989, and has been amended several times since then. The Ministry of Social Development (MSD) is responsible for this piece of legislation. The object of the CYPF Act is to promote the well-being of children, young persons, and their families and family groups by a variety of means.[54] Some of these functions are facilitated through programmes led by MSD, such as Strengthening Families.

Part Two of the CYPF Act is concerned with care and/or protection.[55] Care and/or protection functions are the responsibility of the Department of Child Youth and Family (CYF), and are of particular importance to this review.

Section 14 of the Act defines the children and young people who are in need care and protection. For the purposes of this report several grounds are particularly relevant, and include:
Being harmed — they are being, or are likely to be, harmed (whether physically or emotionally or sexually), ill-treated, abused, or seriously deprived; or

Being neglected — their development or physical or mental or emotional well-being is being, or is likely to be, impaired or neglected, and that impairment or neglect is, or is likely to be, serious and avoidable; or

Harming self or others — they behave in a manner that is (potentially) harmful to the physical or mental or emotional well-being of themselves or others, and their parents (or other carers) are unable or unwilling to control this behaviour; or

Parents unwilling or unable — parents or guardians or other persons having the care of the child or young person are unwilling or unable to care for the child or young person; or
Abandonment — parents or guardians or other persons having the care of the child or young person have abandoned the child or young person; or

Discord between carers — serious differences exist between a parent, guardian, or other person having the care of the child or young person and any other parent, guardian, or other person having the care of the child or young person to such an extent that the physical or mental or emotional wellbeing of the child or young person is being seriously impaired; or

Lack of continuity of care — the ability of the child or young person to form a significant psychological attachment to the person or persons having the care of the child or young person is being, or is likely to be, seriously impaired because of the number of occasions on which the child or young person has been in the care or charge of someone else for the purposes of maintaining the child or young person apart from the child's or young person's parents or guardians (excludes care provided

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[54] See General Objects as set out on pp22-23 of the CYP&F Act (1989 No 24).

[55] The CYP&F Act often refers to care or protection, and occasionally care and protection. It does not suggest that care and protection issues always exist alongside each other, although they may. For the purposes of this report the term care and/or protection is used for clarity.

under the provisions of the CYP&F Act or the Adoption Act, and in boarding schools and hospitals).

Principles

Section 5 of the CYPF Act sets out the general principles to be applied wherever possible in exercising powers conferred by the Act, including:

Involving family — involving parents, families, whanau, hapu, iwi, and family groups in decision-making

Strengthening relationships — strengthening the relationship between the child or young person and their parents, families, whanau, hapu, iwi, and family groups

Considering impact on both child and family — considering how any decision will affect the welfare of the child or young person; and the stability of their parents, families, whanau, hapu, iwi, and family groups

Child's wishes to be taken into account — consideration should be given to the wishes of the child or young person

Participant's agreement preferable — endeavours should be made to obtain the support of the child or young person and their parents, guardians, or other caregivers to the exercise of any powers conferred by the Act

Timely implementation — decisions to be implemented in a timeframe appropriate to the child or young person's sense of time.[56]

Section 6 of the CYPF Act states that in the administration and application of the Act:

> *"the welfare and interests of the child or young person shall be the first and paramount consideration"*

Further to these over-arching principles, section 13 of the CYPF Act identifies principles specific to the care and protection of children and young people. These have been simplified and summarised below, highlighting the most important principles with respect to this review:

Protection, rights and welfare to be ensured — children and young persons must be protected from harm, their rights upheld, and their welfare promoted.

Primary care role with family — the primary role in caring for and protecting a child or young person lies with the child's or young person's family, whanau, hapu, iwi, and family group.

Family to be supported in that role — the family, whanau, hapu, iwi, and family group they should be supported, assisted, and protected as much as possible.

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[56] *List paraphrased from General Principles as set out on p24 of the CYP&F Act (1989 No 24).*

Intrusion in family life to be minimised — any intervention into family life should be the minimum necessary to ensure a child's or young person's safety and protection.

Continuity to be maintained — when a child or young person is in an out-of-home placement they should, wherever practicable, live in an appropriate family-like setting in the same locality as that in which they were living previously, where their links with family, whanau, hapu, iwi, and family group may be maintained and strengthened. Furthermore, participation in education, training, or employment should be allowed to continue without interruption or disturbance.

Out-of-home placements a last resort – a child or young person should be removed from his or her family, whanau, hapu, iwi, and family group only if there is a serious risk of harm to the child or young person. Wherever practicable, the necessary assistance and support should be provided to enable the child or young person to be cared for and protected within his or her own family, whanau, hapu, iwi, and family group. Where a child or young person is removed to an out-of-home placement, wherever practicable, the child or young person should be returned to, and protected from harm within, that family, whanau, hapu, iwi, and family group (in a timely fashion).[57]

Sense of belonging to be preserved — when a child or young person is in an out-of-home placement and cannot be returned to their family, whanau, hapu, iwi, and family group, the child or young person should live in a new family group, or an appropriate family-like setting, in which he or she can develop a sense of belonging, in which their sense of continuity and their personal and cultural identity are maintained.

Preferred care arrangements — in determining the person in whose care the child or young person should be placed, priority should, where practicable, be given to a person who is a member of the child's or young person's hapu or iwi (with preference being given to hapu members), or, if that is not possible, who has the same tribal, racial, ethnic, or cultural background as the child or young person; and who lives in the same locality as the child or young person.

Importance of permanency and attachment — where a child or young person cannot remain with, or be returned to, his or her family, the child or young person should be given an opportunity to develop a significant psychological attachment to the person in whose care the child or young person is placed.

New Zealand Bill of Rights Act

While the CYPF Act and the Care of Children Act have broad application and contain important statements of the law, UNCROC and the New Zealand Bill of Rights Act 1990 have an even broader reach. The high-level statements found in UNCROC and the NZ Bill of Rights Act affect all domestic law.

Section 5 of the NZ Bill of Rights Act prohibits the state from reading down rights (which include the right to freedom from discrimination on the grounds of disability) in laws.

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[57] Author’s addition in brackets

APPENDIX THREE:
Proposed Memorandum of Understanding

MEMORANDUM OF UNDERSTANDING

BETWEEN

THE DEPARTMENT OF CHILD, YOUTH AND FAMILY SERVICES

AND

THE DISABILITY SERVICES DIRECTORATE
OF THE MINSTRY OF HEALTH

MARCH 2006

This Memorandum of Understanding is made on xx March 2006

Between The Chief Executive, Department of Child, Youth and Family Services

And The Deputy Director-General, Disability Support Directorate, Ministry of Health

Introduction

1. The role of the Department of Child, Youth and Family Services (CYF) is to support families to achieve well-being for their children and young people. CYF is responsible for the provision of care and/or protection and youth justice services to all children and young people. Its statutory role is defined by: the Children, Young Persons and their Families Act 1989, the Adoption Act 1955, the Adult Adoption Act 1986, the Adoption (Inter-country) Act 1997 and the Care of Children Act 2004.

2. The Ministry of Health is responsible, through the Disability Services Directorate (DSD), for the provision of disability support services to people with disabilities who "have 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 results in a reduction of independent function to the extent that ongoing support is required."

3. This agreement covers the provision of services for Children and young people with disabilities[58] who are the subject of a process under Part Two the CYPF Act, or who are receiving care and other services in terms of Part Two of the CYPF Act.

Purpose

4. The purpose of this Memorandum of Understanding is to set out the agreement between CYF and DSD on the principles, processes and funding arrangements related to children and young people with disabilities who are the subject of a process under Part Two the CYPF Act, or who are receiving care and other services in terms of Part Two of the CYPF Act.

Agreement

5. CYF and DSD agree that:

   We will apply the principles set out in Schedule One

   We will use the processes described in Schedule Two

   We will apportion costs of care for children and young people with disabilities for whom they have shared responsibility as described in Schedule Three.

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[58] That is, those who meet the prevailing Ministry of Health definition of disability for the purposes of the Health and Disability Act.

SCHEDULE ONE – GUIDING PRINCIPLES

In implementing this Memorandum of Understanding, we will give effect to the principles in the UN Convention on the Rights of the Child, the Children, Young Persons and their Families Act 1989, the Care of Children Act 2004. In particular, we will ensure:

- That the rights of children are recognised and that they are not diminished by the presence of a disability

- That the best interests of the child are our primary concern

- That the unique and complex support needs of this particular population are recognised by a response that takes a whole-of-life perspective, protects and strengthens natural resources, and uses available resources flexibly to develop individually tailored support packages

- That the child lives with or is regularly cared for by its own family for as much of the time as possible

- That at least as much support is made available to maintain the child with its family as would be provided for an out-of-home placement

- That the care provisions of section 139 and/or section 140 will be used and every effort made to strengthen the capacity of the family to resume full-time or regular care of the child, before an out-of-home placement under section 141 is considered

- That when an out-of-home placement is being considered, the child will have an independent voice in the process and the child's interests will be recognised

- That when an out-of-home placement is being arranged, the child's involvement in education and other aspects of community life will be maintained with as little disruption as possible

- That when an out-of-home placement is required, care should be provided by (in order of preference) members of its own family, another family, or in a residential setting that is as family-like as possible

- That an out-of-home placement under section 141 will be a last resort

- That no child under the age of seven years will be placed under section 141.

SCHEDULE TWO: PROCESSES

CYF and DSD agree to:

1. *Work collaboratively towards our common goal*

We will support each other to develop an integrated package of services for each child and young person with a disability who is the subject of a process, or who is receiving care and other services, under Part Two of the CYPF Act.

We will seek the advice of the other agency on the suitability of proposed services and placements for these children and young people before making any decisions.

2. *Assign responsibilities to designated staff in our organisations*

At the local level, CYF will designate an experienced staff member to take decision-making responsibility for children on the CYF caseload who have a disability and DSD will ensure that the local NASC designates an experienced staff member to take responsibility for liaison and decision-making in conjunction with CYF.

In each region, CYF will designate a regional director and DSD will designate a service manager to:

- Provide advice and support to CYF front-line staff and to the NASC
- Work collaboratively to make decisions related to the children for whom both agencies have a responsibility when local CYF staff and the NASC do not agree on funding and respective responsibilities.

At National Office, CYF and DSD will each designate a suitably experienced and qualified staff member to:

- Take responsibility for ensuring that the MoU and supporting guidelines are implemented
- Liaise between CYF, DSD and other agencies at the national level
- Make decisions about agency responsibilities and funding commitments in particular cases, when local and regional processes have not reached agreement.

The commitments and functions set out in this MoU have been assigned to existing organisational structures and positions in DSD, NASCs and CYF. Should these structures or positions change, we will ensure that responsibilities are appropriately reassigned. From time to time the MoU will be updated to reflect the structures and positions that inherit these commitments and functions.

3. *Establish a process for co-ordination and joint decision-making*

At the local level, CYF and NASC staff will set up a regular meeting process to:

- Ensure that they identify children and families with whom both agencies are involved

- Co-ordinate integrated packages of care and disability support services
- Reach agreement on each agency's responsibilities and contributions for particular children and families.

In each region, designated CYF and DSD staff will meet regularly (and at least once a month) to ensure that the exchange of information and the resolution of issues is occurring and that interagency co-operation and communication is effective. Minutes of these meetings should be kept to enable continuity through personnel changes.

At National Office, designated staff will meet as required to make decisions on cases where local and regional processes have not reached agreement. They will also meet periodically to address policy and inter-agency issues raised by staff, by the reporting process, and by other agencies.

Training is essential to the successful implementation of this MoU. All front-line CYF staff will receive training in disability awareness and all NASC and DSD staff working with children will receive care and/or protection awareness training.

All designated staff in CYF, NASCs and DSD will receive on-going training related to the MoU. There should be a national training programme that is attended jointly by CYF and DSD/NASC staff (and other agencies as appropriate).

CYF and DSD will also update their operations manuals and make the MoU available on departmental websites, so that information is readily available to all front-line staff.

Designated staff at National Office will be available to provide advice and guidance on issues related to the operation of the MoU.

4. *Collect data and report on the process*

Designated CYF and NASC staff will report on agreed information. (Details subject to CYF and DSD agreement on data collection, the reporting template, and frequency of reporting.)

5. *Monitor and evaluate the process and make changes as necessary*

CYF and DSD will monitor the implementation and functioning of this MoU, evaluate progress annually and, if necessary, adapt processes to ensure that the MoU works effectively.

6. *Ask each other for advice*

In relation to individual children and young people with disabilities and their families:

- CYF will consult the local NASC whenever it considers that a child may have a disability so that the NASC can determine the significance of the disability issue.
- Each NASC will consult CYF whenever it considers that there may be care and/or protection concerns for any child with whom it has contact, and assist

CYF to assess the level of risk. CYF will determine the significance of the care and/or protection concern.

- CYF and the NASC will consult each other before taking action related to children for whom both agencies may have a responsibility, except where urgent action is required to protect a child from harm.

7. *Meet the following timeframes*

In relation to individual children and young people with disabilities and their families:

- DSD: Where a child or young person with a disability is the subject of a process under Part Two of the CYPF Act and a referral has been made for a needs assessment, the NASC will respond to the referral within the following timeframe:

  Urgent: within seven days (the date received plus six calendar days)

  Non-urgent: within 27 calendar days, plus date received.

  A response means that the referral will be accepted, a needs assessor will be assigned and an initial discussion between the CYF social worker and the assessor will have taken place.

- CYF will respond to a section 15 report from a needs assessor or other person within the following timeframes:

  Critical: immediate response (must be the same day)

  Very urgent: within two days (the same day or the day following notification)

  Urgent: within seven days (the date received plus six calendar days)

  Low urgency: within 27 calendar days, plus date received.

  A response means that the referral will be accepted, a Social Worker will be assigned and an initial discussion between the Social Worker and the needs assessor will have taken place.

8. *Assign a lead agency responsibility for each child*

Whenever both CYF and DSD are funding or providing services for a child, they will agree which of them will take the lead agency role.

It is agreed that CYF has the lead agency role whenever care and/or protection issues are under investigation and in all cases where care and/or protection matters remain unresolved.

9. *Jointly develop a transition plan for each child*

Local CYF and NASC staff will meet to develop a transition plan for each child who will cease to be involved with CYF but who will have an ongoing need for disability support services

Transition planning will *commence* before the child turns 16

Transition planning will *be completed* at least six months before the child turns 17, or otherwise leaves CYF care.

SCHEDULE THREE:
APPORTIONING COSTS BETWEEN THE AGENCIES

General rules

CYF is always responsible for funding care and/or protection services. CYF does not cease to be responsible for care and/or protection issues when the child has a significant disability and DSD has taken the lead agency role.

DSD is always responsible for funding disability support services. DSD does not cease to be responsible for disability support services when there are care and/or protection concerns and CYF has taken the lead agency role.

Specific costs

1. *The cost of Family Group Conferences and implementation of FGC agreements*

CYF will meet the costs of all CYPF Act processes, including the administrative costs of organising Family Group Conferences, and any follow-up required.

CYF will monitor the child's safety and wellbeing, and adherence to the conditions of the FGC agreement, and will reconvene the FGC at least annually to review the arrangements.

DSD will monitor the delivery of disability support services as set out in the FGC agreement.

2. *The cost of the section 141 certifier role*

Subject to decisions on implementation, DSD will lead the contracting of a provider to undertake the section 141 certifier role, and meet any related administrative costs.

The direct cost of purchasing section 141 certifier capacity and/or services shall be shared equally by DSD and CYF.

3. *The ordinary cost of food, shelter and clothing etc*

These costs will ordinarily be met by parents, with assistance from Work and Income if they are eligible for assistance. They are the ordinary expenses of caring for any child or young person. CYF may pay such costs at its discretion where they cannot be paid by parents/W&I. These costs do not cover expenses above the norm that are directly attributable to a child's or young person's disability, such as incontinence supplies.

4. *The base costs of an alternate caregiver*

The base cost of an alternate caregiver for any child or young person placed under Part Two of the CYPF Act will be met by CYF. This is a payment to the alternate caregiver in recognition of the service they provide in the place of the parents.

5. *A premium to be paid in recognition of extraordinary caregiver challenges*

In addition to the base costs specified above, a premium may be payable at the discretion of CYF to any caregiver who cares for a child or young person who is particularly challenging. This recognises the higher level of input required or stress involved in providing care for a particular child, whether or not they have a disability. It is, in effect, a higher rate of payment to the caregiver for a more difficult parental role.

6. *The additional cost of a disability support services provided by a specialist caregiver*

A specialist disability caregiver is allocated when there are significant and specific disability support services to be provided within the home environment, which can only be provided by a specialist disability caregiver.

The difference between the costs of a caregiver outlined in items 4 and 5 above, and that of a specialist disability caregiver, will be paid by DSD together with the costs of selecting, supervising and supporting the specialist disability caregiver.

7. *The additional cost of disability support provided in a residential setting*

The difference between the costs of a caregiver outlined in items 4 and 5 above, and the costs of a residential disability support service, will be paid by DSD.

8. *The cost of other disability support services*

Access to publicly funded disability support services will be based on the assessed needs of the child and or young person and their parent or alternate caregiver, irrespective of the care arrangements in place, and costs will be paid by DSD. These will include disability-specific supports and services such as carer relief, behaviour management support and environmental supports.

9. *The cost of care and protection related supports and services*

CYF will pay for care and protection related supports and services which include counselling, training and education, and therapy that is not disability-specific. For example, relationship counselling, parenting skills development and private drug rehabilitation would be included, but disability awareness and strategies for caring for a person with a disability would not.

10. *The cost of support and services provided in an education setting*

Neither CYF nor DSD is responsible for the costs of services provided to a child or young person within an educational setting. These costs will be met from Education funding.

11. *The cost of transport to and from school*

Where the costs of transport to and from school increase because of a change in care arrangements, the Education sector will continue to pay the original cost, and NASCs will need to negotiate with the Education sector about the increase in the cost of transport when this is outside normal eligibility criteria.

APPENDIX FOUR: Guidelines to the MoU

Overview

The Memorandum of Understanding between CYF and DSD outlines the agreement between CYF and DSD about the principles that guide service delivery and the processes to be used so that, together, the agencies can develop solutions for individual families and children. The MoU is, first and foremost, a commitment to working together.

The essential point is that the children and young people and the families whose needs the Memorandum of Understanding is intended to address have complex situations and disability support needs, and CYF and DSD will have to work together, because they both have a role in the lives of these families and children.

The children and young people covered by the MoU

The MoU covers children and young people with disabilities who are the subject of a process under Part Two the CYPF Act, or who are receiving care or services in terms of Part Two of the CYPF Act. It is the NASCs who determine whether or not a child or young person meets the definition of disability. CYF determines whether or not there are care and protection concerns for any child or young person.

The principles

The principles in the Memorandum of Understanding do two things. They acknowledge our commitments under the UN Convention on the Rights of the Child and our responsibilities under New Zealand law (in particular, the Care of Children Act 2004 and the Children, Young Persons and their Families Act 1989). They also set the direction – they outline the approach that CYF and DSD will take.

The principles are not new. They are drawn from UNCROC and current legislation, and make an explicit link to the children and young people with disabilities who are involved with both CYF and DSD. They reinforce the idea that children and young people should be with their families, that the efforts of the agencies are directed towards supporting families to care for children and young people with disabilities, and that when the family can no longer support the child at home, the child's best interests are the determining factor in finding a suitable alternative.

The principles are also a benchmark against which the solutions we develop can be measured. Our way of working and the service packages for the children and young people with disabilities need to meet the standard set by the principles.

Processes

The Memorandum of Understanding sets out the agencies' commitment to working together. The key elements of the process are:

- Having designated staff at local, regional and national levels who can make decisions in relation to the children and young people with disabilities
- Having a joint process for co-ordinating CYF and DSD involvement and for making decisions

- Having a clear escalation path in each agency so that when agreement cannot be reached, issues can be resolved without delay.

The intention is that decision-making responsibility is clearly assigned to particular staff members and that decisions are made as close as possible to the child or young person and their family. Where it is not possible for one reason or another to reach agreement and make decisions locally, the staff at the local level should know who to refer the matter to for a decision and for further discussion with the other agency.

The other important components of the process are:

- Joint and ongoing training
- A complementary approach to information-gathering and to the monitoring of activity.

Joint and ongoing training is required to develop and maintain expertise and shared understanding, and to support effective working relationships between the agencies. The training will have to be developed nationally to ensure that the content and key messages are consistent throughout the country.

The intention is that:

- All operational CYF staff receive training in disability awareness
- All DSD staff working with children receive family ecology and care and protection awareness training
- All DSD and CYF staff working with children have access to a copy of the MoU
- All designated staff in CYF, NASCs and DSD receive on-going training related to the MoU. There should be a common training programme that is attended jointly by both CYF and DSD/NASC staff (and other agencies as appropriate).

It is also intended that policy and operations manuals will set out how each agency plans to give effect to the principles and processes specified in the MoU.

- Updated operations manuals should ensure that information is readily available to all operational staff
- CYF regional managers and DSD service managers will need to identify staff training needs, be responsible for staff training in their area and facilitate joint training opportunities.

Processes related to individual children and young people with disabilities

In relation to individual children and young people with disabilities, CYF and DSD have agreed to:

- Ask each other for advice
- Meet the specified timeframes for responding
- Assign lead agency responsibility for each child
- Jointly develop a transition plan for each child.

The purpose of this is to ensure that the agencies co-ordinate their involvement when they both have a role with a particular child or young person. One part of the task is to ensure each agency knows about the involvement of the other. Another part is to ensure that transitions – the exit of CYF, for example, when a child turns 17 – are flagged well in advance and that the agencies work together to ensure new arrangements are set up in plenty of time.

The funding responsibilities of each agency

The Memorandum of Understanding outlines the agreement between CYF and DSD about their respective funding responsibilities.

The essential point is that each agency will continue to be responsible for funding the services it usually funds. In the past, in relation to children and young people with disabilities, the agencies tried to establish the primary cause of the out-of-home placement (either the child's disability or care and protection issues in the family) and then expected the responsible agency to meet all of the costs, whether or not they would normally have funded those services.

The intention of the agreement set out in the new Memorandum of Understanding is to make it clear that, whatever the main reason for an out-of-home placement, each agency will continue to have a role and each will continue to fund or provide the services it would normally be responsible for. (It is also intended that this approach should apply to Education, in relation to the services normally provided through the child's school, and through Group Special Education.

APPENDIX FIVE: Information for Parents and Families

Proposed content for a pamphlet to be provided to families and parents of children and young people with disabilities –

Introduction

The Department of Child, Youth and Family and the Disability Services Directorate of the Ministry of Health (DSD) have recently reviewed the way they support families, children and young people when a child or a young person has a disability, and both agencies are involved.

CYF and DSD have agreed on improved ways of working together, to ensure that families get the support they need before a crisis develops.

Their first objective is to support families to look after their children and young people with disabilities. They recognise that, in a small number of cases, an out-of-home placement will eventually be necessary for a child or a young person but they will focus on providing support at home to prevent or at least delay this.

When an out-of-home placement is required, the strengthened process will mean that the best interests of the child are considered and that the different responsibilities of each agency are clearer to everyone. This, in turn, will mean that decisions about placements and funding will be more straightforward than in the past.

Principles

CYF and DSD have agreed that their support for families, children and young people with disabilities will be guided by the following principles. They will ensure –

- That the rights of children are recognised and that they are not diminished by the presence of a disability
- That the best interests of the child are our primary concern
- That the unique and complex support needs of this particular population are recognised by a response that takes a whole-of-life perspective, protects and strengthens natural resources, and uses available resources flexibly to develop individually tailored support packages
- That the child lives with or is regularly cared for by its own family for as much of the time as possible
- That at least as much support is made available to maintain the child with its family as would be provided for an out-of-home placement
- That the care provisions of section 139 and/or section 140 will be used and every effort made to strengthen the capacity of the family to resume full-time or regular care of the child, before an out-of-home placement under section 141 is considered
- That when an out-of-home placement is being considered, the child will have an independent voice in the process and the child's interests will be recognised

- That when an out-of-home placement is being arranged, the child's involvement in education and other aspects of community life will be maintained with as little disruption as possible
- That when an out-of-home placement is required, care should be provided by (in order of preference) members of its own family, another family, or in a residential setting that is as family-like as possible
- That an out-of-home placement under section 141 will be a last resort
- That no child under the age of seven years will be placed under section 141.

Getting access to support services

Through the Ministry of Health

The Ministry of Health is responsible for disability support services. The local Needs Assessment and Service Co-ordination agency (NASC) is the first point of contact. (Contact details for all the NASCs to be included.) The NASCs assess the level of need and can provide:

- Information – about services and helping organisations
- Early intervention and support
- Support at home for children and young people
- Support at home for the family
- Respite and other short-term support away from home
- Intensive service co-ordination, for the children and young people with the most complex needs. This is a much closer working relationship between the service co-ordinator and the family and child than normally occurs. It includes co-ordination with other services, such as the school, Group Special Education, the District Health Board, Work and Income and other support services in the local community.
- Funding support for individually tailored services when the available services do not meet the need
- A long-term involvement with children, young people and their families, including support with the transition from school and other services to adult disability services.

Through CYF

CYF's main function relates to care and protection, with a focus on safety and security for children and young people. When necessary, it intervenes in family situations to protect children and young people from harm.

CYF usually becomes involved with a family when there is a care and protection concern. When a child also has a disability, CYF will consult with the local Needs Assessment and Service Co-ordination agency about the services related to the child's disability.

When the main issue is the child's disability and the family's ability to continue supporting the child, CYF's role is to

- Ensure that all the possible support options are explored before an out-of-home placement is considered
- Organise the Family Group Conference
- Ensure – especially when an out-of-home placement is being considered – that the decisions being made are in the child's best interests.

A significant improvement in service delivery

The two agencies acknowledge that the children and young people with the most complex disabilities have not always been well served. The "mainstream" support services have often been inadequate, because of the unique circumstances of these children and their families.

The approach that is outlined here is a significant change and should result in:

- A higher level of early support for families and children with disabilities
- Better co-ordination among sectors such as Disability, Health and Education and better working relationships with all of the services involved with any particular family and child
- A reduced need for out-of-home placements for children and young people
- An extension of the time before a child or young person needs an out-of-home placement
- Better decisions about services and funding for the children and young people with the most complex disability support needs.

More information

You can get more information from:

Name Title Department of Child, Youth and Family PO Box 2620 Wellington (04)918-9100 www.cyf.govt.nz	Name Title Disability Services Directorate Ministry of Health PO Box 5013 Wellington (04)496-2000 www.moh.govt.nz/disability

APPENDIX SIX: Consultation List

NON-GOVERNMENTAL ORGANISATIONS

Ahrens, Michael	Residential Services Manager, Hohepa Home, Napier
Axford, Sarah	Team Leader, Open Home Foundation, Auckland
Barnett, Glenys	Director, Mount Cargill Trust, Dunedin
Bawden, Jane	Member, Autism New Zealand, Auckland
Benjamin, Mark	Project Manager Vocational Services/Co-ordinator, SAMS
Bird, Lesley	Team Leader, Richmond Fellowship, Hamilton
Booker, Jane	Social Worker, Mount Cargill Trust, Dunedin
Brown, Sally	Community Support Co-ordinator, Northern Region, CCS
Buel, Audrey	Adviser, Northern/Midlands Region, SAMS
Campbell, Caroline	Team Leader, Northern Region, CCS
Capie, Angus	Director, SAMS
Collins, Wendy	Social Worker, Canterbury, CCS
Cosgriff, Kate	Regional Manager, Waikato, CCS
Cowan, Christine	Operations Manager, Ngati Kapo, Hastings
Doig, Claire	Co-ordinator, Otago Family Network, Dunedin
Forrester, Karen	Trust Director, Wilson Home Trust, Auckland
Frazer, Lyn	Family Support Worker, Canterbury, CCS
Garrett, Tania	Service Manager, Christchurch, Idea Services
Gibson, Paul	Special Projects Manager, National Office, CCS
Green, Lynn	Service Advisor, Northern Region, CCS
Hampton, Julie	Care Co-ordinator, Brackenridge Estate, Christchurch
Hilsgen, Laurie	Chief Executive, Carers New Zealand
Huaiti, Stephanie	Early Intervention Service, Canterbury, CCS
Hutton, Barbara	Family/whanau Co-ordinator, Dunedin, Idea Services
Innes, Kate	Community Worker, Dunedin, CCS
Jarman, Lyn	Early Intervention Service, Canterbury, CCS
Jones, Hamish	Manager, Dunedin, Idea Services
Lee, Hoi	Social Worker, Waikato, CCS
Maidaborn, Viv	Chief Executive, National Office, CCS
Martin, Bell	Community Support Co-ordinator, Northern Region, CCS
Miller, Pete	Area Manager, Barnardos Waikato
Mirfin-Veitch, Bridget	Researcher, Donald Beasley Institute, Dunedin
Moss, Jan	Complex Carers Group, Auckland
Parkinson, Stephen	Psychotherapist, True Colours, Hamilton
Potts, Chris	Regional Manager, Northern Region, CCS
Price, Rachel	Co-ordinator, Brackenridge Estate, Christchurch
Sawkill, Robyn	Co-ordinator, Auckland, Idea Services
Schon, Barbara	Community Respite Co-ordinator, Waikato, CCS
Smith, Candy	Team Leader, Northern Region, CCS
Smith, Tilly	Co-ordinator, Hamilton, Idea Services
Snedden, Bridget	Manager, Parent and Family Resource Centre, Auckland
Steed-Conway, Les	Team Leader, Hamilton, Community Living Trust
Steur, Marja	Manager, McKenzie Centre, Hamilton
Te Nahu, Sylvia	Dunedin, CCS
Tuitahi Taaha'afe, Leota	Project Manager, Tongan Tamaki Langafanua Community Centre, Auckland
Walters, Barbara	Service Co-ordinator, Hamilton, Community Living Trust
Ward, Cynthia	Manager/Nurse Specialist, True Colours, Hamilton
Wilcox, Denyse	National Office, IHC
Wilkinson, Anne	CEO, Parent-to-Parent, Hamilton
Worsley, Kania	National Administrator, Ngati Kapo, Hastings

DHB CHILD DEVELOPMENT STAFF AND OTHERS

Andrews, Gaye	Resource Nurse, Child Protection Team, Waikato Hospital
Bartlett, Shona	Child Protection Nurse, Dunedin Hospital
Court, Liz	Psychologist, Child Development Centre, Waikato Hospital
Derrett, Michelle	Social Worker, Paediatric Department, Dunedin Hospital
Galyer, Karma	Psychologist, CDC, Waikato Hospital
Joll, Karli	Physiotherapist, CDC, Waikato Hospital
Keen, Natalie	Psychologist, CDC, Waikato Hospital
Kenny, Gerard	Child Protection Co-ordinator, Dunedin Hospital
MacAulay, Anne	Social Worker, CDC, Waikato Hospital

Marks, Rosie	Paediatrician, Starship Hospital
Newman, David	Paediatrician, CDC / Waikato Hospital
Palmer, Lisa	Occupational Therapist, CDC, Waikato Hospital

SECTION 141 CERTIFIERS

Armstrong, Karen	Christchurch
Breen, Tanya	Hamilton
Buel, Audrey	Auckland
Liz Soper	Auckland
Vercoe, Tina	Havelock North

CHILD, YOUTH AND FAMILY

Aish, Helen	Care and Protection Co-ordinator, Auckland
Bartlett, Stu	Senior Legal Advisor, National Office
Blakemore, Michele	Care and Protection Co-ordinator, Timaru
Bryce, Jeanette	Social Worker, Christchurch
Burns, Yvonne	Manager, SW Quality Assurance, National Office
Campbell, Beverley	Care and Protection Co-ordinator, Invercargill
Campbell, Rachel	Social Worker, Christchurch
Clarke, Diane	Care and Protection Co-ordinator, Dunedin
Dawson, Sue	Advisor, FGC Co-ordinator Services
Deans, Judy	Supervisor, Christchurch
Eastgate, Nikki	Social Worker, Christchurch
Guest, Peter	Site Manager, Dunedin
Gully, Megan	Social Worker, Christchurch
Harper, Rob	Senior Advisor, Operations, National Office
Hastie, Nicola	Practice Leader, Christchurch
Hollebon, Di	Social Worker, Dunedin
Katterns, Grant	Manager, Northern FGC Co-ordinator Services, Auckland
Kerse, Dave	National Manager, Approvals, National Office
Kravcenko, Sue	Co-ordinator, FGC Co-ordinator Services
Martin, Kristy	Social Worker, Christchurch
McIvor, Janine	Social Worker, Christchurch
Menzies, Christine	Practice Manager, Invercargill
Moss, Sue	Care and Protection Co-ordinator, Sydenham
Munnelly, Mike	Manager, Care and Protection, National Office
Murphy, Jim	Manager, Strategy and Planning, National Office
Nader, Megan	Social Worker, Dunedin
Newcombe, Barbara	Social Worker, Christchurch
Preston, Miriam	Care and Protection Co-ordinator, Sydenham
Quested, Jan	Supervisor, Care and Protection Co-ordinators, Sydenham
Rahe, Deslie	Social Worker, Christchurch
Salmond, Deidre	Social Work Supervisor, Dunedin
Tarrant, Cynthia	Manager, High and Complex Needs Intersectoral Unit, National Office
Temple, Yvonne	Care and Protection Co-ordinator, Dunedin
Turnbull, Mavis	Social Worker, Dunedin
Tyler, Paula	Chief Executive
Vostinar, Vera	Senior Practitioner, Christchurch
Wells, Philippa	Senior Policy Analyst, National Office
Woodhead, Stacey	Social Worker, Christchurch

DISABILITY SERVICES DIRECTORATE

Bleckmann, Amanda	Service Manager, Northern Operations
Carroll, Chris	Senior Policy Analyst
Chrisp, David	Manager, Business Support
Clode, Kylie	Manager, Policy
Delaney, Carol	(ex-HFA, retired)
Gill, Rob	Development Manager Intellectual Disability
Hibbert, Terry	Project Manager, NASC intersectoral trials
Johnson, Andrea	Service Manager
Jolley, Roger	Manager, Maori Development
Lua, Manase	Project Manager, Pacific
Moor, Jenny	Development Manager, NASC
Mundell, Lester	Chief Advisor, DSD
Primrose, Sue	National Contracts Manager
Smith, Valerie	Senior Advisor
Watts, Rod	Manager, Planning and Development

Weir, Therese	Service Manager, Northern Operations
Woods, Geraldine	Deputy Director-General, Disability Support Directorate

OTHER MINISTRY OF HEALTH STAFF

Arnold, Basia	Principal Technical Specialist, Mental Health Policy and Service Development
Tuohy, Pat	Chief Advisor, Child and Youth Health

NEEDS ASSESSMENT AND SERVICE CO-ORDINATION SERVICES

Bennett, Pauline	Special Projects, Service Development, Taikura Trust, Auckland
Druskovis, Peter	Team Leader, Taikura Trust, Auckland
Ellering, Rosalie	Manager, Northland Disabilities Resource Centre
Hansson, Sue	Manager, Access Ability, Dunedin
Hughes, Debbie	Service Leader, Capital Support, Wellington
Komene, Alison	Chairperson, NASCA
McClean, Anne	Intensive Service Co-ordinator, Taikura Trust, Auckland
Ormsby, Karina	Team Leader, Access Ability, Auckland
Preston, Angela	Service Coordinator, Access Ability, Dunedin
Richards, Janine	Intensive Service Co-ordinator, Taikura Trust, Auckland
Simpson, Ann	Manager, Life Links, Christchurch
Smart, Jackie	Service Coordinator, Life Links, Christchurch
Strachan, Jude	Intensive Service Co-ordinator, Taikura Trust, Auckland
Thomas, Kaye	Service/Intensive Co-ordinator, Northland Disabilities Resource Centre
Tutavaha, Karolina	Service Co-ordinator, Needs Assessor, Access Ability, Auckland

MINISTRY OF SOCIAL DEVELOPMENT

Allison, Amy	FACS
Angus, John	National Advisor, FACS
Elworthy, Juliet	Senior Adviser, Office for Disability Issues
Johnson, Lesley	Manager, FACS
Nana, Jenni	Manager, Child and Family Policy
Scown, Jan	Director, Office of Disability Issues
Williamson, Neil	Legal Adviser

MINISTRY OF EDUCATION

Hope, Yvonne	Group Special Education, National Office
Hunter, Jenny	Early Intervention Adviser, Christchurch
Mareroa, Maria	Maori Strategy Manager, Auckland Regional Office
Morris, Leonie	Service Manager, Early Intervention, Manukau
Pease, Mary Ann	Early Intervention Adviser, Dunedin
Richards-Troon, Shirley	Service Manager, Auckland
Riley, Beryl	District Manager, Manukau
Roberts, Murray	District Manager, Special Education, Christchurch
Schwart, Lucus	Christchurch
Stowers, Linda	Early Intervention, Manukau/Otahuhu
Wilson, Tony	Service Manager, Manukau

OTHER KEY INFORMANTS

Boshier, Peter	Principal Family Court Judge
Carr, Peter	Manager, Policy, Ministry of Youth Development
Fletcher, Michael	Group Manager, Policy and Research, Families Commission
Parker, Wendy	Family Law specialist
Ruri, Mereana	Office of the Children’s Commissioner
Win, Suzanne	Disability consultant, Motueka

PROJECT WORKING GROUP

Burns, Pamela	Senior Policy Analyst, DSD, Ministry of Health
Joyce, Elaine	Senior Policy Analyst, CYF, National Office (Convenor)
Scott, Karen	Development Manager, Children and Families, DSD, Ministry of Health

APPENDIX SEVEN: Summary of the Literature

Other jurisdictions - introduction

We reviewed the literature to see how other countries organised services for disabled children with high and complex needs and how they managed the interface between disability support services, care and protection services and other social supports for children and their families.

We looked at material from the UK, Scotland, Canada, Australia (mainly Victoria and Western Australia), the USA and some European countries. An impressive array of material has recently been published in support of Every Child Matters, the UK strategy to implement the Children Act 2004. The work on the (UK) National Service Framework for Children, Young People and Maternity Services is also very comprehensive: the most useful material, from our perspective, is the service standards, although there is also guidance on inter-agency collaboration, such as *A Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks.*

We also came across two overview papers that were very helpful. The first was the Nucleus Group's *Review of Current Responsibilities of Meeting Service Needs of People with Disabilities and the Effectiveness of Strategies to Support Families*[59]. This focuses mainly on Australian services but includes examples of service delivery in other jurisdictions. Its framework for analysing approaches and service models – and the examples it gives – are very useful. The second was *The Road to Recognition: International Review of Public Policies to Support Family and Informal Caregiving*[60] which summarises family caregiver policy in six countries.

What we observed

It was clear that other countries are grappling with similar issues and questions. The common themes across countries included –

- *how to support families better*, how to provide more responsive service packages, and the exploration of direct payments as a way of giving families more flexibility to meet their needs
- *better co-ordination across agencies and sectors*, the specification of a lead agency role, and the development of common assessment processes
- *the development of key worker and advocate roles*
- *better management of the transitions* for children and young people – note, for instance, the requirements of the UK Children (Leaving Care) Act 2000, that every eligible young person should receive a comprehensive pathway plan when they turn 16 and that a duty rests with the local authorities to keep in touch with care leavers until they are at least 21.
- *workforce issues*, training and collaborative working based on functions.

Different systems of government and divisions of responsibility mean that systems in other countries look quite different from New Zealand. For example,

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[59] The Nucleus Group, June 2002

[60] Anne Montgomery and Lynn Friss Feinberg, September 2003, for the Family Caregiver Alliance National Centre on Caregiving

- the roles and responsibilities of central government compared to the local authorities in the UK
- the roles of the states compared to the federal government in Australia and the USA
- the roles assigned to statutory authorities, such as the Advocate for Children in Care in Victoria, Australia
- the distribution of functions across government agencies – for example, disability support services are most often funded/provided through departments of Health and Human Services, but sometimes through a separate agency, such as the Disability Services Commission in Western Australia.

Also, countries use a variety of mechanisms to bring about change. Examples related to child protection and children with disabilities include –

- *Framework legislation* – see the UK Children Act 2004, which creates new statutory duties and sets expectations for local authorities. Note, in particular, section 10 of the Act, *co-operation to improve well-being*, which places an obligation on each children's services authority to make arrangements to promote co-operation.
- *A detailed regime set out in the legislation* – see Alberta's Family Support for Children with Disabilities program, where the FSCD Regulations prescribe the processes and the regime, including the detail of entitlements – the maximum number of hours per week/month and rates per kilometre, per day and per year for the specified support services.
- *Standard-setting* – see the eleven standards in the UK National Service Framework for Children, Young People and Maternity Services, including *Standard 8 – Disabled Children and Young People and those with Complex Health Needs*, the main themes of which include:
    - services being co-ordinated around the needs of the child and family;
    - services providing early identification of health conditions, impairments and other barriers to inclusion, through integrated diagnosis and assessment processes;
    - better early intervention and support to parents of disabled children through the development of multi-agency packages of care, including the use of direct payments and the employment of key workers;
    - services having robust systems to safeguard disabled children and young people, who are more vulnerable to abuse than non-disabled children;
    - and multi-agency transition planning to improve support for disabled young people entering adulthood.

- *Guidance from central government* – see Every Child Matters: Change for Children – an overview of cross-government guidance. The guidance on effective service delivery includes:
    - The Common Assessment Framework (CAF), which provides a common approach to needs assessment that can be used by the whole children's workforce
    - Lead Professional Good Practice Guidance, which sets out a broad framework of the key responsibilities, skills and knowledge required by practitioners to carry out this role
    - A Multi-agency Working Toolkit, which is a web-based resource that supports managers and practitioners delivering multi-agency services to children and young people

  - Guidance is also being developed on information-sharing, on the legal framework for, and good practice in, sharing information about individual children and young people.

- *Funding programmes*, such as the Flexible Support Packages programmes in Victoria, Australia, which resulted from the alignment of three pre-existing programmes and the consolidation of management responsibility. The alignment of the programmes "reduces the fragmentation of services and provides the capacity to implement whole-of-life planning that promotes a continuum of care for children and adults, their families and carers".[61]
- *Administrative arrangements*, for example, the Western Australian *Interagency Collaborative Framework for Protecting Children, October 2003* sets out the roles and responsibilities of seven government agencies, as well as those of community agencies and the Ethnic Communities Council of Western Australia in relation to child safety and protection. Its purpose is to strengthen collaboration and partnerships and involves a commitment by the government and community agencies as employers, service providers, funding or regulating bodies, and inter-agency partners.

Common concerns, similar approaches

The notable feature of the review of other jurisdictions is similarity of issues and approaches between New Zealand and other countries related to children and young people with disabilities who are in need of care and protection.

It is also important to note the very significant commitment of time and resources involved in supporting the implementation of programmes like the Every Child Matters strategy in the UK, and the Family Support for Children with Disabilities programme in Alberta.

While there are valuable lessons to learn and overseas experience to draw on, there is no ready-made answer that we can take off the shelf and use in New Zealand. A lot of the systems and processes we have looked at are not specific enough for our purpose, which is to address the issues at the CYF / DSD interface. The crux of the issue is decision-making between the agencies and the way that funding responsibilities are defined and joint funding is worked out.

In fact, some of the New Zealand material was the most useful, in terms of providing working examples that can be adapted to the specific issue we are addressing.

New Zealand experience – introduction

We reviewed New Zealand reports and experience related to:

- Inter-agency collaboration generally
- Co-ordination and service purchasing related to children, young people and families, and people with disabilities
- Specific collaborations and joint purchasing arrangements.
- We also noted the advice in earlier reports about this area, or about related issues.

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[61] *Flexible Support Packages Guidelines*, Disability Services Division, Victorian Government Department of Human Services, Melbourne, September 2003

The case for inter-agency collaboration?

Alison Gray, in her literature review for the Review of the Centre Regional Co-ordination Workstream[62] concludes (p38) that "there is little evidence that co-ordination, collaboration or integration in themselves improve outcomes for individuals and/or their families/whanau. What benefits there are tend to accrue to participating agencies in the form of improved processes, better relationships and a clearer sense of direction. In some cases, communities may become stronger through participating in regional initiatives, but to date there is no evidence that the lessons learned feed back into the system as a whole. At a wider level, power structures and non-collaborative modes of operating remain."

She says that the results of reviews and evaluations of integrated service-based initiatives (one-stop shops, wraparound services and examples of co-ordinated case management) "have been inconclusive at best, particularly in relation to the effect of integration. As a result, only a few small-scale evaluations are referred to… A comment by Glisson and Hemmelgarn (1997) explains the situation and summarises the views expressed by others:

> *"Many states in the US have experimented with organisational strategies for improving children's service systems, for example, inter-organisational co-ordination of services among child welfare, juvenile justice, education and mental health systems. This is based on the belief that the relatively low cost of improving services co-ordination among these systems will ensure that each child receives the most appropriate services, regardless of which system has first contact with the child. It is assumed that more appropriate services will result in better outcomes for children. To date, results of evaluations have been disappointing, providing little or no evidence that inter-organisational services or other innovative organisational configurations significantly improve service outcomes for children."*[63]

The Interagency Officials Group, in their *Review of Needs Assessment and Service Co-ordination for People with Disabilities under 65*[64] noted "that, although some protocols have been developed and some services were able to maintain effective co-ordination across sectors, pressures of addressing unmet need, the "silo" impact of public sector reforms, barriers created by differing definitions, and the pressures of multiple restructurings in all the sectors providing services to people with disabilities, worked against efforts to improve inter-sectoral collaboration".

A lot of the advice about inter-agency collaboration was at a broad level and was not particularly helpful to us, given the specific issues we were focussing on. But note the following cautions and comments from John Angus's paper[65] -

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[62] *Integrated Service Delivery and Regional Co-ordination: A Literature Review,* October 2002

[63] Glisson, C & Hemmelgarn, A (1997) *The effects of organisational climate and interorganisational co-ordination on the quality and outcomes of children's service systems* in Child Abuse and Neglect, Vol 22 No 5 pp401-421

[64] *Review of Needs Assessment and Service Co-ordination for People with Disabilities aged under 65: Improving Intra and Intersectoral Collaboration,* July 2003

[65] *Getting the Best Outcomes from Interdepartmental Partnerships – Reflections on Experience* – a paper presented to a conference, 1 November 1999

> *"Despite what is often written in reviews of services, co-operation and collaboration cannot overcome problems such as grossly inadequate baseline funding, poor management and morale within agencies, and (unless effective programmes exist) the intractable nature of some social problems. Collaboration is not a cure-all: the challenge of determining resource levels and of finding the right balance between integration and specialisation remains."*
>
> *And – "A serious foray into collaboration needs a long-term commitment of resources, and is not to be undertaken lightly. When does it make sense? An examination of Bardach's definition, the SSC work on service integration, and the Strengthening Families experience, suggest that the preconditions for a collaborative initiative include:*
>
> - *Some reasonably well-founded belief that the public value will be enhanced by collaboration*
> - *Common goals*
> - *Some common understanding of the factors which influence goals being attained*
> - *Buy-in (at the very least) from chief executives and ministers, or better, (as Strengthening Families has had) active management."*

John Angus also says…

> *"A collaborative approach to service delivery require(s) a culture change, away from the silo and bunker mentalities of the 1990s to more flexible co-operative approaches to the relationship between agencies. That change in culture requires the usual sorts of things:*
>
> - *Entrepreneurial advocacy for the 'new way' – and best from respected practitioners, not Wellington proselytisers*
> - *Stories of success – using the power of the anecdote*
> - *Persistent reinforcement*
> - *Information-sharing, in particular, of best practice*
> - *Evidence that the centre is doing its bit – eg, by developing and resourcing new programmes*
> - *Some devolution of power from the centre to the new local collaborative management groups."*

Other comments on interagency collaboration

The important points out of this more general advice related to the level of buy-in and senior-level support that was needed for success, and the level of resourcing needed for the collaboration process. The following, from an MSD working paper on case co-ordination is a good summary.[66]

> *"The conclusion from the literature and consultation is that any co-ordination model decided upon will need:*
>
> - *Policy support (ie, a mandate from the top levels of each organisation involved; and a lack of any legal impediment)*
> - *Management support – at national, regional and local levels*

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[66] *Case-by-case Co-ordination in Child Protection and Family Violence Cases* – background scoping paper, Ministry of Social Development, April 2004

- *Resources for the costs of needed infrastructure – ie, for*
  - *Co-ordinators, meeting and training venues*
  - *Administration – organising meetings, record keeping, correspondence, information exchange*
  - *Relationship-building activities – to allow diverse organisational structures and cultures to function well together*
  - *Regular joint training – to develop a common understanding and joint vision*
- *Agreement from all contributing agencies and groups to provide the staff to attend actual case conferences and participate in case planning and monitoring, plus to attend meetings, joint training etc*
- *Resources for skilled facilitation…*

"Other key elements of successful systems include:

- *A balance of frontline "doers" and uninvolved "experts". The right mix between involved workers and uninvolved experts provides an important check and balance. One of the strengths of some 1980s models was the ability to bring together the current frontline workers with knowledgeable but uninvolved subject experts. Similarly, HCN combines local decision-making assisted by planning advisors with expert oversight at national level.*
- *Local development: Strengthening Families, HCN and the Child Protection Teams of the 1980s all set a broad framework that allows local areas to develop a configuration that fits local circumstances.*
- *Set-up time: the initial stages of securing community and agency buy-in."*

Services for families

Philip Gandar and Miles Shepheard[67], referring to the recent review of Child, Youth and Family Services, comment on:

> *"the significant gap in relation to the provision of leadership and co-ordination of services that support families and whanau. This is exemplified in the experience of many providers:*
>
> *"In general it is agreed that provision of support and ease of access to services is most effective when agencies and providers co-operate closely, but this often does not happen, in part because of agency processes such as competitive bidding and in part because of the difficulty of intersectoral collaboration.*
>
> *"Most organisations are providers of specific services, aimed at a family member, or very occasionally at the whole family. Each is understandably interested in the provision of its own service, and limits the scope of its own providers to prevent creep in the demands placed on its available funds. This in part causes the lack of co-ordination. Compounding this difficulty is the general lack of provision for co-ordinating and advocacy roles; for example, the role of social workers who co-ordinate the provision of services. Providers are not funded for this co-ordination role, yet are acutely aware that its lack hampers an holistic approach."*

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[67] *Families and Whanau – Proposed Outcomes Hierarchy,* for Family and Community Services of MSD

Commenting on challenges, they refer to:

> *"the effective provision of funding. Funding through 'functionally aligned' government agencies is generally not well aligned with outcomes for the family itself. As a consequence, funding priorities are usually determined by the functional priorities of each department – the family outcome often being a secondary consideration. Furthermore, contracts let by those departments to other agencies generally focus on outputs for that functional department with little, if any, consideration given to the contribution that the contract could make to the wider family outcomes ('well-child' contracts are a good example.) Consistent with this approach, additional costs for agencies to work in a collaborative way such as through the Strengthening Families initiative, are not adequately funded by these existing contracts. Another focus for the strategy must be the provision of mechanisms to make collaboration simple, efficient and cost-effective."*

On family resilience

Gandar and Shepheard also describe the:

> *"commonly accepted assumptions and core concepts which have been distilled from discussions, and which help to define the frame of reference for (their work).*
>
> *"The ability of the family to support its members should be the focus of any framework*
>
> *"All families face challenges, from minor to major, such as illness, death or departure of a family member, or the loss of economic stability. Families grow and develop through adapting and learning from these challenges – not all families cope successfully. The degree of resilience in a family is one determining factor in how it responds to these challenges and how it handles the shocks which befall many families. Increasing family resilience can have a marked influence.*
>
> *"Where resilience is low, the family needs support to understand the stages and transitions and develop the skills to manage them successfully.*
>
> *"Family/whanau is the institution in our society which ensures the well-being of future generations. It has primary responsibility for children at a time when their most rapid cognitive development takes place, and when they establish closest relationships with others. Families provide the context within which a child develops healthily or unhealthily.*
>
> *"Families and their members, particularly obvious in the case of children, grow and develop along a developmental pathway, with well understood stages and transitions. These stages and transitions provide particular challenges, and it is essential that families successfully negotiate them.*
>
> *"Such support is largely provided through community efforts, both voluntary and those paid service deliverers funded from the taxpayer through government agency contracts."*

Co-ordination in specific areas

The most useful NZ material was more specific. It included:

- The CAT/SAT protocol between CYF and Police

The CAT/SAT[68] protocol is a protocol under the Memorandum of Understanding between CYF and Police. It sets out the agreed systems, processes and collaboration between the agencies on child abuse cases. We have drawn on this protocol in redrafting the MoU between CYF and DSD. The examples we felt could be drawn from this were:

  - Setting out the agencies' agreement about the fundamentals, such as always notifying the partner agency when a case of child abuse came to the attention of one of the agencies, and ideally before any action was taken
  - Assigning responsibility for co-ordination to designated people in each organisation
  - Setting out an escalation path for decision-making
  - Establishing processes for regular meetings, joint training and reporting and monitoring.

- HCN, the High and Complex Needs process

Specifically:

  - The focus on building capability of the agencies involved
  - The focus on local ownership, with the exceptions being dealt with at the national level
  - The development of a joint plan by the agencies making the application to HCN
  - The plan advisors, as a way of supporting local staff, building capability and improving quality and consistency
  - Pooled funding and a decision-making mechanism for the most complex cases
  - Joint agency training.

And others

A number of good examples of integrated and responsive services were mentioned to us during the consultation phase of the project. These included:

- *The CCS/FACS Pilot On Intensive Flexible Family Support*, which ran from January to June 2005. The purpose of the project was:

> *"to reduce the trend for disabled children to be placed into temporary or permanent residential care due to family/whanau breakdown by: developing an interagency strategy and set of protocols that ensure that the rights of disabled children are protected; developing a model of intensive support and early intervention that ensures lasting and sustainable individual and community outcomes for the family and the disabled child; and to pilot the model with a small identified number of families."* [69]

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[68] CAT refers to the Police Child Abuse Team; SAT refers to the Serious Abuse Team in CYF.

[69] *Intensive Flexible Family Support Project – Report to the Ministry of Social Development. V Maidaborn, C Potts, P Gibson and E Maddren*

For each of the children and families who took part in the demonstration project, CCS provided some or all of the following supports:

- Support for the child and the development of a relationship with the child to determine their fundamental needs, preferences and choices.
- Intensive family support and establishing the fundamental needs of the family related to the care of the child with the disability and the wider issues independent of the disability including: family breakdown, parenting skills, parental health issues, socio-economic constraints, family isolation and parental mental health.
- Exploration and development of care options within the wider family and local community.
- Extensive collaborative work with other agencies such as CYF, NASC, Education and the Ministry of Health.
- Supporting the wider family and whanau alongside an expectation that the natural family will maintain or resume the care of the child wherever possible and with sufficient support to sustain safe care of the child.
- Creating maps of the natural supports available for the child. This involves identifying all the existing and significant relationships that the child has, that might be able to be nurtured and supported. All of the children involved with the demonstration model have ended up with known carers, although some had an initial period with a new carer.
- Ensuring the relationship between the care family and the natural family is built with the desired outcome being that the care family will have an enduring and positive role in the child and family's life. Sourcing care families to either take temporary, full-time or shared care of the child and giving them intensive support to enable them to succeed.
- Support to the natural family to resume the care of the child.

- *The On Tracc Service For Refugee Children* who have severe behavioural difficulties or mental health needs. The service opened on 21 October 2005 and is being funded jointly by the Ministries of Health and Education and the CYF as a two-year demonstration pilot through the High and Complex Needs Unit. The service is based in Auckland and offers assessment, therapeutic intervention, and family and school support to young people up to the age of 19 from countries like Ethiopia, Somalia, Sudan, Eritrea, Afghanistan, Iraq, Iran and Burma.[70]

- *The Maternal Mental Health Service At Waikato DHB.* The purpose of the service is to provide an early clinical assessment, short-term intervention and co-ordination service for women (their babies, partners and families/whanau and significant others) who are experiencing mental health difficulties either ante- or post-natally. The service –
  - is recovery focused
  - is fully integrated and involved with primary health care providers and community agencies
  - does not treat women, babies and family/whanau in isolation
  - employs a wrap-around approach of co-opting the most appropriate healthcare provider or community agency when needed.

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[70] Auckland DHB news release

Recommendations in earlier reports

It is interesting to note the advice that has been given and the recommendations that were made in earlier reports.

- The report, *Just Surviving*[71], commented that:

> *"the general pattern appears to be that over time the child's needs increase, and the parents' capacity to meet their needs decreases, resulting in a situation that is no longer sustainable. 'Every year it gets harder, it never gets better.' Parents said that if they had high quality and timely support they would probably be able to cope better, and for longer. Few families envisaged that they would be able to continue to care for their child with high support needs in the family home indefinitely. All families said they wanted to be able to maintain an ongoing relationship with their child throughout their lives. Every parent wanted to have his or her child in reasonably close proximity."*

- Judge Mick Brown, in his report, *Care and Protection is about Adult Behaviour*[72] recommended

> *"(5.1) That the basis for taking children and young people into care must only be in accordance with the objects and principles of the Act and, in particular, children should not be removed to care solely to secure resourcing for the services they require.*
>
> *"(5.3) That consistent processes be developed for maintaining and rebuilding family links and relationships for children and young people placed apart from their genealogical family, especially with siblings.*
>
> *"(5.6) That if a child is assessed as being unlikely to be able to return home, extensive plans be made for permanent placement (guardianship), based on significant psychological attachment (s13(h), CYPF Act).*
>
> *"(5.7) That consideration be given to 16 year-olds in care with insufficient support being placed in the guardianship of the Chief Executive and supported constructively through their transition to adulthood at least to the age of 20.*
>
> *"(5.9) That <u>all</u> informal family placements resulting from Family Group Conference or other decisions be monitored, and data recorded on these children and families.*
>
> *"(5.14) That the issues contributing to placement shortages be researched so that solutions may be found.*

He also commented, in his conclusion:

> *"Another area of crisis is in the area of diminishing resources of caregivers. Here I believe it may be required to commence a national campaign to attempt to create that resource.")*

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[71] *Just Surviving – talking to parents of children with very high disability support needs about how they get by* December 2000. Carpinter A, Irwin C, Rogers G

[72] The Ministerial Review of the Department of Child, Youth and Family Services, Report to the Minister of Social Services and Employment, December 2000

And that

> "*the realisation that for every criticism and imperfection that was pointed out, these have been previously conveyed to the Department in its various incarnations and in many cases appear to have already been the subject of various reports.*"

- The report on Autism Services in New Zealand[73] concluded:
  - That gaps in services can be closed or reduced by the establishment of an existing agency or organisation with a clear leadership role for the co-ordination of services to people with autism and their families (para 423)
  - That there is a need to co-ordinate and lead the efforts of professionals contributing to the care and attention of a person with ASD and their family and this needs to be done through the clear identification of a lead care provider, or case manager, in every case (para 427) and recommended that by 31 March 1999 all agencies and organisations agree to the clear identification of one appropriate case manager responsible for each person with ASD (para 430).
  - That planning of services is hampered by a lack of accurate statistics and information upon which further policy, planning and funding decisions can be made.

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[73] *Autism Services in New Zealand*, a report by the interdepartmental "Autism Services Project" team, 9 October 1998

APPENDIX EIGHT: Selected Bibliography

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