DISABLED PARENTS: DIVERSITY, EXPERIENCES AND SUPPORT NEEDS

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Acknowledgements

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Preface

The Families Commission developed this resource to share existing knowledge about the needs and experiences of disabled parents and to identify and discuss related issues. We have drawn on selected national and international research literature, strategies and other material, undertaking a literature scan rather than a full review. The scan was supplemented by a small number of consultations carried out with the disability sector, considered alongside findings from other consultations and forums such as those undertaken by the Ministry of Health's Disability Support Services. Government initiatives aimed at the wider disability community are referred to.

We highlight the support and initiatives that contribute to positive outcomes for disabled parents, their families and whānau. These include recognising parents' strengths and resiliencies, valuing family and whānau diversity, and allowing parents to identify their changing needs and priorities.

We focus particularly on the following topics:
•   issues and challenges facing disabled parents
•   practices, guidelines and initiatives available to support disabled parents, their families and whānau
•   the identification of services and support 'delivery gaps'
•   barriers to disabled parents accessing particular services and support.

Key findings
•   Disabled parents' needs for support vary widely, and any support required is likely to change over time.
•   Parents should be able to define how much, or how little, support they require.
•   Various types of government-funded assistance for disabled parents have emerged at different times and for different purposes, and this has resulted in the fragmented provision of services.
•   These gaps in services are a result of the spread of support across a number of agencies, and are not necessarily the most responsive way of meeting individual or family needs.
•   In some families, support is only provided when the child of a disabled parent is identified as being 'at risk' or when a crisis is reached within the family. Providing early support to disabled parents and their families increases the likelihood that risks and crises can be averted.
•   Disabled parents remain a relatively 'invisible' group and continue to face attitudinal and other barriers – identifying their needs and preferences will better inform policy and practice.
•   Influences affecting the wellbeing of disabled parents and their families and whānau include poverty, low incomes, social isolation, and inadequate professional support .

Resource overview

The parenting experience
•   Every family is unique and there are multiple factors that influence parenting, whether or not a parent is disabled.
•   These factors include cultural beliefs and practices, values, age, gender, sexual orientation, parents' own experiences of being parented within their own family

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and whānau, individual and collective networks and resources, health, children's needs, and the wider social and economic context.

- Structural and attitudinal barriers affect how disabled parents parent.
- The experiences of disabled parents are shaped not only by the intrinsic differences between different impairments – cognitive, physical, sensory or psychiatric – but when the impairment arose.
- The experiences of parents with acquired disabilities are likely to differ from those born with an impairment.

Variations in the range, frequency and type of support needed
- Disabled parents have a wide range of impairments: some will affect parenting and others are unlikely to.
- Parents with the same impairment can have differing needs, capabilities, limitations and strengths.
- At various points in life and for differing periods of time disabled parents may require support with parenting, as well as other forms of support.
- Support must be flexible and responsive to changes in individual and family circumstances, non-judgemental and easy to access.
- Support should not undermine/overwhelm family integrity.
- Needs may fluctuate over time, eg in response to shifts in parental physical and mental health, and children's growth and development.
- Parents should be able to define how much, or how little, support they require.
- Agencies working with families should consider factors limiting disabled parents' access to mainstream support.
- Agencies working with disabled adults must consider their needs as parents.
- Disabled parents, their families, whānau, formal and informal support providers should be well-informed about the available support and resources, and it should be easy to find and access.
- All parents, whether disabled or non-disabled, need adequate income and housing as a starting point.

Timing of support
- Ideally, support spans pre-parenthood, pregnancy, labour and delivery, and continues throughout the parenting years.
- Existing resources addressing relationships and sexuality for disabled young people (eg those developed by IHC and Family Planning) provide a basis for discussion.
- When disabled adults become parents, they may need support from agencies and networks with which they have had no previous contact.
- Handover processes can ease the transition from one support agency to another, and/or the introduction to new sources of support to complement support already received.
- Information and support for disabled parents is often targeted at early parenthood; knowledge about parenting older children needs to be further developed and shared.

Education and professional development
- Mainstream parenting support and family service providers may need additional education to ensure that they are better informed about disability and up-skilled to provide appropriate support to disabled parents.

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- Regular professional development will help to ensure that people who work with and for disabled parents are well-informed about existing and emerging best practices.
- Engaging with and supporting communities to be more inclusive of disabled parents will mean coming up with new ways of understanding and developing relationships between families, communities and facilitators of support.

Children's education
- Positive interactions with the education system contribute to good outcomes for disabled parents as well as for their children.
- Children are likely to benefit if their parents are actively involved in their education.
- Everyone associated with an early childhood education service or school – including teaching and non-teaching staff, other parents and children – can work towards overcoming attitudinal barriers.
- Addressing structural barriers (eg by improving access to the school environment) makes it easier for disabled parents to be actively involved in the school community.

A 'whole family' approach
- The needs of everyone in the family must be taken into account.
- From an ecological perspective, the needs of the child are considered alongside parental strengths, capacities and resources, which in turn are influenced by the wider social and economic environment.
- For children's needs to be met, any support that their parents need to look after their children must be in place.
- Older children and young people should not be expected to take on inappropriate caregiving tasks and responsibilities.
- If adequate and appropriate support is provided to the child as well as to the parent – and to their family and whānau – individual needs can be balanced and addressed.

Attitudinal barriers
- Disabled parents continue to face attitudinal barriers, including discrimination and misunderstandings about their abilities, and their right to parent may be questioned.
- Parents with intellectual disabilities, and parents experiencing mental illness, are particularly vulnerable.

A need to gather and share knowledge
- The needs of disabled parents are often overlooked when policies and services are being developed.
- The experiences of disabled parents in New Zealand – fathers as well as mothers, and across ethnic groups – need to be better documented.
- Sharing knowledge about parents' lived realities, needs, preferences, and strengths can inform policy and practice and build on existing evidence about factors contributing to positive outcomes for disabled parents, their families and whānau.

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Many disabled parents develop coping strategies and with appropriate formal and/or informal support networks in place (as and when needed) demonstrate strengths and resiliency and parent effectively.

We hope that this resource will prompt further consideration within and across sectors of the diverse needs and experiences of disabled parents, whose perspectives must be taken into account when policies and practices are being developed or reviewed.

Introduction

The needs of disabled parents are often overlooked when policies and services are being developed.

This Families Commission resource draws on research and discussions with disabled parents, as well as information shared by individuals and agencies within the disability sector, to describe the range and nature of support that contribute to positive outcomes for disabled parents and their children. We outline principles for consideration when supporting and engaging disabled parents and their whānau. We include verbatim comments drawn from research reports and other publications, as well as from our 'Disability and Family Life' on-line Couch poll[1] (2006) and information provided by disabled parents as part of a panel we initiated.[2]

Clarke and McKay (2008) observe that positive experiences of family life in the context of disability are under-represented. There are many examples shared throughout this resource of disabled people parenting successfully.

Background and Objectives

The work of the Families Commission focuses on solutions that improve the strength, resilience and wellbeing of New Zealand's families and whānau.

Participants in our nationwide *What Makes Your Family Tick?* consultation, (Seth-Purdie et al, 2006) identified a need for improved services and additional support for families with a member who has special learning, physical, or health needs, including addiction problems.

Subsequent contact with the disability sector identified a range of challenges faced by disabled parents. The Families Commission has developed this resource to share existing knowledge about the needs and experiences of disabled parents and to identify and discuss related issues. Drawing on national and international material, the resource focuses on the following topics:

> The challenges disabled parents face (including pre-parenthood)
> The barriers disabled parents face accessing services and support

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[1] Thirty percent of Couch members who took part identified themselves as a disabled person, some of whom were parents.

[2] In 2011, there were 10 Families Panels, each including eight to twelve participants sharing similar circumstances; one group consisted of disabled parents. Each group met three times a year for two years. http://www.familiescommission.govt.nz/listen/families-panels/what-are-families-panels

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> Identification of gaps in services and supports for disabled parents
> Practices, guidelines and initiatives for supporting disabled parents and their families and whānau.

The New Zealand Disability Strategy (Minister for Disability Issues, 2001) notes that many disabled people are unable to reach their potential or participate fully in the community because of barriers they face doing things that most New Zealanders take for granted. These barriers include restricted access to facilities, (negative) societal attitudes, and a lack of awareness of disability issues.

Objective 2.3 of the Strategy is to:

Educate agencies responsible for supporting children and families about the rights and abilities of disabled parents.

Approach

A brief review of national and international research was undertaken to locate key published papers and reports, particularly those addressing disabled parenting in New Zealand and related topics. This literature scan was supplemented by contact with individuals and agencies at various times from 2007 to 2012.

Those contacted included the Office for Disability Issues (ODI) and their Disability Advisory Council, Work and Income, and Child, Youth and Family (Ministry of Social Development), ACC, the Ministry of Health, the Ministry of Education, the Human Rights Commission, the Health and Disability Commission, the Mental Health Commission, the Ministry of Women's Affairs, Disabled Person's Assembly (DPA), IHC, CCS and other disability sector organisations, researchers and academics (in New Zealand, as well the United Kingdom), and Wellington and Christchurch City Councils. The Commission heard from disabled parents who took part in our online polls and panel discussions, and we also held a discussion with members of the Office for Disability Issues' Disability Advisory Council.

Conceptual models of disability are outlined, alongside consideration of an ecological approach to parenting. We provide an overview of the disability sector in New Zealand presenting key issues drawn from consultations and research literature with knowledge gaps identified.

We outline how disabled parents' experiences and perspectives are influenced by individual characteristics, experiences, gender roles, culture and ethnicity, as well as the type of impairment they live with.

We explore needs and opportunities for enhancing the support provided with education, housing, and social and recreational opportunities.

We include an overview of the needs of 'young carers', including the need to balance their rights with the rights of their parents.

National and international support initiatives and campaigns are identified throughout, with additional resources and links in the appendices.

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Conceptual Approaches to Disability

New Zealand's Office for Disability Issues (ODI) notes significant national and international shifts in approaches and responses to disability over time:

> The traditional medical model – under which disability has been seen as an individual problem to be 'cured' or at least contained – has been largely replaced by the social model which focuses on the relationship between people with impairments and their social environment, and locates the required interventions within the realm of social policy and institutional practice (ODI website) [3]

The New Zealand Disability Strategy (Minister for Disability Issues, 2001) is based on the social model, making a distinction between impairments (which people have) and disability (people's experience of barriers to participation in society). Impairments may be physical, sensory, neurological, psychiatric, intellectual, or 'other'.

The medical and social models are summarised in Appendix A. The World Health Organization (WHO) and The World Bank (2011) suggest that although the medical model and the social model are often presented separately, disability should not be seen as purely medical, nor as purely social. An earlier WHO report (2002) notes that disability is an interaction between individual characteristics and the overall context in which a person lives; both medical and social responses are appropriate to the challenges associated with disability.

Guided by Objective 2.3 of the Strategy,[4] this paper provides an overview of what needs to be in place for disabled parents who require support with parenting at any point on the continuum: from consideration of parenthood, to pregnancy, labour and delivery, and throughout the parenting years. At the same time, it must be recognised that every family is unique and there are multiple factors that may influence parenting, whether or not a parent is disabled.

We use the term 'disabled parents' to reflect the terminology of the New Zealand Disability Strategy; the term 'parents with disabilities' is also used in the literature. Olsen and Wates (2003) note that some disabled parents do not identify themselves as disabled. The following quote from a disabled mother demonstrates the complexities associated with the term.

> *I don't particularly like the word 'disability'. ... Because at some fundamental level I think you could say we all have disabilities. So how do you define what is a disability and what isn't? And sometimes disabilities can become strengths and abilities. I think they become opportunities to develop other skills. So that's why I don't particularly like the term. But I guess, um, probably for want of a better word it's somebody who … has some long-term condition; something that makes some aspect of living hard.*
> (Mother, Raffensperger et al, 2012)

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[3]   http://www.odi.govt.nz/

[4]   To educate agencies responsible for supporting children and families about the rights and abilities of disabled parents.

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Ecological Theory and Parenting

Olsen and Clarke (2003) draw on the 'ecological' approach to parenting, referencing the work of Bronfenbrenner (1979) and Belsky and colleagues (Belsky et al, 1984; Vondra and Belsky, 1993). They describe how the ecological perspective views parenting as a set of activities influenced by three 'domains':

> the developmental needs of the child
> the capacities and personal resources of parents in meeting those needs
> the wider social and economic context in which parents operate

The ecological approach provides a basis for consideration of parental needs and potential sources of support and may guide policy and practice.

> [The ecological perspective] draws our focus towards structural factors (poverty, inaccessible housing and transport, and so on) as well as towards the individual strengths of parents themselves. It therefore offers the opportunity for looking at the barriers and difficulties faced by parents rather than automatically assuming that parenting deficits are the responsibility of parents themselves. (Olsen and Clarke, 2003, p.22)

Researching Disabled Parents' Experiences

Researchers have used diverse approaches to learn about the experiences of disabled parents.

During 2006 Child, Youth and Family contractors held focus groups[5] to investigate the support needs of groups of parents with a range of disabilities including autism, intellectual disabilities, physical disabilities, deafness, and sensory disabilities. Subsequently, in 2008, five disability advisor positions were created within CYF to ensure that disabled children and young people (and their families and caregivers) who come to the attention of CYF have their needs met. The role of the Regional Child Disability Advisors includes developing effective relationships with external organisations, and facilitating and supporting successful negotiations to ensure the needs of the disabled children and young people are met. The disability advisors also advocate for the needs of disabled parents.[6]

Raffensperger et al (2012) explored the strength and resilience of twenty New Zealand families that include a parent with a disability, through interviews with parents, children, and family friends. Their study aimed to draw attention to the families' strengths and resiliencies, without diminishing the challenges that they faced. They note that although the families in their study were diverse in terms of family structures, socio-economic status and the challenges associated with different disabilities, the families' strengths were remarkably similar. Through a systems approach, Raffensperger et al considered how the individuals within the families they met adapted and worked together as a family to meet the demands of family life.

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[5] http://accforum.org/forums/index.php?/topic/3750-disabled-parents-focus-groups/ Cleland (2007), who co-facilitated the focus groups, also drafted related literature reviews.
[6] Personal correspondence, 2010.

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Clarke (2006) undertook research to look at how disabled parents and their families experience impairment, disability and service responses in the United Kingdom. Her research used a social model approach, with parenting situated as a social activity, and identified disabling societal barriers. Clarke refers to three lenses through which parenting and family experiences may be perceived:

1. A 'risk' lens focuses on the child 'in need' and on support for the child, with limited responsiveness to the needs of the disabled parent. With this lens in place, parents are anxious about seeking support, for fear of the possible consequences (eg their parenting being judged).

2. A 'functional' lens focuses on impairment and functioning without attention to social needs and contexts. For example, although home modifications may be approved, assistance may not be provided so that a parent can attend a child's sports event. The provision of functional-focused support may result in a divided home space, where the parent can access only certain areas of the house.[7]

3. A 'barrier' lens focuses on how changes to social settings and attitudes can remove the barriers to equal opportunities to family life. Disabled parents' support needs are seen as no different to the needs of other parents. Disabled parents are likely to benefit from greater provision of information, increased accessibility (eg the removal of physical barriers) and timely support that is responsive to changes in family needs, as well as professional understanding of the social barriers they face.

Clarke's lenses provide a context for exploring the challenges faced by disabled parents, and potential solutions, and prompt consideration of what is being looked at – or overlooked – when various lenses are applied. The 'risk' and 'functional' lenses have limitations, as outlined above, whereas the 'barrier' lens has a broader focus encompassing both responsiveness and change. This aligns well with the underlying theory of change within the context of the social model of disability, as explained by the Office for Disability Issues:

"…agencies, whether government, non-government or private, alter their policies, processes and services to foster positive life changes for disabled people. In addition, disabled people themselves, their membership organisations, their families, whānau and friends, and wider society will also experience, and contribute to, change.[8]"

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[7]   See CHRANZ report (2007), p.28, which refers to a refusal for funding for a widened doorway to a child's bedroom for access by a disabled parent.

[8]   http://www.odi.govt.nz/nzds/progress-review/a-framework-to-measure-progress.html

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Disability Support in New Zealand – An Overview

Support for disabled people and their families and whānau comes from key government agencies ACC and the Ministries of Social Development, Health, and Education.

Other government agencies providing support include Housing New Zealand, the Ministry of Transport (the Total Mobility scheme), and the Economic Development Group of the Ministry of Business, Innovation and Employment (the Telecommunications Relay Service).

District health boards (DHBs) are responsible for providing or funding the provision of health services within districts. Disability support services and some health services are funded and purchased nationally by the Ministry of Health. Non-government agencies also contribute to disability service delivery and the provision of support.

As noted in the ODI's Briefing to the Incoming Minister (2011), the various programmes of government-funded support have emerged at different times and for different purposes, with fragmented service provision:

> "They do not always make up a coherent package of supports. Their eligibility criteria produce unequal treatment, based on impairment, and also gaps through which some people fall (p.7).
>
> The current system of supports, spread across several agencies, is not always good at being responsive to individuals' or families' needs, nor does it enable them have much choice or control over their lives. Changes are needed to allow disabled people to have more flexibility, control and choice over supports they use in daily living." (p.21)

The first Disability Action Plan was approved by Cabinet in 2011. It outlines opportunities for rethinking how the government supports disabled people to live an everyday life, based on priorities identified by disabled people that are currently not adequately addressed. The Action Plan areas are:

> - Making disability supports more flexible and responsive
> - Mobility and access (what government can do to enable disabled people to move around their community and access the built environment and information)
> - Jobs (what government can do to promote disabled people getting into paid work).

The New Zealand Disability Support Network[9] notes the increasing importance of 'natural supports' (family, whānau, friends) and community connections for disabled people, particularly in the move towards a model of Supported Independent Living - a service that helps disabled people to live independently by providing practical support in areas of their life where help is needed such as shopping and banking.

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[9]   http://www.nzdsn.org.nz/Blogs/67/76/fostering-natural-supports-for-people-with-disabilities/

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The portfolio of the Minister for Disability Issues was established in 1999, and the New Zealand Disability Strategy was released in 2001. The Strategy "provides an enduring framework to ensure that government departments and agencies consider disabled people before making decisions"[10], and its implementation is informed by the United Nations Convention on the Rights of Persons with Disabilities. The Strategy states:

> Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. (The New Zealand Disability Strategy, p.7)

The Strategy framework provides a foundation for the development of an inclusive and enabling society and the ODI website links to a range of resources (eg reports, guides and toolkits) to encourage this. The ODI recommends that the Strategy be updated, to enable better priority-setting and to achieve a clearer and more coherent policy environment within which progress can be measured.

The Office for Disability Issues

The Office for Disability Issues within the Ministry of Social Development was established in 2002. The primary responsibilities of the Office include promoting and monitoring the implementation of the New Zealand Disability Strategy in government and wider society, and providing policy advice on disability issues.

The international Convention on the Rights of Persons with Disabilities and its Optional Protocol were opened for signature at United Nations Headquarters in New York on 30 March 2007. New Zealand signed the Convention at the United Nations at that time, and ratified on 26 September 2008.

Article 23 of the Convention - Respect for home and the family - states that parties "shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others". (See Appendix B.)

Budget 2010 funding allocated $3 million over three years to promote positive attitudes and behaviours towards disabled people.[11] This initiative will work with existing programmes that promote attitude change on disability and support community-level initiatives. The key goals of the campaign are:

> - to increase the participation of disabled people in all aspects of community life
> - to change social attitudes and behaviours that limit opportunities for disabled people.

MSD and ODI are working in partnership with employers, educational and health services, community organisations and the media to develop a programme of activities

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[10] http://www.odi.govt.nz/nzds/
[11] http://www.odi.govt.nz/what-we-do/improving-attitudes-and-behaviours/index.html

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that raise public awareness of the issues facing disabled people in New Zealand. This includes building on the social change experiences of the Ministry of Social Development's 'It's not OK' family violence prevention campaign, SKIP's positive parenting initiative and the Ministry of Health's Like Minds, Like Mine campaign.

Disability Prevalence Data

Statistics New Zealand report that they use a "functional concept of disability" in their disability surveys,[12] with a focus not on identifying the nature of the disorder or disabling condition, but rather the limitation resulting from it:

> "… any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." (World Health Organization)

Statistics New Zealand defines a disability as any limitation in activity resulting from a long-term condition or health problem. Disabilities often coexist. Disability increases with age;[13] this has implications for the growing numbers of New Zealand grandparents who are raising grandchildren.

In Statistics New Zealand's 2006 Household Disability Survey, disabilities reported by adults were categorised into the following disability types: Hearing, Seeing, Mobility, Agility, Speaking, Intellectual, Psychiatric / Psychological, Other (includes a long-term condition or health problem that causes ongoing difficulty with the ability to learn or remember, or causes difficulty with or stops people from doing everyday activities which people their age can usually do). Some people reported having more than one disability.

Findings from the 2006 Disability Survey show that an estimated 660,300 New Zealanders reported a disability, representing 17 percent of the total population.

> Twelve percent of adults aged 15 years and over had a physical disability (an estimated 383,500 adults). This was the most common disability type for adults, affecting two-thirds of adults with disability.
> Sensory disabilities (hearing and/or seeing disabilities) were the second most common disability type for adults, affecting 8 percent of adults (42 percent of adults with disability, or 239,000 adults).
> Seven percent of adults (39 percent of adults with disability, 224,500 adults) reported having other types of disability, such as difficulty speaking, learning, remembering or doing everyday activities.
> Diseases or illnesses were the most common cause of disability for adults, followed by accidents or injuries and ageing.

The 2006 New Zealand Household Disability Survey estimated that 95,700 (17 percent) of Māori were living with a disability. Despite the younger age structure of the Māori

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  http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey2006_HOTP06.aspx Note: "People were not considered to have a disability if an assistive device (such as glasses) completely eliminated their limitation. A concept of time was included as an additional filter; the disability must have lasted or be expected to last for six months or more".

13 http://www.socialreport.msd.govt.nz/people/nzers-experiencing-disability.html

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population its rate of disability overall (17 percent) is the same as for New Zealand Europeans. **This is due to the higher disability rates for Māori compared to non-Māori across all age groups**.[14]

How many disabled parents are there in New Zealand?

Better data is needed as exact numbers are not known. International literature suggests some parents choose not to identify as disabled due to fear of stigmatisation or fear of having their children removed.

As a starting point, Statistics' New Zealand's 2013 Disability Survey will link a number of variables from the Census, one of which will be 'Individual's Role in Family Nucleus' eg parent and spouse/partner in a family nucleus. From this, it should be possible to output data on the number of disabled parents in New Zealand.[15] The previous Disability Surveys (held in 1996, 2001, and 2006) did not ask if respondents were parents.

The Living with Disability in New Zealand summary (2004) reports that in 2002, just over half (54 percent) of all adults with a disability - an estimated 340,000 adults - had a partner or spouse. Men with disability (63 percent) were more likely than women with disability (48 percent) to have a partner. Some of these disabled adults with partners are likely to be parents, although because this figure includes *all* adults many are likely to be older people with age-related disabilities who are no longer actively parenting.

Mirfin-Veitch (2003) estimates that in New Zealand approximately 2.5 families per 1000 include at least one parent with an intellectual disability. Australian researchers[16] estimate that approximately 1-2 percent of families with children aged between birth and 17 years include at least one parent with a learning disability. The Mental Health Commission and Kites' *Mums and Dads* report (2005) states that up to 50 percent of people who experience mental illness are parents.

CYF does not routinely collect data on parental disability. Anecdotal reports suggest that parental disability types vary across the CYF regions. Although CYF's Regional Child Disability Advisors are available to work with cases where there is parental disability, this is not a big part of the work that comes to the regional disability advisors from the CYF sites. Families with disabled parents are typically referred to non government organisations (NGOs)[17] so they can access advocacy and supports.

Olsen and Wates (2003) suggest the lack of data about disabled parents contributes to their relative invisibility and funders can be reluctant to support initiatives for a statistically invisible group.

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[14] http://www.health.govt.nz/publication/uia-tonutia-maori-disability-research-agenda

[15] Personal correspondence, September 2011
[16] http://raisingchildren.net.au/articles/parenting_with_an_intellectual_disability.html#Challenges
[17] Health and Disability NGOs include a wide range of frontline service delivery organisations; services offered primary care, mental health, personal health, and disability support services, some of which are offered by Māori and Pacific providers.

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Parenting support literature, for example, commonly identifies groups of parents who may require additional support (eg teen parents, lone parents, fathers) yet disabled parents are rarely mentioned.

Olsen and Wates emphasise that it is important to look beyond the desire for numbers, as the impact of barriers can be identified and addressed without needing to know exactly how many disabled parents there are.

Becoming a Parent

Becoming a parent is a major life transition. All parents want their children to be loved, supported, safe and well cared for.

Disabled parenting experiences are shaped by the intrinsic differences between different impairments (eg cognitive, physical, sensory or psychiatric), the extent to which disabled parents have integrated impairment and disablement, and when the impairment occurred – during childhood or adulthood; before or after having children.

Clarke (2007) points out that becoming a parent as a disabled person may involve challenging societal assumptions and expectations about personal aspirations towards, and future prospects for, relationships and parenthood.

Parents who acquire an impairment *after* becoming parents may have to adapt their parenting style, particularly if it is a physical impairment that limits their ability to be involved in or manage their children's activities. Acquired impairment may also mean that changes are needed with housing, transportation, and equipment.

A Human Rights Commission (2004) report[18] refers to a strong call for more public education to remove the stigma attached to disability and the prejudice and discrimination experienced by disabled people. The report refers to the lack of support for disabled people as parents and a lack of acknowledgment of their reproductive rights.

> *There is … a wide range of barriers to disabled people marrying, having children and living in an independent household. Reaching a just balance between the right to marry and found a family with the responsibility to protect and care adequately for children remains a social challenge. There is little public discussion about the reproductive rights of disabled people, such as access to assisted reproductive technologies, and little support for disabled people as parents.* (p. 81)

Although many disabled parents develop coping strategies and with appropriate formal and/or informal support networks in place parent successfully, disabled parents often face attitudinal barriers, including discrimination and misperceptions about their abilities.

> *Disability is so closely associated with dependence and social isolation that it is hard for people to imagine a disabled individual at the centre of family life in the role of primary carer…* (Wates, 1997, in O'Toole, 2002)

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[18] http://www.hrc.co.nz/report/printchap/Chapter 05.doc

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There is an attitude that is still active in the community that I shouldn't work and shouldn't have children…and there is a perception that any children [I may have] will have disabilities! (Disabled parent, Families Panel participant)

O'Toole (2002) refers to "training against motherhood", resulting from factors such as a lack of sexuality education, a lack of family expectations (independent living, relationships and parenthood are a viable option), prejudices about the rights and abilities of disabled people to parent, and anxiety about the potential removal of any children born to a disabled parent.

Parents may have concerns that the long-term care of a child born to a disabled son or daughter may eventually fall to them. There is some evidence to support this. For example, Worrall's (2009) study of grandparents raising grandchildren shows that the reasons for children coming into care included parental mental illness and parental intellectual disability.

Father drug addict left relationship (our son); mother…brain damaged after teenage car accident able to care for self not capable of remembering to care for child. (p. 32)

She describes many carers in her study as having multiple caring roles, which sometimes included cross-generational care:

They care not only for their grandchildren, but also for partners (most frequently husbands) with deteriorating health and/or their own children with physical or mental health issues (most frequently the parents of the children in their custody). (p. 61)

"Letting go"

Parents may not initially see partner relationships and parenting as options for their disabled son or daughter, or may anticipate difficulties in relationships being developed.

All parents are protective, but when the [young person] is disabled, you need to "actively let go" whereas in a normal situation, it would happen "organically". (Philip Patston)[19]

Ewing (2005) notes that the process of allowing the young person to explore their sexuality is all the more difficult when the young person is heavily reliant on their parents for support, resources and transport.

Baker (2007) notes that there has been a lack of opportunities for young disabled people to talk about the complexities of intimate relationships and related matters.

I think that that's a real service gap for young disabled people [in New Zealand], to actually be able to really talk about those complex ideas, which are quite scary.

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[19]   'Disability and Sexuality'. *Networker* (September, 2005). Auckland: Parent & Family Resource Centre newsletter.

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And, if their family and friends are assuming that they want to have relationships, intimate relationships with disabled people and imposing those limiting beliefs on them, then there are not a lot of places to go and talk about those things.

Decision-making

Excitement about becoming a parent may be diminished by the stress involved in finding information, seeking support, and convincing other people that they are competent to parent. Payne et al (2007), in their study of mothers with multiple sclerosis, note that women may face disapproval of their decision, discouragement, or conflicting advice. They found that the decision to become pregnant may involve discussion and consultation with people other than the woman's partner, particularly medical specialists and family members:

The decision may move from being a private to a public experience.

The sudden onset of disability has implications for consideration of parenthood. Each year, many New Zealanders acquire a temporary or permanent disability through accident or illness. This can have a major effect on life plans for the disabled individual, as well as their partner.

[*The*] *financial strain is huge e.g. if my husband never returns to work that is the rest of his lifetime's worth of potential income seriously affected, which means we may never be able to afford our own home, or to have children, or to reach other milestones we'd planned as a couple before his injury.* [Couch poll respondent]

Exploring Sexuality, Relationships, and the Possibility of Parenthood

Olsen and Clarke (2003) recommend adopting a "life-course perspective", allowing young disabled people to articulate and explore their hopes, choices and expectations for parenthood. This perspective takes a holistic view of the entire life path, rather than viewing specific events or phases separately.

Payne et al (2007), in their study of mothers with multiple sclerosis, suggest supportive and well-informed discussions can reassure women that motherhood is feasible and they can meet the associated demands and responsibilities.

In New Zealand, IHC has developed and implemented a Relationships and Sexuality Policy, which provides guidance for ways in which professionals can understand and support individual needs, including privacy, education, establishing relationships and self-growth.

Family Planning has developed a resource for use with people with mild to moderate learning disabilities. 'Safe Relationships, Safer Sex'[20] covers sexuality related issues including public/private places, public/private body parts, relationships, and keeping sexually safe. The booklet includes question and answer prompts as well as 'real life' scenarios to encourage discussion around its key messages. Groups consulted during

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[20] http://www.familyplanning.org.nz/LinkClick.aspx?fileticket=jGQwtuMcyDE%3d&tabid=699

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development of the resource included providers, young adults with disabilities, and parents.

Conder et al (2010) interviewed 19 parents with a learning disability, and highlight the experiences of six of these parents. They found although most of the women in their study had a degree of choice about parenthood, some women's choices were limited by a lack of contraceptive knowledge. They suggest a combination of family support and appropriately responsive services is essential to the development of a positive parenting context. They recommend those who work with young people with a learning disability provide education and support that will allow them to make informed decisions about contraception, pregnancy and parenting:

> *To enable more positive outcomes, people with a learning disability should be provided with good information that gives them control of their fertility and also be assisted to think about how they might realistically manage if they choose to become a parent. Secondly, once [they are] pregnant…support has to be responsive to the parent and their social networks.* (Conder et al, 2010, p. 111)

Disabled Parents and Adoption

The first New Zealand report on implementing the UN Convention on the Rights of Persons with Disabilities notes Article 23 (Respect for home and the family) affirms that a disabled person has the same right to marry as any other person:

> There are no distinctions based on disability in relation to adoption, fostering, access to family planning services or whether a couple is eligible for publicly funded in vitro fertilisation.[21]

However the report notes that some disabled people, particularly those with an intellectual disability, report negative societal attitudes. (The report does not specify whether this includes attitudes to adoption.)

There appears to have been very little study of the topic of disabled parents and adoption in New Zealand. However, Pacific participants in the Ministry of Health's Disability Support Services Consumer Forums (2009) mentioned the right for disabled people to adopt children as an area for improvement.

Ethical and Bioethical Issues

Stace (2007) observes, "the language around disability often focuses on interventions, cures or even elimination through pre-birth genetic testing" (a medical model), despite the attitudes of 'curing' and 'fixing' conflicting with the principles of the New Zealand Disability Strategy. Kleinsman (no date) reports that genetic testing in the area of human reproduction falls into three broad categories:

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[21] http://www.odi.govt.nz/documents/convention/first-report-on-implementation/article-23.html

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> Prospective parents wanting to know the likelihood of future children having disabilities or diseases, and on the basis of such knowledge, deciding whether or not to have children.

> Parents who have already conceived wanting assurance that their foetus is healthy.

> Testing of embryos prior to implantation in the womb – a practice known as Pre-implantation Genetic Diagnosis (PGD)

It is beyond the scope of this report to address bioethical issues, or discuss arguments for and against genetic testing and screening processes (pre and post birth). The perspectives and experiences of disabled people on these issues must be included in ethical and bioethical debates, as noted in the New Zealand Disability Strategy.

Being a Parent

At various points in their life, and for differing periods of time, disabled parents may require support with parenting. Support can be provided by partners, other family members, whānau, and friends, as well as by disability support services.

Parenting is assessed without taking disability into account.
Disability is assessed without taking parenting into account.[22]

Funding and resources available to disabled parents in New Zealand vary depending on whether a disability is caused by an illness or medical condition, or due to an accident.

Different approaches and perspectives such as conducting needs assessments and funding services may mean that not all of the needs of disabled parents and their families are addressed. Cross-service and cross-agency communication are essential.

Appendix C reproduces a checklist developed by British researchers Olsen and Wates (2003) who suggest that local authorities and other relevant agencies may find it useful for enquiring into and reflecting upon existing practices and services for disabled parents. Although it includes references to British legislation, many of the questions raised would also be applicable to New Zealand agencies.

1. Are disabled adults recognised as service users with support needs in relation to parenting?

2. Where policies/protocols/procedures [for disabled parents] exist, are they in use and are all staff and relevant bodies aware of what they say?

3. Are mechanisms in place that ensure timely and effective cross-referencing between different agencies and across organisational divisions to ensure that disabled adults with parenting responsibilities are effectively keyed in to mainstream and specialist supports?

The following comment was made by a parent who responded to a Families Commission online Couch poll. Although the mother who made the comment did not identify as a disabled parent but rather was supporting a disabled child within the family, the comment

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[22] Wates (2003) http://www.leeds.ac.uk/disability-studies/archiveuk/wates/clock.pdf

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summarises some of the challenges that families may face finding their way through the system.

> *[There are challenges] getting answers to difficult questions. The help is OK if the questions are easy. Constant change in government policy, organisations, criteria etc. Knowledge of entitlement or access. Policy and access is available, but finding out about it is often very hard or impossible. Word of mouth is often the only way - parents talking to parents.* [Couch poll respondent]

Families Panel participants talked about getting to know and trust people in various government agencies and how beneficial that was when negotiating assistance. One commented:

> *Government agency staff shouldn't judge us. We didn't ask for this (disability) to happen, but we do need help.* (Disabled parent, Families Panel).

Engaging with Families: Principles for Consideration

Within the following sections, principles for consideration when engaging with families that include a disabled parent are outlined and the general support needs of disabled parents are described. Subsequently, the support needs of specific groups of parents are summarised, by disability type and by parental role. The needs and experiences of disabled grandparents are also briefly discussed.

Raffensperger et al (2012, p.6) propose five principles to bear in mind when engaging with families that include a parent with a disability:

1. **Every family is unique.** While there are general principles that can be applied to many families, there is no 'one size fits all' model. Take time to get to know the specific family you are engaging with.
2. **Disabilities co-exist with abilities and strengths**. When engaging with families, keep their abilities and strengths at the forefront because these will buoy them when they encounter challenges.
3. **Spending time together having fun helps to build family resilience.** Appointments with professionals, time spent in hospitals, time spent in therapy and the ordinary demands of family life can crowd out time for fun. When suggesting interventions for families, it behooves professionals to safeguard families' downtime. Extended family, whānau, and the wider community can play a vital role in providing opportunities for families to have fun together.
4. **Families function as a unit.** In a family situation, a parent's disability is not theirs alone; family members adapt and work together to meet the demands of family life. Support and interventions targeted to individuals alone do not harness the strengths within the family unit. Some parents with a disability in this study expressed distress at having their partners excluded from meetings with professionals.
5. **Poverty and social isolation are challenges in themselves.** When families that include a parent with a disability are facing numerous challenges, the root cause may be underlying poverty or social isolation, rather than the

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disability itself.[23] When families are well resourced, financially and socially, they are better able to meet day-to-day challenges posed by the disability.

These principles provide a foundation for the consideration of other findings and recommendations outlined in this resource, many of which confirm and complement the principles.

Universal and Specialised Support Needs

Olsen and Clarke (2003) propose that the needs of disabled parents are intrinsically no different to those of non-disabled parents, with the following needs being paramount:

> adequate income
> secure and accessible housing
> a network of informal support [likely to include friends, family and whānau]
> access to leisure activities.

Wates (2003) suggests that disabled parents require access not only to universal services but also to specialised support. Parents with the same impairment can have differing needs, capabilities, and limitations.

> *The key question is how to plan and deliver service responses at both routine and crisis service entry points in ways that do not isolate and potentially stigmatise families but rather key parents in to mainstream parent education, maternity services and family support. Alongside inclusion in mainstream services, disabled parents also require access (via routes that they perceive as non-stigmatising), to specialist back up support services as relevant.* (Wates, 2003)[24]

As well as being easy to access, support should take the following factors into account, at the same time recognising and valuing family and whānau diversity. These factors are drawn from research literature, as well as from principles developed by the Social Care Institute for Excellence (SCIE, 2007)[25] in the United Kingdom (where noted); see Appendix D. They emphasise that "good practice is underpinned by an approach that addresses needs relating to a parent's impairment or illness and the disabling barriers of unequal access and negative attitudes" (p.10).

Timing of Support

For some families support is only provided when a child of a disabled parent is identified as being 'at risk', or when a crisis point is reached within the family. Support available to disabled parents should span a continuum, from consideration of parenthood, to pregnancy, labour and delivery, and throughout the parenting years. Existing

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[23] McConnell et al (2000) also note that when a disabled parent experiences difficulties, these may be attributed to the disability, although the difficulties may be due to factors such as poverty, poor housing, harassment, social isolation and lack of appropriate services.

[24] http://www.leeds.ac.uk/disability-studies/archiveuk/wates/clock.pdf

[25] http://www.scie.org.uk/publications/guides/guide19/files/guide19.pdf

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information and support for disabled parents is often targeted at early parenthood, although knowledge about parenting older children should also be shared.

Ideally, within an inclusive society people are comfortable both offering and giving support, and asking for and accepting support when needed. Establishing systems for 'handover processes' into specific (and widely available) support services for families where there is either a disabled parent or a disabled child – particularly around the provision of early support – would help to ensure a positive climate in which support services are accepted. This could counteract any parental reluctance to admit that support may be needed. Some disabled parents may resist asking for support for fear of being perceived as 'needy' or inadequate.

Flexibility of Support

When disabled adults become parents, they may need to ask for support from agencies with which they have had no previous contact, as well as developing new networks.

Payne et al's report (2007) describing women's experiences with multiple sclerosis and motherhood highlights the need for support to be adaptive to changing circumstances:

> The relative place of impairment in women's lives is variable and likely to require ongoing consideration rather than one-off static assessment or action. Ongoing considerations should include the women's life context as well as their pregnancy and impairment. (p.4)

Support must be flexible, recognising the extent of the assistance needed may change as parental health changes, and/or children mature (eg can get to school on their own). Some support needs are short-term, others are enduring; for example, the support required by parents with intellectual disabilities is likely to be ongoing.

Support should be responsive not only to individual needs, but also the changing needs of family and whānau:

> Generally speaking, and all the more so in relation to family life, the experience of impairment cannot be seen as a fixed variable but rather as something that is liable to change in both foreseeable and unforeseeable ways in relation to everything else that is going on within a family. Partners, and children too, move between different welfare and health categories from time to time, while particular medical and social labels may become somewhat arbitrarily fixed to individuals. The relative impact of different conditions varies in relation to the changing situations of family members, while all individual and family changes take place within broader economic and social contexts that can, in large part, determine access to any additional resources that might be needed. (Wates, 2003, in Olsen and Wates, 2003, p.9).

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Consider the Needs of the Whole Family and Whānau

An ecological perspective ensures the needs of the whole family and whānau are also taken into account. Support must fit in with family and whānau life to assist parents to care for their children, as well as themselves.

> *[I receive] ongoing day to day help with tasks I am at times unable to achieve e.g. cooking a meal, mowing lawns, bathing my child, altering clothes so I can wear them.* (Disabled parent, Couch poll respondent)

Support should not be solely targeted to individuals.

> *Agency responses should address the needs of parents and children in the context of the whole family and not as individuals in isolation from one another.* (SCIE, 2007)

The needs of non-disabled partners should also be considered - how caring and support roles coexist within the broader context of the partner relationship.

Sole Parents

We were unable to locate any data on the total number of disabled sole parents in New Zealand.

Disabled parents whose relationships with partners have ended may face additional challenges parenting in a home with only one adult. Practical support previously provided by the partner may no longer be regularly available. Relationships with ex-partners' families and whānau may also need to be re-negotiated, particularly if they have also been providers of practical or other forms of support to the disabled parent.

Culture and Ethnicity

Whānau ora (total wellbeing) is derived from a holistic understanding of the totality of whānau experiences that contribute to the wellbeing of whānau.

Individual, family and whānau experiences and perspectives of disability are influenced by culture and ethnicity; values, practices and beliefs must be acknowledged and respected[26].

The influence of disability culture is also acknowledged, albeit the literature offers differing definitions of what disability culture embraces – and some writers question whether it exists. Barnes and Mercer (2001) describe disability culture as celebrating a positive disabled identity and consciousness…and "central to confronting the social exclusion of disabled people" (p.532). Galvin (2003) observes that the other strands of

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[26] A later section of this paper outlines the experiences of disabled Māori parents and disabled Pacific peoples.

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identity affecting the diverse experiences of disabled people should not be overlooked (eg culture and gender). Brown refers to intersecting cultures:

> …Disability culture is a set of artifacts, beliefs, expressions created by disabled people ourselves to describe our own life experiences. It is not primarily how we are treated, but what we have created. …we recognize that disability culture is not the only culture most of us belong to. (Brown, 2001)

Respecting Individual and Family Privacy

> Professionals should respect and support the private and family lives of parents who have additional support needs associated with physical and/or sensory impairment, learning disabilities, mental health problems, long-term illness or drug and/or alcohol problems (SCIE, 2007).

Privacy should be respected. Some disabled parents may want to include their family members in decisions and discussions about care and support; others may not. For example, some disabled parents in Raffensperger et al's study (2012) were distressed that their partners were excluded from meetings with professionals. Consideration should be given to the broader family and whānau context in which parenting takes place, including relationships between partners.

Parents may need guidance as to how best to explain to their children the impact of their disability. Confidential relationship support and counselling may assist family members, adults as well as children, to explore disability-related issues.

> [It is a challenge] having a mother who is occasionally bedridden or hospitalised. We have had to deal with the impact of this illness on one of our children who required counselling. (Couch poll respondent)

Work and Income allows a Disability Allowance to be paid for counselling fees if the need for counselling is directly related to the person's disability, and the full cost of counselling is not met by another agency (for example, the Ministry of Health, or ACC).[27] Assistance can be provided for the cost of transport to counselling if the need for counselling is directly related to the person's disability.

How Much, Or How Little, Support Is Required?

Not all disabled parents will need, seek, or welcome support. Some may perceive offers of assistance as unnecessary and intrusive. Some disabled parents are reluctant to approach social services in case this is seen as a sign that they are having difficulties; this can mean that they are not aware of the support that they are entitled to.

Looking beyond the formal support offered by government agencies and other providers, family, whānau, friends and other networks are all potential sources of support.

A participant in a Disability Advisory Council discussion told the Families Commission of a network of Deaf parents who support each other to enable a break from their caring roles.

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[27] http://www.workandincome.govt.nz/documents/disability-allowance-couselling.pdf

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Although Families Panel facilitators observed that some disabled people continued to struggle for acknowledgement and acceptance in the wider community, panel participants also spoke about the support that they had gained from, and shared within, the disability community.

> *Having a disability yourself makes you more compassionate…you can contribute to your disability community by giving back what you have learned, to solve problems.* (Disabled parent, Families Panel)

Examples of informal support initiatives for disabled parents in other countries include peer support networks for visually impaired parents, and ante-natal support groups for mothers with learning disabilities. There are a number of online forums where disabled parents exchange ideas and experiences.

The Financial Impact of Disability

> *[There are] incredible costs associated with both disabilities - my medications [as a parent] cost nearly $100 a month; son's glasses and specialist visits have cost nearly $700 just in the last 6 weeks … Everything is an extra stress, and extra cost and an extra battle I could do without.*
> (Couch poll respondent – disabled parent with a disabled child)
>
> *I have a spa pool for my back, but it takes a lot of electricity and it's becoming hard to sustain its use.* (Disabled parent, Families Panel)

There are inequities in government-funded support for disabled people, highlighted in the Cost of Disability report (Disability Resource Centre, 2010):

> *Participants raised well-publicised current inequities between those who acquired an impairment through accident and were primarily provided support by ACC and those who were born with their impairment or acquired one through illness and were primarily provided support by the Ministries of Health and Social Development.* (p.22)

The goal of the Cost of Disability research was "to identify the additional resources (support, equipment, transport and time) and the costs associated with these resources that disabled people aged 18-64 years require to live in the community and to achieve an ordinary standard of living" (p.9).

The scope of the research was constrained to people with physical, sensory, intellectual and mental health impairments for practical reasons, and excluded participants with dependent children.

The research looked at how the costs associated with disability differed according to individual needs and personal circumstances. Common themes arising in the report, which will also be applicable to disabled parents, identified the need for support in the following areas: human support (such as sign language interpreters, a friend to provide emotional support), transport, technology such as specialised software, and life transitions (such as adapting to a change in impairment, living situation or relationship). Time trade-offs were also highlighted:

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The reality for many disabled people is that life is a series of carefully managed trade-offs between time, energy/effort and available support. (p. 24).

A submission[28] made by Women With Disabilities Australia (WWDA) to the Review of the Commonwealth Disability Strategy (Stage Two; 2005) confirms that disability is linked to increased cost of living, highlighting the additional costs for some disabled mothers:

There are … costs of medication, medical supplies and visits to medical professionals; the costs of mobility aids; the costs of labour saving devices (a microwave oven can be an essential tool for someone unable to get hot dishes from an oven); the cost of house cleaning; the cost [of] taxi transport for those unable to use public transport; and the cost of attendant care and support services. In addition to these barriers, women with disabilities have additional costs in terms of dollars and energy in finding adequate childcare, in maintaining their households, and meeting their domestic and parenting duties.

Participants in Raffensperger et al's study (2012) explained that extended hospital stays, the cost of disability-related equipment and loss of former abilities posed substantial financial challenges.

In New Zealand, although disabled children are eligible for a Child Disability Allowance, there is no corresponding benefit targeted at disabled parents (Work and Income, personal correspondence, October 2011). However, Work and Income have a variety of Extra Help assistance available to all clients, whether they are disabled parents or not. Eligibility for the assistance will depend on their individual circumstances.

If disabled parents are facing high costs related to parenting, Work and Income offer Temporary Additional Support which is a non-taxable supplementary benefit that can be paid as a last resort to help people with their regular essential living costs that cannot be met from their chargeable income and other resources. This assistance is income and asset tested and can be paid for a maximum of 13 weeks. However, if their costs continue, parents can re-apply for assistance for another 13 weeks.

Applicants must ensure that they are accessing all other assistance (ie Child Disability Allowance, Disability Allowance, Childcare Assistance Programme etc) available to them and take reasonable steps towards reducing their costs and increasing their chargeable income. A person does not have to be receiving a main benefit to qualify for Temporary Additional Support.

More information about this assistance can be found at the Work and Income website.[29]

Although disability is associated with additional costs, families with members with disabilities and/or chronic health problems are more likely to have decreased family incomes. Statistics New Zealand (2008), drawing on data from the 2006 Disability Survey, reports that close to one in every six people of working age (aged 15 years and

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28   http://www.wwda.org.au/cdssub2.htm
29   http://www.workandincome.govt.nz/manuals-and-procedures/income_support/extra_help/temporary_additional_support/temporary_additional_support.htm

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over) in New Zealand had a disability (17 percent). This translates to 539,000 people, less than half (45 percent) were in the labour force, compared with over three-quarters (77 percent) of non-disabled people of working age., Although there are no data specific to disabled parents, we have summarised key points:

> Participation rates for disabled men were higher than those for disabled women, across all age groups, reflecting trends in the general population.
> Employed people with a disability were no less likely to work full time than those without a disability, although they were generally under-represented in skilled occupations.
> The incomes of employed people with disabilities were lower on average than those without disabilities.
> Adults aged 15–64 with a sensory (seeing or hearing) disability were more likely to be in the labour force than those with other types of disability. People with psychiatric/psychological, and intellectual disabilities had the lowest levels of labour force participation.

Four Families Panel participants who were in paid work (one, part-time) expressed concerns about their precarious standards of living. In the UK, Clarke and McKay (2008), citing Stickland and Olsen (2006), report that disabled parents who are employed are more likely than non-disabled parents to be in low-paid, insecure and part-time work.

Preston (2006), in her discussion of disabled parents and welfare reform (again, in the UK) draws on the personal experiences and viewpoints of a small number of disabled parents to outline the impact that disability has on parents' and children's lives, record parents' attitudes to, and experiences of, paid employment, question the accessibility and adequacy of disability benefits, and consider the availability and appropriateness of services.

Participants spoke about the challenges of balancing paid work and being a parent – challenges that many non-disabled parents also face. Preston notes that paid work can be costly for disabled parents – not only because of disability-related costs, but in terms of family relationships and their own health.

> *Work is good, if it's a job you like doing and it's reasonably well paid and it's not too stressful and it's not taking its toll on your health...and you've got support for your children.* (Disabled mother, Preston, 2006, p. 61)

In November, 2011, the Minister for Social Development and Employment and the Minister for Disability Issues announced a new Disability Innovation Fund. The $500,000 fund is aimed at supporting innovative projects from employers, NGOs or disabled people's organisations to either get disabled people into employment or to retain them in employment.

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Educating Support Providers

Use contact with professionals as an opportunity to increase their knowledge about your condition; you, after all, are the expert. (Mother with spinal cord injury)[30]

Mainstream parenting support and family service providers may need additional education and ongoing professional development to ensure that they are better informed about disability and upskilled to provide appropriate support to disabled parents. Anecdotal accounts suggest that some disabled parents in New Zealand express a preference for receiving parenting support as part of their disability package, rather than from the family support sector. For example, it was suggested to the Families Commission that rather than having to train a worker who assists with childcare about disability issues, it would be more appropriate for workers trained and funded through the disability sector to assist with childcare.

Every Family is Unique – Many Factors Influence Parenting

Multiple factors influence parenting whether or not a parent is disabled.

In addition to culture and ethnicity, other influences on parenting include age, gender, sexual orientation, parents' own experiences of being parented, personal networks and resources, health, the child's needs, and (in accordance with the ecological perspective) the wider social and economic context in which disabled parenting occurs. In the following section, the needs of specific groups of parents are outlined, taking into consideration the influences of particular types of disability on parenting.

Disability Types and Parenting

The support needs and experiences of parents with a range of disability types are described here, with a particular focus on the needs of parents with intellectual disabilities and parents experiencing mental illness, and Deaf, blind/visually impaired, and physically disabled parents.

Disabled parents' roles are influenced by individual characteristics and experiences and a subsequent section explores how motherhood, fatherhood, living with disabled children, living with non-disabled partners, identifying as Māori, identifying as Pacific, and grandparenthood influence parenting.

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[30]   http://www.dppi.org.uk/journal/66/experience2.php

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Parents with Intellectual Disabilities

Mirfin-Veitch (2003) draws on research to caution that competence cannot be, and should never be, judged or predicted on a simple measure or label of intellectual disability in a parent. Mirfin-Veitch observes that the majority of people with intellectual disability who become parents are those with milder degrees of intellectual disability. Because of the stigma associated with a label of intellectual disability, parents may hide their learning difficulties. They may or may not identify as a person with a disability or use disability related services.

Intellectually disabled parents have been described as a "hidden population" (Johnston et al, 2007). Mirfin-Veitch (2003) also notes that parents with intellectual disabilities are largely invisible in terms of formal identification as a group. As mentioned earlier, it is conservatively estimated that approximately 2.5 families per 1000 in New Zealand include at least one parent with an intellectual disability. This figure is likely to increase as a greater percentage of adults with an intellectual disability form partnerships and become parents.

Llewellyn et al (1998) report that intellectually disabled parents usually have profound and enduring socio-economic disadvantage, affecting housing and finances. They may not have learned how to manage money well, and may be in debt as a result. They may also be reliant on benefits. Support is not always forthcoming, and parents as well as children may be socially isolated as a consequence. [31]

Citing the advice of Hardy and Streett (1989) Llewellyn et al stress that disabled parents must address 'survival and maintenance issues' - keeping their family housed, fed and clothed, and paying bills - before they can focus on parenting and health matters.
The Child, Youth and Family website[32] notes that collaboration between child protection and disability agencies supporting intellectually disabled parents is difficult for reasons including:

> A value clash between the 'best interests of the child' and the 'parental advocacy' approach of disability support agencies who are informed by the social model of disability
> The complexity of obtaining funding to support parents in both crisis and long term situations, and arguments about whether health or welfare should be funding a particular case
> The shortage of people who are sufficiently trained to provide long term, intensive and individualised support in the home.

Lamont and Bromfield (2009) caution that the literature around parents with intellectual disabilities is based on limited research and small sample sizes, and more research is needed to build an evidence base.

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[31] A Disability Advisory Council member suggested to the Families Commission that teenagers whose parents have a disability (not necessarily an intellectual disability) may be more at risk (eg socially) than others of the same age, as they may not have access to the broader networks that their peers have.

[32] http://www.practicecentre.cyf.govt.nz/service-pathways/disabilities/key-information/parental-intellectual-disability.html

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"Good Enough" Parenthood

A study by Willems et al (2007), commissioned by the Ministry of Health in the Netherlands, sought examples of successful parenting by adults with intellectual disabilities and explored the factors that contributed to their ability to parent successfully. Drawing on research literature and legal categories, 'successful parenthood' was defined as 'good enough' parenthood,[33] meaning that there were no indications for child abuse and/or neglect, no dealings with child protection agencies and no child placed under legal custody.

The qualitative component of their study identified the interplay of a range of factors indicating the likelihood of parenting successfully. These included being prepared to ask for help and support, having a strong and non-[intellectually] disabled partner, and in particular the presence of a strong and supportive social network, and adequate professional support.

Undermining influences included poverty, debt and low incomes, social exclusion, absent or inadequate professional support and the negative public image of parents with intellectual disabilities.

Willems et al suggest that poorly coordinated support systems may undermine the parenting skills of already vulnerable parents. Conversely, well-structured and integrated professional support – right from the start – can enhance the chances of success. O'Mara et al (2011) cite Tarleton and Ward (2007) in noting that "ongoing support for parents with intellectual disabilities can reduce the likelihood of future problems that might otherwise warrant the intervention of child protection professionals"(p.26). Central to the provision of support are decisions about how the interests of children and the interests of parents can be appropriately and successfully balanced.

Challenges as Children Mature

Parents with an intellectual disability may face additional challenges as their children grow older. For example, if the child's knowledge and abilities surpass their parents, it may be increasingly difficult for parents to assist with homework. Setting boundaries, disciplining appropriately, and providing guidance about healthy eating and hygiene may require support from adults other than the parents.

As children mature, they have to come to terms with their parent's 'difference' and disability.

Combination of Education and Support Services Needed

Conder et al (2010) identify "a combination of family support and appropriately responsive services ... as critical to the development of a positive parenting context" (p. 105). They recommend this combination includes information about contraception, pregnancy and parenting.

Healthy Start[34] is a national Australian strategy for professionals and volunteers working in the health, welfare and education sectors that support parents with learning difficulties and promote a healthy start to life for their young children. It facilitates the exchange of knowledge, expertise and resources and is based on the following principles:

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[33] The concept of 'good enough' parenting was introduced by Winnicott, a British paediatrician.
[34] http://www.healthystart.net.au/

> Thinking about the whole child, whole family and whole community to ensure safe and supportive environments for young children of parents with learning difficulties
> Being aware of critical periods in the life course, to provide effective and timely support for parents with learning difficulties and their children from the antenatal period and early childhood development onwards
> Recognising and acknowledging the strengths of parents with learning difficulties, and appreciating these are the foundations for learning new parenting skills
> Valuing an evidence-based approach: using and sharing research-based programmes, contributing to new knowledge and evaluating outcomes.

Complementing the Healthy Start principles, McConnell and Llewellyn (2002) identify broad agreement about the key elements needed in parenting programmes for intellectually disabled parents: individual tailoring to their learning needs; topics of interest to the parent; concrete skills taught in the environment in which they are to be applied; modelling and opportunities for practice accompanied by feedback; and periodic maintenance sessions if required.

Care and Protection Services

Research literature suggests the children of intellectually disabled parents are over-represented in care and protection services in a number of countries. Lamont and Bromfield (2009), Australian researchers, note although parental intellectual disability *may* adversely affect parenting, not enough is known about whether the risk of abuse or neglect is higher or lower than the risk for other parents. The following issues can play a part in this over-representation:

a. Intellectual disability contributing to parents experiencing stressors such as social isolation, poverty and health problems – all of which are associated with an increased risk of child abuse and neglect
b. Prejudicial and incorrect beliefs about parents' ability to provide care, alongside inappropriate assessment and an over reliance on IQ testing.

McConnell and Llewellyn (2002) say becoming a parent is now a more realistic aspiration for young adults with intellectual disability,[35] compared with previous generations. However, like Lamont and Bromfield, they suggest children may be unnecessarily removed on grounds not necessarily related to the protection of the child, but based on misguided or prejudicial beliefs about parenting skills. Lack of local support services may also increase the likelihood children will be removed.

Johnston et al (2007) refer to the Children, Young Persons, and Their Families Act (1989), under which a child can be declared in need of care and protection (and later removed from their parents' care) if the parents are unable to. Because the act could potentially be used to argue a parent with an intellectual disability is unable to parent effectively, Johnston et al state it is essential any judgement details specific grounds or reasons explaining how a person's cognitive impairment has affected their ability to parent. They advise care and protection issues arising for intellectually disabled parents are more likely to be due to 'under-protection', rather than abuse. Under-protection may

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[35] Inconsistent terminology is used to describe intellectual disability (with variations including "learning disability" and "developmental disability"); there is no generally accepted definition.

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result from a lack of knowledge or insight into the parenting role, particularly if parents have few role models in their lives.

Johnston et al note there is currently no legislation within New Zealand designed to provide assistance in the area of parenting by adults with disabilities and there has been very little New Zealand research into the experiences of parents with an intellectual disability in the legal system. Many of the experiences of parents with an intellectual disability are not documented, as some parents do not continue through the legal system for reasons including a lack of understanding, a lack of legal advice, insufficient resources, or a lack of physical and/or emotional energy. Researchers from the Donald Beasley Institute[36] note parents with intellectual disabilities in their study were often not sure why their child(ren) had been removed from their care, and/or why supervision of parents was required during access visits.

Additional discussion of the needs of intellectually disabled (and other disabled) parents and care and protection issues is presented in Kerslake Hendricks and Stevens (2012). Their report cites Kovacs' (2002) observation that there will always be some families with disabled parents in which external support with parenting will be needed, and others where removing children will be necessary. Johnston el (2007) also emphasise removal of the children will, in some cases, be the only reasonable action the Court can take to ensure children's safety and wellbeing.

A link within the CYF website[37] discusses the impact of parental disability on children, outlines the difficulty of both protecting children and supporting intellectually disabled parents, and provides guidelines for social workers working with intellectually disabled parents. It presents key questions concerning the 'interests of the child' for consideration when balancing the needs of children and parents, including taking into account the nature of the disability, any long-term supports in place to protect a vulnerable infant, how the child is coping with the parent's disability, and the child's level of resilience.

Parents Experiencing Mental Illness

Because of my illness, it was anticipated that I could experience difficulties when I tried to have children. This was because of the high doses of medication and the risk of postnatal difficulties for someone with my type of illness. When I did get pregnant, at 27, I went to my GP. She immediately linked me with maternal mental health services and they were brilliant. They considered my situation, my history and my feelings about the pregnancy, labour and beyond. Together we developed a plan which involved some medication changes. (Mother, Kites and Mental Health Commission report, 2005, p.4)[38]

I've got 10 years to make these children the best they can be and if I need help then I'm going to get it. I have to look after me before I can look after them, have early nights, make sure I take my pills every day, eat sensibly and not party too much. (Mother, Kites and Mental Health Commission report, 2005, p. 27)

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[36] http://www.donaldbeasley.org.nz/publications/newsletter_dec2006.pdf
[37] http://www.practicecentre.cyf.govt.nz/service-pathways/disabilities/key-information/parental-intellectual-disability.html
[38] Mental Health Commission Report (2005) http://www.kites.org.nz/pdf/mums-and-dads.pdf

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The Mental Health Commission report (2005) states up to 50 percent of people who experience mental illness are parents. Parents experiencing mental illness can face challenges related to their fluctuating needs for support in the care of their children and the stigma attached to mental illness. Parents who use mental health services have a wide and varied range of complex issues they are required to deal with, although some parents will require minimal assistance.

Kites is an organisation which helps families to develop plans[39] for children whose parents experience mental illness and become unwell. Kites' purpose is "to increase the active participation of people experiencing mental illness in the community".

> *It's not a nice feeling to be manic or depressed. It's really hard work. And it's a lot of stress and pressure on the family*. (Mother, Raffensperger, 2012)

Parents with drug and alcohol related physical and mental illnesses may find parenting difficult without appropriate support. Providers should consider the needs of the whole family, taking into account factors such as parental history, comorbidity (substance abuse and mental illnesses often coexist), levels of parental illness and wellbeing, parent-child attachment, and the child's health - some infants will undergo substance withdrawal at birth.

With support, many parents with mental illness manage well. Raffensperger et al (2012) reported that looking after their mental well-being so they could look after their children was a high priority for the parents in their study who experienced mental illness.

A hui sponsored by the Ministry of Health in September 2001[40] brought together "consumers/tangata whaiora, mental health and family support agencies" to explore the needs of families where there is parental mental illness. Key findings and recommendations from this hui included:

> > Funding and resourcing must target families and allow for flexibility in service delivery
> > A service whose focus is on individuals is less effective than a service that considers the needs of the whole family.
> > Mental health services must ensure parents and children have access to each other and this access is safe, uninterrupted, and private
> > Parents and children should have time together, particular when mothers and babies are establishing a bond
> > Alternatives to 'taking children away' from their parents should exist, such as respite opportunities. If immediate care or placement is required, this needs to be done without devaluing the parent's role or self-esteem.
> > The voices of children as well as adults must be heard.
> > Networking between sectors is needed to assist in developing shared understandings of each service so gaps in service provision can be identified and addressed

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[39] http://www.kites.org.nz/pdf/hcn1468-kites-kids-plan-v3.pdf
http://www.kites.org.nz/pdf/hcn1468-kitessfactsheets-fin.pdf

[40] Partnerships, Potential and Possibilities. Report of a hui exploring the needs of families with parental mental illness. September, 2001, produced for the Mental Health Directorate of the Ministry of Health http://www.kites.org.nz/pdf/parents-hui-report.pdf

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> Concerns were expressed that residential support services are short term and may require families to relocate to new communities
> Funding is directed at services for adults; these services may not support children and families
> There is a lack of advocacy for parents whose children are removed from their care
> Parents may have to relearn how to parent after a time lapse [eg after a period of hospitalisation and/or separation from their children]
> Parents need education about how hereditary influences may affect their children. Some may welcome counselling and reassurance for children and parents who have concerns about continuing patterns of mental illness within the family (eg drug addictions, depression, suicide).

[It is a challenge] constantly dealing with the symptoms of depression while raising a 3 year old. [It would make a difference to have] in-home support [and] information on the symptoms and the effects of depression on myself and my family [and] education for [my] family on mental illness so they get an idea and can try [to] understand how it is a struggle to do everyday things. (Couch poll respondent)

Trying to parent and work full time when also dealing with severe depression has been really difficult, though I have done it. Not being able to afford as much childcare as was needed has been a major stress in relation to this. (Couch poll respondent)

Mental illness and child care concerns can act reciprocally – anxiety about arrangements for children can adversely affect mental health, which can lead to longer periods of admission for the parent with mental health issues, which can lead to further problems caring for children.

The *Respect Costs Nothing* study[41] (Peterson et al, 2004) explored the needs of parents experiencing a mental illness. Discrimination from family members, including children, was revealed to be a major issue. The key findings are reproduced below:

> Mental health services could play a greater role in helping to educate family members about mental illness
> Support should be available for parents with mental illness, just as it is for other groups who face difficulties when parenting
> None of the survey respondents described receiving positive help when it came to parenting, other than occasional help from family members
> If support is needed by parents and is not provided there is a risk children will lose their connections to their family
> Discriminatory attitudes, particularly based on stereotypes of danger to children or bad parenting, may influence professional decision-making. As a result, inappropriate interventions may be used and have a profound negative impact on parents with experience of mental illness and on their children.
> Helping people who are experiencing mental illness, rather than removing their children, is a more positive approach

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[41] The study reports the findings from a 2003 survey of 785 people with experience of a mental illness.

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> > The fluctuating nature of mental illness must be taken into account, rather than agencies making judgements at a certain point in time may not be revisited when the parent is well.

In the Mental Health Commission's *Mums and Dads* report (2005)[42], from which the following quote is drawn, twelve parents living with mental illness shared their experiences and coping strategies. They also described the support they have received from formal and informal support networks which has contributed to positive outcomes for themselves and their families. This included friendship and emotional support, practical support and role modelling, counselling and psychotherapy, support from the church and from community mental health services.

> *Today I have a really happy life. My husband and I get on better than we ever did before. Our children are happy and we are positive about the future. My mental health has never been so stable. I can appreciate all the events of the past as imperative to me making positive changes for my life, and my children's lives.*
> (Darcey's story, p. 9)

New Mothers with Mental Illness
The need for need for specialist services for mothers with mental illness, including women with severe post-natal depression and mothers who have a pre-existing ongoing mental illness, has long been recognised (eg *Blueprint for Mental Health Services in New Zealand: How Things Need to Be,* 1998).[43]

New Zealand's Perinatal Mental Health Services Mental Health and Addiction Services Service Specification[44] notes "the effect of perinatal mental illness has the potential for rapid deterioration and high associated risk on the mother's relationship to their infant". An urgent / immediate response is required for mothers with a history of bi-polar affective disorder or a psychotic disorder. The service covers pregnancy and the first postnatal year, recognising the significant effects parental mental illness can have on the foetus, infant and toddler.

Maternal health teams exist in many regions of New Zealand. For example, the Capital and Coast District Health Board provides services for women who develop mental health problems during their pregnancy, and for up to nine months after their baby is born. Services offered include specialist assessments, treatment options and planning, information about and liaison with community support services, and individualised counselling and therapy.

A Couch poll respondent wrote about how much she appreciated the support she had received from similar services:

> *GP support [is] fantastic for both mine and my son's disability. Mental health support good – maternal mental health services remain a major source of support.*

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[42] http://www.kites.org.nz/pdf/mums-and-dads.pdf
[43] http://www.cimh.org/downloads/handouts/Resource4%20England%20NZ%20Blueprint1998.pdf
   A new Blueprint was completed in June 2012:
   http://www.hdc.org.nz/media/207642/blueprint%20ii%20how%20things%20need%20to%20be.pdf

[44] http://www.nsfl.health.govt.nz/apps/nsfl.nsf/pagesmh/350

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Even though I rarely see them, the fact they are there and remain responsive is fantastic. (Couch poll respondent)

Dwyer (2009)[45] notes although most primary health organisations (PHOs) have established primary mental health initiatives, funding for primary mental health care is still relatively small and services are being provided to only a small number of patients. There remains a significant gap in service delivery for people with mild to moderate mental health problems.

Dwyer's study reports screening for Post Natal Depression for New Zealand women was not systematic or universal and often took the form of the provider simply asking the mother how she feels.. Dwyer suggests that this subjective approach was inevitably resulting in some women with PND being missed. However, some participants in her focus groups reported receiving proactive support:

Both midwife and Plunket were really [good]; I've had depression in the past so that was in my notes from my obstetrician so the midwife at that six-week visit said 'Look, you're going to need to be aware sleep deprivation and tiredness could bring this back and we are going to need to really keep an eye on it together', and she actually also was speaking to my husband about that and signs and things to look for and then … I mean we had only met her at the 36-week visit but she was great and I get along with her so I felt I could tell her anything, and then Plunket, I don't know whether it got, I assume it must have got transferred in my notes, but our Plunket nurse has been really … proactive about asking how I'm feeling and how I'm doing and how I'm getting along with it and everything, but we've also had a very good GP as well. (Focus Group participant, in Dwyer, 2009, p. 81)

Deaf Parents

Deaf parents face a number of challenges not faced by other disabled parents, in particular social isolation. Communication barriers may limit participation in social and community networks. It can be difficult for Deaf parents to access parenting support in appropriate formats.

New Zealand Sign Language is an official language of New Zealand and the first language for many families. Access to technologies allowing families to communicate over distance (eg via Skype) is important. Deaf advocates have told the Families Commission that families who cannot afford – or do not have access to – broadband technology and rely instead on dial-up and cannot use sign language to communicate (eg via Skype) because transmission is too stilted due to the slow speed of dial-up technology.

A SCIE briefing paper (2005)[46] notes deaf parents in the United Kingdom have requested practical, technical support, such as equipment to alert them when their babies are crying, and more access to interpreters particularly to help them engage more effectively with the education system. In New Zealand, the Deaf Aotearoa website[47] lists

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[45] http://www.nzfamilies.org.nz/sites/default/files/downloads/RF-Childbirth-Education.pdf

[46] http://www.scie.org.uk/publications/briefings/briefing13/
[47] http://www.deaf.co.nz

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available equipment and devices, including a baby alarm. Equipment is available free of charge if parents meet criteria set by the Ministry of Health.

Deaf advocates have told us they would like more subtitles provided for TV programmes so that parents can gauge whether programmes are age- and content-appropriate for children. The Television New Zealand website reports 90 percent of prime-time programmes on TV ONE and TV2 are captioned (sub-titled); over 200 hours of NZ television go to air with captions every week, including a number of children's programmes. Captions are also available for some TVNZ 6, TVNZ 7 and TV3 programmes. Captions are fully funded by New Zealand On Air.

Carter (2011) conducted a survey about captioning of TV programmes. 392 people responded, with the majority in favour of mandatory legislation. The findings were summarised with a view to providing evidence to the New Zealand Government to encourage legislation to make captioning mandatory, as is in Australia and other countries. Carter describes the initiative for the survey as arising from "the sense of injustice and frustration felt by many in the Deaf and hearing impaired community of New Zealand" due to insufficient captioning of entertainment, current affairs and news items.

A Human Rights Commission (2011) consultation with the disability sector identified insufficient captioning and audio description on television – especially for official announcements and important public information – as one of the major issues raised by disabled New Zealanders.

A member of the Disability Advisory Council urged consideration of how accessible telephone-based services (such as Healthline) are for disabled parents. The initial evaluation of the Healthline service (Kalafatelis et al 2002) made no mention of accessibility for Deaf or hearing impaired callers, although the similar NHS Direct service in the United Kingdom is referenced in the report with a comment "dimensions of inequality of access to NHS Direct may exist, and may present difficulties for those with communication disabilities or for those whose first language is not English".

The *Cost of Disability* report (2010) notes Deaf Māori noted the impact of a lack of trilingual Sign Language/Te Reo interpreters. The summary of the DSD Consumer Hui for Māori participants (2006)[48] also identifies a "huge need" for trilingual translators to be trained and qualified. If Deaf parents are relying on their hearing children to communicate with service providers, teachers or other adults – whether in English, Te Reo or another language – this can place pressure on children.

> *I have a daughter who attends kura kaupapa. It is hard for me to attend parent interviews as there are not enough Māori-speaking interpreters or communicators who can support me. This is distressing for me as I can only rely on my child to sign to me about how she is doing at school. It is good that all my children know sign language.* (Kathy, Deaf mother, *Life is for Living* report, 2005)

Smiler (2006), whose mother is Pakeha Deaf and whose father is Māori hearing, refers to the role she and her siblings played as "cultural brokers" between the Deaf and hearing communities.

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[48] http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/consumer-forums-hui-fono/previous-consumer-forums

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The need to switch between cultural contexts was common, and my siblings and I were expected to navigate Te Ao Māori, the Deaf World and mainstream New Zealand society from a young age. (Smiler, 2006, p.109)

Blind and Visually Impaired Parents

Blind and visually-impaired parents have unique needs, particularly related to ensuring the environmental safety of young children as well as finding 'lost' children and belongings, receiving information in appropriate formats from early childhood services and schools, and transportation. Blind parents need to ensure their own safety, as well as the safety of their children.

A Gravitas (2006) report exploring the cost of blindness in New Zealand raised a number of issues for disabled parents. A blind parent described reduced opportunities to link into existing parent support networks, due to being unable to contribute to the activities members of such networks typically undertake such as participating in a car pool.

The report also notes blind parents were restricted in the range of activities that could be undertaken with their children. As they are unable to drive extra time needs to be allowed for walking or using public transport. Getting children to activities requires planning and effort, regardless of the mode of transportation. Because of the challenges involved blind parents also mentioned they were less likely to leave their children at activities and do something else during that time. This means the parents may have less free time, and limited opportunities to have time away from their children.

> *…There is no provision for time out. As I said, sighted people could drop kids off at the kindergarten for the afternoon, but if it took you half an hour to walk to the kindergarten and then stay with them, it would take you half an hour to walk home again.* (Female Older Adult, Gravitas Report, p. 106)

Study participants also noted domestic duties may take longer for someone with a visual impairment. For example, identifying, using and putting back ingredients can have a substantial impact on the amount of time spent cooking. It may be difficult to assess how clean a surface is, leading to over-cleaning or the unnecessary repetition of tasks.

> *…housework, it takes you at least twice as long because if you're vacuuming a floor, you'll go over an area more than you need to, to make sure it's clean.* (Female Older Adult, p.81)

A blind parent participating in a Commission's Families Panel talked about the positive support received from the Foundation of the Blind.

> *They upskilled me to have a new life. When I was partially sighted I didn't fit anywhere – I had no community. I now have a sense of belonging and a new peer group.* [Disabled parent, Families Panel]

A parent in Raffensperger et al's study (2012) described how she and her daughter, from infancy, successfully adapted to the mother's visual impairment:

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This is where having no sense of vision was difficult. Again I had to find a way to gently drag the spoon up without getting it on to her, over her chin and into her mouth. And then after a while I got other things to help like touching my finger to her chin and then putting the spoon in above that. 'Cause it's easy to feed yourself when you can't see but it's quite difficult with another person and then after a while she would just grab the spoon and after a while she put her little hand on mine and guided the spoon to her mouth… It's a really good little way she adapted to help Mum who couldn't see. …I thought, '[expletive], I'll have to do all this', but it didn't occur to me she would adapt and she began to adapt in her own little way to get the food in. (Mother, Raffensperger et al, 2012)

The Royal New Zealand Foundation of the Blind and Strategies with Kids, Information for Parents (SKIP) have partnered together to produce a small selection of SKIP booklets in accessible formats, including DAISY audio, e-text and Braille. SKIP supports parents to raise their children in a positive way, through a network of community groups, NGOs and parents. (See Appendix E.)

Physically Disabled Parents

Physically disabled parents may have specific needs related to individual impairments. For example, some parents find it difficult to lift or bend towards their children, or to move quickly.

> *I cannot walk fast, and cannot run…and have to be careful of any taxing events. This limits my family…we cannot go on walks together, I cannot chase my wee kids and play active games with them.* (Disabled parent, Couch poll respondent)

Physically disabled parents have described the challenges associated with caring for young children, particularly around road safety. They also mention restrictions imposed by lack of appropriate equipment, inaccessible environments -including maternity wards and playgrounds- and unsuitable housing. A SCIE briefing[49] notes fathers with physical disabilities have reported experiencing their greatest frustration in being unable to engage in physical activities with their children, particularly when their children are older.

The following quote illustrates how modifications made parenting more manageable for a disabled mother when her children were young.

> *When the children were young I got by through designing and modifying things to suit my needs. When they were babies I had them on a sheepskin with two wooden handles so I could pick them up. When they started crawling they'd wear a little harness or I'd dress them in overalls. I had a change table and bassinette modified to suit my chair, and used a bath that supported the babies well.* (Mother, wheelchair user)[50]

A related SCIE briefing (2005)[51] refers to potential solutions for parents with arthritis, including alternative techniques for lifting and handling children, and furniture

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[49] http://www.scie.org.uk/publications/briefings/briefing13/
[50] http://raisingchildren.net.au/articles/parents_with_physical_disability.html
[51] http://www.scie.org.uk/publications/briefings/briefing13/

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adaptations. The SCIE authors caution there is limited research on the effectiveness of the solutions described in such articles. However, they also note research demonstrates parents value equipment and techniques (eg for lifting children) that make a difference, for example by lessening stress and pain. Parental confidence and feelings of independence can develop as a consequence.

The suggestions presented throughout this paper and the resources identified in Appendix E indicate the range of supports that can make parenting easier for physically disabled parents and contribute to positive outcomes for parents as well as children.

The Roles of Disabled Parents

In addition to the type of impairment disabled parents live with, their roles as parents are also influenced by individual characteristics and experiences. We look at how the following factors can influence disabled parenting: motherhood, fatherhood, living with disabled children, living with non-disabled partners, identifying as Māori, identifying as Pacific, and grandparenthood.

Disabled Mothers

Disabled mothers often juggle multiple priorities meaning their own needs are not met. They may require information about the combined effects of pregnancy and their disability. Disability resources addressing pregnancy may focus on a medical perspective, not taking social and emotional needs into account.

> *Taking the children out by myself is very energy sapping and at times stressful. Having to adjust to the fact I can't give full input to the children and keep the house clean and tidy and cook. So the choice is the children which means feeling like you are inadequate as you can't do both like most other young Mums. Going up and down mentally with bouts of depression over feeling inadequate, being fed up with having pain all the time and of course dealing with two small children every day.* (Mother, Couch poll respondent)

> *[Even] with free services available at the hospital, it is just not possible to do things like hydro therapy or have physio regularly, as with my condition and having two pre schoolers, I can't manage it, so I miss out on these things which might help if I could do them.* (Parent, Couch poll respondent)

> *It is not recognised I have a problem even though I walk with an obvious limp. Because there isn't a cast, bandage or other form of obvious indication of damage, my pain gets overlooked sometimes. It would be nice if the family would remember the problem is ongoing, even when they in turn are tired or not the best. 'Mums' of the family are still expected to keep going and it's pretty hard sometimes to be positive and cheerful and get on with life. That includes being nurse, driver, tutor, listener, housekeeper, cook and general jack of all trades.* (Mother, Couch poll respondent)

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[A challenge for our family is dealing with] the loss of job (psychological), loss of mobility, isolation, financial [stress] and not being able to be the mother I should be to my children as I deal with the condition and its associated side-effects (medications). (Mother, Couch poll respondent)

Women With Disabilities Australia (WWDA), in their submission to the Queensland Review of Maternity Services[52] in 2004, offered the following suggestions for making maternity services more inclusive and supportive for disabled women:

> > Information should be provided in accessible formats and accessible to women in isolated or 'out of the ordinary' settings
> > Training to staff at all levels is needed to raise awareness of disability from a human rights perspective, and awareness of the issues, experiences and circumstances of women with disabilities
> > Support should be made available to women with disabilities, including peer support
> > The range of choices available should be made accessible to all women with disabilities, or fully explored so the choice is the woman's (eg not making assumptions about delivery methods, or screening choices)
> > Access to supports and technologies, parent education classes, and necessary equipment and resources before, during and after birth (including any extra needed due to disability needs) should be offered
> > Appropriate unbiased information on prenatal testing, including accuracy of testing, risks associated with testing methods and referral to counseling and appropriate information about supports should be available
> > Clear referral pathways and support to access extra services if needed, and to ensure integration with community follow-up such as child health services and disability services. Links with agencies that have support and information for women with disabilities should be established and maintained.
> > Flexibility to extend support if it will assist women with disabilities to develop as parents.
> > Policy of providing support to women with disabilities before choosing removal of children, and if necessary creating support.

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52   http://www.wwda.org.au/matern.htm

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A SCIE (2005) briefing on helping parents with a physical or sensory impairment [53] refers to research[54] that resulted in a set of practice recommendations for breastfeeding mothers with arthritis, addressing topics such as posture and positioning, medication, and the coordination of professional support (GPs, health visitors and therapists).

A participant in a Disability Advisory Council discussion advised us fertility issues for disabled women in New Zealand need to be explored, such as access to fertility support and advice for people with spinal injuries.

United Kingdom researchers note that disabled parents' access to antenatal education and parent support on the ground is very limited (particularly for parents with learning difficulties, Deaf parents and parents with visual impairments). Echoing similar concerns, Baker (2007) describes her experiences as a disabled mother in New Zealand.

> *If I was to reflect on my experience as a disabled parent, I received no support to do with my impairment either during my pregnancy or following the birth of my child. I know that that's a significant gap still, that disabled parents are not well supported, that there is no funded support for them. And I actually think that that gap comes from an historical perspective that disabled people were never meant to have children.* (Disabled mother)

Violence and Abuse

A paper prepared by Women With Disabilities Australia (2008) states that disabled women "are … greatly at risk of violence and abuse due to structural, cultural and contextual issues such as: discrimination, poverty, exclusion from the labour market, isolation, lack of services and support [and] lack of autonomy". The paper notes disabled women may be denied rights related to reproductive choice and parenting.

CCS (2006) advises disabled women are subject to the same risks as all women in the community and require strong, extended support networks. CCS cites findings from the British Crime Survey (1995) that disabled women are twice as likely to experience domestic violence as non-disabled women, and they were likely to experience violence over a longer period of time.

Sexual and domestic violence can result in short and long term disability, for example, brain injuries and mental health problems (Domestic Violence and Disability Working Group, 2012).

Disabled women experiencing family violence may be reluctant to move out of their own home to seek support, for example if their home has been modified to meet their disability support needs.[55] CCS (2006) recommends planning for more accessible services for disabled women and their children, as disabled women experiencing violence often find options for support services are limited, with refuges and counselling services rarely able to accommodate their needs[56]. Limited options are also noted by the

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53 http://www.scie.org.uk/publications/briefings/briefing13/
54 Wade M.I., Foster N.E., Cullen L.A., Barlow J.H. (1999). Advising mothers with arthritis. Breast and bottle feeding for mothers with arthritis and other physical disabilities. Professional Care of Mother and Child, 9 (2), 35-38.
55 http://www.womensaid.org.uk/domestic-violence-survivors-handbook.asp?section=00010010008000100350003
56 CCS Media Release, 23 November 2006. Domestic violence twice as likely for disabled women

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Domestic Violence and Disability Working Group (2012), as well as by Hager (2011) who looked at the provision of specialised domestic violence and refuge services for disabled women and other women who find it difficult to access mainstream services. Hager observes finding suitable refuge accommodation is especially difficult for disabled women who require caregiver support for daily needs.

Healey et al (2008) looked at family violence policies and service provision in Victoria (Australia) and the extent to which these recognise and provide for disabled women experiencing violence. They say little is known about the help-seeking experiences of disabled women experiencing violence. They also say family violence sector standards, codes and guidelines provide insufficient information about how to support disabled women, and most family violence workers consulted had minimal or no training on how to provide such support. The Domestic Violence and Disability Working Group (2012) confirms these are also issues of concern in New Zealand.

Healey et al note assumptions about disabled women's parenting capacities can have a bearing on their experiences of seeking help. They suggest this is compounded for disabled women with disabled children. For example, teenage children with behaviour problems or cognitive impairments may not be welcome in some alternative accommodation options.

Two New Zealand groups who are actively addressing issues related to disability, violence and abuse are DCAV (the Disability Coalition Against Violence; a national organisation founded by DPA and the National Network of Stopping Violence Services) and DVD - the Auckland Domestic Violence and Disability Working Group whose briefing paper is referred to above.

Domestic Violence and Disabled People is a resource booklet produced for the 'It's not OK' campaign; see Appendix E. It identifies barriers for disabled people that may make it difficult to talk about abuse, as well as outlining ways in which disabled people can increase their safety and how and where they can get help.

Mothers with Multiple Sclerosis
Payne et al (2007) interviewed nine women in New Zealand with multiple sclerosis (MS) who had become mothers in the past five years. Women were asked individually about their experiences of pregnancy, birth, and mothering their preschool-aged children.

The researchers note the lack of New Zealand research about the experiences of mothers with MS, stating that it is vital that research focuses on how best to ensure appropriate health and disability policy is developed, and quality health and social services and support are available to disabled women wishing to become parents. The researchers also suggest that rising awareness of human rights, improved medical treatments, and changing attitudes towards chronic health conditions, have lead to increasing numbers of disabled women choosing to become mothers.

Payne et al draw on other research to describe how any stress associated with the adjustment to parenthood may be compounded. They note the physiological changes occurring during pregnancy have an impact on MS and living with MS influences the physical, psychological and social experiences of pregnancy, birth and motherhood.

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Payne et al emphasise the importance of professionals, family, friends and colleagues listening to women's stories prior to making assumptions about their aspirations and support needs in relation to motherhood. They stress the importance of ongoing, rather than one-off, consideration of how impairment may be affecting women's lives. Women described how they balanced their activities inside and outside the home, limiting the demands they placed on themselves in recognition of the relationship between becoming stressed and relapsing. Although Payne et al caution the findings of their research are not generalisable, the following key messages will likely have relevance to other disabled women considering motherhood.

> Women on medications that may have detrimental effects on the developing foetus are advised to plan their pregnancies so the possibility of alternative medications can be considered. The potential risks and benefits to both mother and baby need to be weighed up.

> The effect of medications on breastfeeding needs to be taken into account.

> Conditions such as multiple sclerosis, which may fluctuate in their intensity and effects, may remain 'in the background', with women being physically able and capable for long periods of time.

> Unpredictable relapses have implications for a mother and her family. Partners and other family members have a vital role to play in the provision of support (which is not always forthcoming).

> Negotiating with agencies that assess needs, fund and organise carers can be both time-consuming and energy-sapping (particularly as energy is a finite resource to be managed wisely – with multiple sclerosis, a relapse may be triggered by fatigue and stress).

> Maternity practitioners' knowledge of chronic conditions may be variable. Ongoing access to existing and emerging education about disability and motherhood is recommended for midwives and other health professionals.

> Health (and other) professionals must adopt a flexible approach, acknowledge each woman's experience is unique, and be sensitive to the woman's perceptions of herself and her disability.

> Women may need to re-evaluate their criteria of 'good' motherhood and determine their own standards, recognising and accepting the limitations imposed by their disability.

> The unpredictable and fluctuating nature of conditions such as multiple sclerosis places varying demands on partners, which may affect their ability to continue in paid employment; flexibility and understanding in the workplace is important.

Mothers with Other Physical and Sensory Impairments
A qualitative study undertaken by McPherson et al (2011) explored how to improve health interventions and support for mothers with physical and sensory impairments, particularly during pregnancy, birth and early motherhood. 99 participants took part in the study; participants were women with disabilities (mothers, as well as women who had not pursued motherhood) and health professionals. Recommendations are:[57]

> Professional knowledge deficits should be addressed (eg by teaching disability awareness at all health professional undergraduate levels; by

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[57] The strategies associated with each recommendation are presented in the report.

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> providing continuing education that addresses various types of impairment and their implications on a mother's wellbeing and care).
> Home help provision should be addressed (eg by increasing continuity of care by addressing the high turnover of staff from home help agencies).
> Ensuring appropriate funding resources to reduce inequity (eg by providing funding for midwives and Plunket nurses to be able to extend the number of home visits to disabled women).
> Fostering better inter-sectorial communication and improved cohesion of services.
> Addressing professional attitudinal barriers (ie discrimination and prejudice).
> Addressing physical barriers (eg by ensuring birthing units and postnatal wards are fully wheelchair accessible; making needs assessments more timely so equipment is provided when it is needed).
> Keeping birthing options as open as possible for women with disabilities.
> Supporting mothers' choices around infant feeding options.
> Making relevant info more accessible for women and health professionals (eg by establishing a disability dedicated, fully accessible internet site that is a resource hub for disabled parents and health professionals).
> Supporting accessibility of Plunket nurses.
> Devising appropriate care and communication strategies for women who have sensory disabilities.
> Developing a Best Practice pathway for maternity and child health providers caring for mothers with disabilities (eg a pathway that acknowledges the women's expertise re her condition and needs).
> Fostering strategies that work to create continuity of care (eg by the Lead Maternity Carer establishing and maintaining links with significant health professionals during the antenatal period).
> Addressing rural issues (eg the lack of continuity of care in rural maternity services).

McPherson and her colleagues have begun teaching midwifery students about supporting and caring for disabled women during pregnancy and birth. The findings from the study have been presented at New Zealand midwifery conferences. The recommendations are being disseminated to stakeholders, including government ministers, government agencies and NGOs.

While generally the Ministry of Health does not specifically provide dedicated support to enable parenting of people with disabilities, in some circumstances additional support with personal care may be provided to a mother when she is pregnant or immediately after the birth. Equipment and modification services may also supply equipment, such as a change table.[58]

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58   Personal correspondence, 2011

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Disabled Fathers

> *I guess, like all new parents, we will grow into the role and I'll find out how I can best be a dad. It will be some of the little things I won't be able to do as a dad that will frustrate me. Like with the rest of our lives, we'll plan as best we can – then take it as it comes.* [Paul, a blind parent expecting his first child, quoted in the Life is for Living report, 2005]

As in the 'mainstream' parenting support literature, where there is comparatively less information about fathering than mothering, there is also less information available about the needs and experiences of disabled fathers. Although a number of publications include the experiences of disabled fathers (eg Raffensperger et al, 2012), the literature scan did not reveal any New Zealand research that *specifically* focuses on disabled fathers.
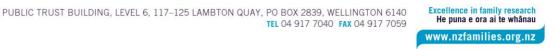
International literature also highlights the shortage of knowledge about disabled fathers, eg Kilkey (2007) who suggests disabled fathers have been marginalised within research. She notes reviews of research on fathering have called for greater recognition of the diverse contexts of fathering, yet have not identified disability as a relevant dimension of diversity.

A SCIE briefing[59] on parents with physical or sensory impairments reports much of the research literature they reviewed focuses on both parents, but tends to equate parenting with mothering, or uses methods that result in mothers taking more of a part in the research than fathers; some studies focus exclusively on mothers.

Sandfield and Unsworth (2007) drew on the findings of a workshop held at the University of Hull (UK) to identify an agenda for research focusing on the needs and experiences of disabled fathers. Workshop participants included researchers, practitioners, and disabled fathers. Sandfield and Unsworth outlined areas in which change is needed, with suggestions for improvement in service provision as well as recommendations for future research. Key points are:

> - More information is needed (eg from health and social service agencies) for disabled men who are to become, or wish to become, fathers. Materials should be current and available in a range of formats, and could include information about their rights as fathers and the effects of particular conditions on fatherhood.
> - Provide networking opportunities for fathers; many of the issues faced by disabled fathers are similar to those of non-disabled fathers
> - Provide forums where fathers can talk honestly about the challenges they face, with negative experiences acknowledged
> - Recognise disabled fathers as engaged parents who can provide as much stability, support and stimulation for their children as non-disabled fathers, although they may do things in different ways.
> - Recognise the complex context of fathering - disabled fathers may be biological fathers, foster fathers, adoptive fathers, stepfathers, separated fathers, and grandfathers. Their experiences of fatherhood will be influenced

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[59] http://www.scie.org.uk/publications/briefings/briefing13/

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> by a range of factors, including their age, their own experiences of being parented, culture [and ethnicity].
> > Recognise disabled fathers may share parenting with disabled or non-disabled partners – fathers' central concerns may not be, or not only be, related to being disabled.
> > Prioritise disability education (eg within professional training courses) to increase levels of understanding and awareness, with emphasis on equality and diversity.
> > Research should examine the assumptions and understandings of disabled fathers drawn on by service providers and others who work with and for disabled fathers.

Sandfield and Unsworth emphasise the importance of researchers and service providers acknowledging the characteristics and experiences disabled fathers share with other parents:

> *Researchers and service providers should view disabled fathers in the social context of their broader relationships and acknowledge the many commonalities shared with nondisabled parents rather than seeing them exclusively as a distinct and different group.* (Sandfield and Unsworth, 2007, p 31)

Disabled Parents with Disabled Children

Some disabled parents are parenting disabled children, some of whom have inherited disabilities. . Some parents acquire a disability such as a back injury or a mental health problem as a consequence of providing care to their disabled child.

> *[Challenges have related to having] a child with a stomach disability, being told nothing was wrong with the child, mother going a bit mental after a year of no sleep due to child not sleeping due to disability, costs of treating child, costs of treating depression, income-tested [barriers] prevents us from getting any outside resources to help with our family life.* (Parent, Couch poll respondent)

> *My husband and I both have back problems, myself requiring chiropractic treatment from all the lifting [of our disabled son].* (Mother, Couch poll respondent)

The unique needs of families with disabled parents as well as disabled children need to be taken into consideration. Parents may need education and guidance if there is a hereditary component to their disability which may affect their children, as well as counselling for children and parents in families within which there are intergenerational patterns of illness (such as mental illness) or disability.

Non-disabled Partners

For disabled parents in relationships with non-disabled partners, caring and support roles coexist within the broader context of the partner relationship. Several of the disabled parents participating in Raffensperger's (2012) study, referred to the impact of their impairment on their non-disabled partner and at least one participant expressed a desire for more support for their partner.

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I think there is a lack of awareness [of] how one disabled person within a family can impact the entire family and certainly the spouse… There is still an expectation on you to be able to carry on living normally and do what they might expect. I think the disability doesn't just stop at the person who's got the disability. It permeates the rest of the family as well. (Partner of a disabled father, Raffensperger et al, 2012)

Even just someone for him [partner] to be able to talk to really and help for him to stay okay … I was encouraged to do lots of different things like eating right and exercising as well as counselling and meds. It would have been nice for [partner] to have … I don't really know what but just support for him so he could be a hundred percent to help me and [our daughter]. (Unpublished quote from transcript, disabled mother, Raffensperger et al study, 2012)

If a non-disabled partner is employed during the day, some disabled parents may need additional support with parenting while their partner is not at home.

One of the underlying principles of the New Zealand Carers' Strategy is 'be inclusive', emphasising the needs of carers, family, whānau, or aiga and the person being supported are often intertwined. Partner's needs must be taken into account, not only by the two partners within a relationship, but also by formal and informal support providers.

Māori Parents

Being Māori brings a different perspective to considerations of disability. Social model concepts can be inconsistent with holistic Māori frameworks for understanding people and their wellbeing, and there are often no equivalent words in Te Reo. Core concepts like independence and manaakitanga may conflict. Historic trends like institutionalisation separated some disabled Māori from their whānau and their culture, and communication barriers may hinder their learning of Te Reo. The impact of colonisation adds complexity. (The Cost of Disability Report, p.21)

Hickey (2005) says although there has been detailed exploration of health research into Māori with mental health issues, other disabilities and related issues for Māori are not discussed as frequently. She notes the importance of exploring issues related to identity and disability from an indigenous perspective, as well as considering the issue of the use of language within the context of disability. Māori cultural values, practices, processes and worldviews must be acknowledged and respected.

Tikao et al (2009) state there is limited academic literature addressing the topic of Māori and disability. Their paper discusses the perception and treatment of the blind (kāpo) in traditional Māori society, drawing on literature – including Māori mythology – and oral histories. They found references to blindness within mythology, including key figures such as Mahuika, the Goddess and Guardian of Fire, who was traditionally depicted and described as having no eyes. In some versions of her story (eg Best, 1924), Mahuika is depicted as a mother with five children: the fingers of fire.

Tikao et al describe how Māori perceptions of disability have changed over time:

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In general it appears Māori in the ancient world who had impairment were people with god-like power and god-like status. They were known for the talents they possessed, not for what they didn't have. As time progressed, this notion appeared to change. …

With colonisation and Christianity, and with the introduction of influenza, measles and venereal diseases the Māori view about birth defects and disability appeared to change and bring shame to the hapū. Today, with better living conditions, socio-economic circumstances, medical care, and rehabilitation services it is hoped this has given way to acceptance and respect of people with an impairment because they can contribute in a valuable way to their whānau and hapū. (Tikao et al, p. 11 and 12)

Te Whare Tapa Wha and Te Wheke Models
Hickey suggests Durie's 'Te Whare Tapa Wha' model, which provides a framework for implementing and measuring the effectiveness of service delivery for Māori in the health services, is also relevant for disabled Māori.

Te Whare Tapa Wha Model

With its strong foundations and equal sides, the symbol of the wharenui (house), the Whare Tapa Wha model illustrates the four cornerstones (or sides) of Māori health and dimensions of wellbeing. These are:

> whānau (family health)
> tinana (physical health)
> hinengaro (mental health)
> wairua (spiritual health).

Should one of the four dimensions be missing or damaged, a person or a collective may become unbalanced or subsequently unwell (Durie 1994: 69-72).

In a traditional Māori approach to health, the inclusion of the wairua, the role of the whānau, and the balance of the hinengaro and tinana are as important as the physical manifestations of illness.

Te Wheke Model

Another model of Māori health is based on Te Wheke, the octopus, and the eight tentacles that collectively contribute to waiora or total wellbeing. The components are:

> wairuatanga (spirituality)
> hinengaro (mental health)
> tinana (physical health)
> whanaungatanga (extended family across the universe)
> mana ake (the uniqueness of the individual and extended family)
> mauri (the life-sustaining principle in people and objects)
> hā a koro mā a kui mā (cultural heritage)
> whatumanawa (relating to emotions and senses).

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The body and head of the octopus represent the whole family unit, and the eyes are referred to as 'waiora' or total wellbeing of the individual and the family (Pere 1991).

Source: Office for the Community and Voluntary Sector (2007), p. 12

The term 'hunga haua' refers to disabled Māori; Hickey suggests the term can be loosely interpreted as 'Māori who are uniquely different'. Hickey says "without a clear definition and understanding of the identity of being hunga haua and without a concerted approach to ensure accessibility and inclusion into not only their own home and immediate whānau environment, this group faces ongoing exclusion and misunderstanding." She reports if hunga haua leave their rural whānau environment to access better services, they are often faced with the loss of their whānau environment, lifestyle and community.

Smiler (2006), whose mother is Pakeha Deaf and whose father is hearing Māori, describes being socialised into the Deaf World and Te Ao Māori (the Māori world) simultaneously from a young age. This included acting as a 'cultural broker' communicating between Deaf and hearing communities and explaining cultural perspectives.

In her paper discussing Māori Deaf identity, Smiler expands on the work of Foster and Kinuthia (2003) in presenting the idea of a star constellation for conceptualising Māori Deaf identity:

Māori Deaf have many stars/identities that make up the 'constellation', which is the person. This model helps explain how Māori Deaf perceive their identity in different situations, and identities, as stars, shine forth in response to different contexts. For example, a Māori Deaf person's constellation of stars/ identities may include – parent, Deaf, Māori, sportsperson, worker, male or female, Deaf Club member, kapa haka member, strong Deaf, mainstreamed Deaf, etc. (Smiler, 2006, p.120)

This model…takes into consideration Māori and Deaf worldviews, acknowledges identities are shifting and ever changing, and finally, that identities are contextual and responsive. (Smiler, 2006, p.122)

Baker (2007), describing her experiences as a disabled Māori parent, says:

"…what I love about engaging with my taha Māori [is that] I am not defined by my impairment. I can be identified through whakapapa, and through birth order, and those sorts of things, and certainly my gender sort of slips in there and your role is somewhat defined by your gender as well."

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Māori parents living with mental illness
We draw from a report[60] in which four Māori talk about their experiences with mental illness. These extracts refer to the challenges they faced as parents:

> *"I couldn't cope with one day being a good parent, happy, active, popular, involved in the community, and then suddenly losing all of that and feeling like I was at the bottom of a pit. I experienced long periods of hopelessness and wondered if I would ever be able to recover and to reclaim my life."*

> *"After my first hospitalisation I went home on a lot of medication to a seven year old child, and was just left to my own devices. I didn't know what on earth was going on. I can remember going back to the hospital and saying, 'You've got to cut down on the medication, I've got a seven year old to look after, and I just keep falling asleep all the time.' I shouldn't have had to do that. I should have had support or some kind of follow up. I had to do it all myself, nobody helped me. I was lucky my whānau looked after my daughter, but in terms of services or any kind of referral or assistance, once you leave the acute services, no way. And then they wonder why we keep coming back. Because you actually aren't given any of the options and the tools you need to stay out. I was in and out of bloody hospital every couple of weeks. Jeez, it was terrible."*

The report emerging from the Ministry of Health's Consumer Hui for Māori participants (2006)[61] does not address the needs of disabled parents per se, however it does emphasise the importance of supporting whānau as well as individuals.

The Whānau Ora approach – identifying strengths, needs, priorities and solutions
This approach has implications for disabled Māori parents and their whānau, including how they access health and social services. Whānau Ora enables whānau to identify their own strengths, needs and priorities and participate in the development of solutions to issues they may face.

An inclusive approach to providing services and opportunities to whānau across New Zealand it empowers whānau as a whole, rather than focusing separately on individual whānau members and their problems.

Whānau Ora will work in a range of ways, influenced by the approach the whānau chooses to take. It is not a one size fits all approach, it is deliberately designed to be flexible to meet family needs.

Some whānau will want to come up with their own ways of improving their lives, and they may want to work on this with a hapū, iwi, or a non-government organisation (NGO). Other whānau will want to seek help from specialist Whānau Ora providers, who will offer them wrap-around services tailored to their needs. Whānau will have a practitioner

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60 http://www.hdc.org.nz/media/200488/recovery%20series%20one%20(march%202000)%20-%20four%20maori%20korero%20about%20their%20experience%20of%20mental%20illness.pdf

61 http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/consumer-forums-hui-fono/previous-consumer-forums

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to work with them to identify their needs, develop a programme of action to address them and broker their access to a range of health and social services.

Whānau Ora is an inclusive approach to providing services and opportunities to whānau across New Zealand. It empowers whānau as a whole, rather than focusing separately on individual whānau members and their problems.

Te Puni Kōkiri http://www.tpk.govt.nz/mi/in-focus/whanau-ora/

Nikora et al (2004) also stress the importance of addressing the needs of the whānau, as well as the disabled individual:

> *As much as a person with a disability will move through lifespan changes and have varying needs, so too will other whānau members. Children will grow up, more children will be added to the whānau, and so too will spouses or partners. Parents will become grandparents… Attention to lifespan changes necessitates a flexible approach to care provision and to understanding the person with a disability and their whānau in context.* (p.49)

Participants in Nikora et al's study observed young children of parents with a disability may be handed the responsibility of providing care to their parents when they demonstrate ability, or circumstances become desperate.

Collins and Hickey (2006) examined the capabilities and wellbeing of whānau when one or more members live with a disability. Although the project does not focus on disabled parents, it is one of the few projects exploring the relationships between disabled Māori and their whānau. They carried out a literature review and interviewed nine Māori with long-term disability. Findings revealed most participants called upon the whānau for help, including physical, material, and emotional support. The authors suggest the strength of the participants' identity and that of their whānau was an underlying factor that ensured whānau wellbeing. Participants drew strength from their cultural heritage, peace of mind from Māori spirituality, a sense of connectedness from Māori customary resources, and a deep respect for people from the values they inherited from their whānau and tipuna.

Māori Disability Research Agenda
In 2011, the Ministry of Health published Uia Tonutia - Māori Disability Research Agenda[62], informed by 304 participants comprising Māori living with disability, unpaid whānau carers, kaumatua and others, at 11 regional wananga and 13 hui (Collins et al 2009. The agenda notes a key concern of whānau living with disability was research that should enable the voices of Māori living with a disability and their whānau to be heard. Their four key priorities were that research about Māori and disability should:

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[62] http://www.health.govt.nz/publication/uia-tonutia-maori-disability-research-agenda

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> Look beyond impairment to quality of life
> Respect participants' identity integrity
> Acknowledge the centrality of whānau
> Take a holistic perspective with respect to disability.

These priorities reflect the components outlined in Te Whare Tapa Wha and Te Wheke models, with their emphasis on whānau and the importance of adopting a holistic perspective would incorporate all dimensions of health and wellbeing.

Although the agenda does not make specific reference to disabled parents, a range of research topics are identified, which would provide opportunities for disabled parents to have their voices heard. For example, a research topic exploring the changing needs of Māori with a disability across the lifespan could incorporate perspectives and experiences of parenthood. This could include consideration of how disability impacts on parents' and children's participation in Te Ao Māori.

> *Better information about the impact of disability on Māori and their whānau will mean more informed decision-making at both health and disability and community sector levels. It will also enable whānau, hapu, iwi and Māori communities to have a greater role in decision-making – and all of this helps us to help ourselves.* (Hon Tariana Turia, speaking at the national Māori disability providers' Hui Taumata, April 1, 2011[63])

Pacific Peoples

We have identified a small number of research papers and other summaries[64] addressing broader disability issues for Pacific peoples, but no work specifically addressing the needs and experiences of disabled parents within Pacific communities.

A Ministry of Health (2008) report encourages consideration of the various ways in which disability is understood within Pacific cultures:

> *The diverse Pacific cultures have various ways of defining disability. However, in general the way Pacific peoples see disability is different from the way non-Pacific people do, particularly in explanation of the origins and root causes of disability. Like the general New Zealand population, Pacific peoples understand disability from a medical perspective, where a disabled person is one who has a physical, sensory or intellectual impairment. However, some Pacific peoples tend to identify different reasons for or causes of disability, which are not biomedical but either religious or cultural.* (Ministry of Health, 2008, p.1)

In this quote from the Mental Health Commission and Kites' *Mums and Dads* report (2005), Vito - a New Zealand-born Samoan living with a bipolar disorder - describes some of his experiences as a Pacific disabled parent. Vito has one son.

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[63] http://www.beehive.govt.nz/speech/039whanau-ora-whanau-choices-what-our-part-this039
[64] For example: Malo, V., (2000); the summary of the Ministry of Health Disability Support Services Pacific Consumer Fono 2011.

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There was quite a lot of shame within my family about me being in a psychiatric hospital. For Pacific Islanders if one member of the family is sick then the whole family is affected. My mother didn't want to see me for a long time. My father was quite supportive as were a couple of other family members, but they didn't want anybody else outside my immediate family to know I was in hospital. My father's church was probably the first to find out and was really supportive. That was the first connection I felt with the church. The church supported my family in supporting me. The fact they didn't discriminate against my family made it a lot easier for my parents to be more open to the fact I'd been affected by mental illness.

…It was also difficult being on the wards and having a child. I didn't get many opportunities to see him, when I went home on the weekends I was often quite sedated and spent most of the time asleep, so I was hardly of any use as a father. I remember one time when my sister brought my son to the ward. Like most wards there was a long stretch of corridor and I was walking down one end as my son and sister approached from the other. I remember feeling bad for what I was subjecting him to. I tried to change from that point to make things better for him and not subject him as much to my own personal shortcomings.

These days my son plays quite a key role. He is a great 'brown wire', earthing me, but sometimes I succumb to the 'symptoms' and it is hard not to be self-obsessed. My mental illness does not change how I am as a parent. I am no less a parent with a mental illness than I would be without. I sometimes wonder 'what if he grows up and turns out just like me?' I guess if I do my job right though and he does go down that track, then at least he would benefit not only from the supports of good services but from having a father who has been there too.
(Mental Health Commission and Kites, 2005, p.18-19)

A Ministry of Health report on Pacific Peoples' Experience of Disability (2008)[65] says there is limited information available about Pacific peoples' experience of disability, and few sources of reliable data.

Pacific participants in the Ministry of Health's Disability Support Services Consumer Fono (2009) mentioned the right for disabled people to adopt children as an area for improvement.

Ongoing research into Pacific experiences of disability is needed, particularly to learn more about the experiences of disabled parents.

Disabled Grandparents

Although we focus mainly on disabled parents, the roles and responsibilities of disabled grandparents who are raising grandchildren should also be considered. They are likely to have similar needs to disabled parents, as well as additional requirements related to their age and the often unexpected nature of taking on the roles such as a sudden need for a larger home, a need for additional income to meet the costs associated with raising grandchildren.

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[65] http://www.health.govt.nz/publication/pacific-peoples-experience-disability-paper-pacific-health-and-disability-action-plan-review

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Worrall (2009) describes the disruptions in grandparents' lives as a consequence of taking on grandchildren. Grandparents who have to move to a new home away from existing social networks can find this very unsettling and the move can contribute to ill health, which can lead to decreased income, if grandparents are unable to continue with paid work:

> *[I am] not able to work anymore due to health issues relating to care. (Carer[66], Worrall, 2009, p. 18)*

Worrall says the results of her study reflect international research shows a significant relationship between health deterioration and the caring role. One hundred and forty-three (69.8 percent) participants in her research described health and disability challenges experienced by themselves and/or their partners, such as the following:

> *Macular degeneration but although my sight is deteriorating I can still drive and read if the print is large enough. However, my driving is limited; osteoarthritis; have had one knee replacement and have trouble with the other.* (Carer, Worrall, 2009, p. 61)

> *I have sleep apnoea and sleep with a CPAP machine. I have arthritis. [The child we care for] wakes every night at 2am and if we do not grab him into bed with us quickly he is awake for the rest of the night.* (Carer, Worrall, 2009, p. 61)

Worrall describes the grandparents in her study as demonstrating resilience and commitment to the grandchildren in spite of 'huge hurdles and difficulties' including ill health and disability. Kerslake Hendricks et al (2010), in their study of the pleasures and pressures of being a grandparent in New Zealand, note improvement is needed in the provision of clear and easily accessible support and information for grandparents in general. In particular, information is needed in the areas of personal development and boundary setting, financial and legal advice, and relationship management. Information and support should be tailored to grandparents' individual needs and circumstances – taking disability into account.

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[66] Eighty-four percent of the carers who took part in Worrall's study were grandparents.

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Parenting Successfully - and Positive Role Models

> *The key thing for families is they are assisted to have a set of expectations about what is possible for them.* (Disabled parent, Families Panel)

Many disabled people are parenting successfully - their stories and positive experiences need to be shared. Willems et al (2007) emphasise the need for more examples of positive outcomes and description of the support that makes a difference in the lives of disabled parents. Raffensperger at al (2012) note although researchers are moving away from a deficit-focused view of disabilities, descriptions of the challenges families face are far more prevalent in the literature than descriptions of the strengths they possess. Kirshbaum, cited in O'Toole (2002) also mentions the tendency to focus on 'dysfunction' in families lead by disabled parents, with competencies and positive outcomes overlooked.

Olsen and Wates (2003) note a lack of research into the context in which the majority of disabled people parent; research is often dependent on the participation of families who are already 'known to services' or identified as being 'in need'. They suggest analysing the factors that make for success is crucially important in the development of effective parent and family support systems. The literature scan located only a small number of studies (most with small sample sizes) identifying factors contributing to positive outcomes for disabled parents in New Zealand; in addition to formal support, the importance of support from partners, parents and whānau is often mentioned.

Raffensperger et al's (2012) report identifies strengths and resiliencies in New Zealand families that include a disabled parent. The families are described as having considerable buoyancy in terms of their family qualities (eg being a close family, having fun together, shared beliefs), personal attributes (eg persistence) and family communication processes. Having sufficient income and adequate housing contributed to family wellbeing. However, not all families felt well-connected to their community and most faced employment and economic challenges.

Thomson et al (2010) present two case studies of parents with intellectual disabilities, outlining both the challenges faced and the supports put in place to enable them to parent successfully. These include ongoing advocacy support, and access to home support through a community based disability provider, who assists the parents with activities of daily living, including parenting skills. The authors note there are a growing number of practitioners (eg social workers) "with the skills, knowledge and lack of prejudice to achieve success for families where parents have an intellectual disability" (p.26). Child, Youth and Family are described as supporting many New Zealand families with disabled parents, either through partnered response ("working with families to connect them to the right service for them in the community, at the right time"[67]) or through direct involvement.

The support that has helped several adults with learning disabilities to parent well is described in Conder et al's (2010) study. This included attendance at an antenatal

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[67] http://www.cyf.govt.nz/about-us/working-here/social-workers-stories.html Partnered response is used where the family needs services rather than a formal Child, Youth and Family response.

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group, specialist intellectual disability services, and support and advocacy from family members. They observe family response when a pregnancy was announced was "pivotal to the future success" for many of the parents who participated in their small-scale study.

During consultation with the sector, it was suggested to the Families Commission a range of methods should be used to communicate positive messages and highlight role models. Information for disabled parents needs to be accessible, using different mechanisms. For example, a Deaf parent suggested an informational video/DVD in NZ Sign Language could be captioned in several languages, so it would be applicable to more than one community.

Resources that present examples of disabled parents who are parenting successfully include:

> The Office for Disability Issues *Life is for Living* report (2005): the collected stories of 25 "ordinary people leading everyday lives" in New Zealand. In the report, 25 New Zealanders living with disability share their experiences; several of them are disabled parents and grandparents.
> Ministry of Health video clips: affirmative stories about living with a disability and the difference getting support can make. Several of the videos feature disabled parents.[68]
> Australia's Raising Children Network website:[69] positive profiles of two disabled fathers (one of whom is separated), who briefly describe in their own words the supports they have in place to assist with parenting. For example, attendance at a parenting programme, support from an ex-partner, and access to childcare.

Additional resources and links relevant to disabled parenting are identified in Appendix E.

Facilitating opportunities for disabled parents to share knowledge and information with other parents is one way to promote role modelling and develop formal and informal peer support networks.

Supporting Disabled Parents

A range of different agencies provide support services for disabled people in New Zealand and their families and whānau. The key government agencies providing support are ACC and the Ministries of Social Development, Health, and Education with potential support options for disabled parents (and their families and whānau) in relation to the education system, housing, and social and recreational opportunities.

ACC can provide support to people who need help because of an injury. The help provided will depend on the individual's needs. If the client is a parent who is having difficulty as a result of their injury, ACC may be able to provide childcare, equipment

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[68] http://www.health.govt.nz/yourhealth-topics/disability-services/video-stories
[69] http://raisingchildren.net.au/articles/parenting_with_an_intellectual_disability.html#Challenges

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and/or home help provided a claim has been accepted by ACC and the need for support has been identified in an assessment. (See Appendix E).

This section draws on two consultations that have explored disability needs in general. It then explores existing and potential support options for disabled parents (and their families and whānau) in relation to the education system, housing, and social and recreational opportunities.

Ministry of Health Disability Support Services Consumer Forums

The Disability Support Services Group of the Ministry of Health runs forums throughout New Zealand to ensure disabled people, their families, whānau, aiga and carers have an opportunity to meet with ministry representatives to express their concerns and ideas. Input from the forums helps to guide planning for future services.

In 2009, 20 forums were held and attended by over 550 people; these included general forums, hui on Marae, and fono for Pacific communities.[70]

The forums covered four main themes:

> General update on services and projects
> What is working – what isn't working – ideas for improvement
> Issues and concerns of consumers attending the meetings
> Discussion on the strategic priorities for the Disability Support Services Group.

The issues raised were grouped broadly under four headings:

> Choice & flexibility
> Support for families
> Workforce
> Communication and information.

In previous years (eg 2006), forum participants identified a general lack of support for disabled parents, particularly in relation to support with the upbringing and care of their children.

Although the needs of disabled parents were not specifically highlighted in the 2009 forum report, many of the findings from the forums are also likely to be applicable to disabled parents. For example, there were concerns expressed about the disparity of service allocation and funding for environmental supports between different agencies. A common theme was the system to access services is too difficult for families to navigate.

Suggestions from forum participants for improving communication and the provision of information included:

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[70]   http://www.health.govt.nz/search/results/consumer%20forums

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> An information pack for people moving into an area from overseas or other parts of New Zealand that tells them what disability support services are available
> Developing information material in accessible formats so all disabled people are fully informed.
> Having a Māori support person available to help access information and navigate through the government agencies (eg MoH, MoE, Work and Income), with all agencies working more closely together to deal with the needs of the whole person and their whānau
> Having a Pacific local coordinator to help families access systems and services, to alleviate the stress currently experienced.

The NZFDIC[71] (NZ Federation of Disability Information Centres) has since developed an information pack, available from the Disability Information Centres throughout New Zealand. The packs identify where to get disability information and provide information on the NASC (Needs Assessment Service Coordination) process to access Government funded services. The packs also include Ministry of Health Disability Support Services fact sheets, available in English, Māori, Cook Island Māori, Samoan and Tongan languages.

The Review of Long-term Disability Supports

More than 400,000 New Zealanders require access to long-term disability support services. These comprise a wide range of services with common goals of participation and independence. They include home-based support, residential facilities, transport support, housing support (modifications), equipment support, carer support (respite care), (re)habilitation training, and financial support (the disability allowance).

The Office for Disability Issues (ODI) observes adequate and appropriate provision of support services can complement social and environmental factors to enable the full participation of disabled people in the economic and social lives of their communities. The ODI also notes if support services are inadequate, there are opportunity losses not only to disabled individuals (who may lack opportunities to reach their potential), but also to society as a whole.

The ODI worked with the disability sector and government agencies on a Review of Long-Term Disability Supports. The review explored how people find out about and get disability (or other) supports they need, how government-funded disability support resources can be shared out fairly, and how across-government work can occur to make things better for disabled people and their families. The goals of the review were to:

> improve the focus on outcomes and measurement
> enhance consumer choice and service flexibility
> build capability

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[71] The Federation nationally promotes and supports the local provision of generic disability information and referral services that are community integrated, needs driven and focused on achieving the aims of the New Zealand Disability Strategy Document. Their objective is to provide an impartial information and referral service, through a network of independent community centres operating to established national standards.

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> improve co-ordination and contracting.

The key findings from the review are on the ODI website,[72] as well as a link to the March 2008 Cabinet paper "Improving Long-Term Disability Supports: Maintaining Momentum". The Cabinet Paper includes several references to disabled parents. For example, the opportunity to revisit current mainstream programme goals and criteria to ensure they include disabled parents on an equal basis with others.

The ODI reports there is now significant work underway across government including: expanding supported independent living; increasing access to individualised funding; moves to outcome focused funding; cross-government initiatives to improve and better align assessment; and a greater focus on preparation and support for disabled people entering paid employment.

The Inquiry into the Quality of Care and Service Provision for People with Disabilities report (2008) also noted parents with disabilities are not well supported and this was identified as a service gap.

The Education System

The Ministry of Education consults with representatives from disability groups in New Zealand in policy development and implementation of programmes that impact on children and young people with disabilities and their families and whānau. The Ministry of Education also partners with the Ministry of Social Development in the Improving Attitudes and Behaviours towards Disabled People campaign.[73]

The Review of Special Education 2010: Discussion Document[74] notes the disability community wants:

> *'For us to be included and have our needs met in all roles, for example, as disabled parents and as disabled teachers.'*

The Review of Special Education in 2010 sought views from disability groups and parent groups – who asked for less bureaucracy and easier access to services and support. This feedback has been taken into account as recommendations from the Review are being implemented. If the Ministry's Special Education team is involved with a family where parents are disabled or have specific needs, then the process would be customised to some extent and similarly schools when they are aware of such needs would seek to meet them within the expectations of the National Education Guidelines[75] and their charters.

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72   http://www.odi.govt.nz/what-we-do/review-dss/index.html
73   The focus of the campaign is to address the constraints of a disabling society; the campaign will fund community-driven social change, strengthen existing initiatives and support new approaches to changing attitudes. http://www.odi.govt.nz/what-we-do/improving-attitudes-and-behaviours/index.html
74   http://www.minedu.govt.nz/theMinistry/Consultation/ReviewOfSpecialEducation.aspx
75   http://www.minedu.govt.nz/NZEducation/EducationPolicies/Schools/PolicyAndStrategy/PlanningReportingRelevantLegislationNEGSAndNAGS/TheNationalEducationGuidelinesNEGs.aspx

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There are two Deaf Education Centres in New Zealand that provide services specifically for Deaf and hearing impaired students: Kelston (for students from the Upper North Island) and van Asch (for students from the rest of New Zealand). The Deaf Education Centres provide appropriate material for Deaf and hearing impaired parents, however arrangements for disabled parents are all made at an individualised and local level.

Planning a school site accessible to all, even if no disabled students are enrolled, can create a safer environment and facilitate access for disabled parents or staff, as well as anyone who has temporary difficulties with accessibility. Improvements to general accessibility include ramps, slopes, hand-rails, and lowered door handles.

The Ministry of Education's Modern Learning Environment (MLE)[76] criteria helps boards of trustees to create modern learning environments in all New Zealand schools. Boards are required to complete an MLE assessment process every five years and use this as part of developing their Property Plans.

All new and significantly remodelled buildings are required to be accessible to all students, parents and staff. Accessibility includes ensuring a school is welcoming to its community and is well sign-posted so that students and visitors can find their way around the site.

Biddulph et al (2003) point out that genuine home/school collaboration can lift children's achievement significantly. Although their review of the evidence includes very little reference to disabled parents, it does outline effective ways in which schools can initiate collaborative partnerships so children's development and learning can be enhanced by involving parents and communities in their education.

As our research revealed a shortage of New Zealand research focusing on disabled parents' experiences with the education sector, this section primarily draws on overseas literature. This is supplemented by several comments made by participants in Families Commission's polls and panels.

Morris (2004a)[77] reports difficulties disabled parents may experience in their relationships with schools are primarily created by attitudinal barriers and inaccessible buildings and communication. Similar findings are echoed by a taskforce of disabled parents in the USA,[78] who describe the following risks for disabled parents within the education system:

> Disabled parents may be excluded from active participation in their children's early childhood centre or school life (eg helping out at school camps)
> Education personnel may be either unaware of, or insensitive to, the needs of disabled parents.
> School buildings may be physically inaccessible (eg for parent-teacher meetings) [A physically disabled mother participating in the 2006 NZ

76

http://www.minedu.govt.nz/NZEducation/EducationPolicies/Schools/PropertyToolBox/StateSchools/Funding/SpEdPropertyProvision/PropModifGuidelinesSpecialEduNeeds/AccesibleModernLearningEnvironment.aspx

77   Morris' report lists barriers faced and successful initiatives offered by a number of schools so that disabled parents could attend meetings and concerts, receive written info etc.
78   http://www.lookingglass.org/announcements/67-news/100-report-task-force-on-bay-area-parents-with-disabilities-and-deaf-parents

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> Disability Support Directorate forum reported she was unable to access her child's kindergarten[79]].
> Methods of communication between home and school may not be appropriate (eg no interpreters for Deaf parents; material for parents who are visually impaired may not be provided in a suitable format. Education personnel may need to be better informed about options for communicating with disabled parents).
> Material may not be sent in a timely manner (parents may need advance notice in order to arrange transport to school events).
> Deaf parents may be expected to use their hearing children to interpret conversations between parents and teachers, which may not be appropriate
> Inaccurate or negative assumptions may be made about parents' capabilities, for example, their ability to help their children with homework.

A lack of response to information from schools may be misinterpreted as a lack of commitment on the part of parents, but this may be due to material being sent in an inappropriate or inaccessible format. A Human Rights Commission report (2011) states access to information was the largest single sub-category of concerns raised during the Commission's community engagement with disabled New Zealanders. This included information from schools - such as school reports, newsletters and homework diaries - not being accessible.

Schools and early childhood centres should allow sufficient time for meeting with disabled parents, and explore alternative methods for engaging with parents other than face-to-face meetings.

[A barrier for our family is] people's lack of understanding of [the] needs of deaf people. We have to deal with this constantly - this includes agencies, exhausting. [Ministry of Education] supportive. Cooperative with family over white board bullet point presentations, minimal speech. Teacher at local intermediate refused extra time for meet [the] teacher for deaf parents. 15 mins not adequate for a signed interview, whānau organised meet[ing] with Deputy Principal. Communication via email arranged. (Couch poll respondent living in a family with deaf parents and hearing children).

Schools are not proactive at supporting you as a blind parent. (Blind parent, Families Panel participant)

Wates (2003) heard from disabled parents in the United Kingdom that disabled parents with disabled children sometimes have better access to information and support in relation to schools and support services than disabled parents with non-disabled children. In particular, Deaf parents and parents with visual impairments reported educational services were far more 'geared up' to supporting disabled children than to assisting Deaf or visually impaired parents.

Early childhood services and out of school services can also be part of a disabled parent's support network. New Zealand families may be eligible for Work and Income subsidies:[80]

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[79] http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/consumer-forums-hui-fono/previous-consumer-forums

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> A Childcare Subsidy of up to 50 hours of childcare a week for each pre-school aged child, if the family is below a certain income limit and if the child's main caregiver is seriously ill or disabled.
> An OSCAR (Out of School Care and Recreation) Subsidy for children aged 5-13 years (or up to 18 years if they receive the Child Disability Allowance). This helps pay for before and after school care, and care during the school holidays. Subsidies may be available for up to 20 hours a week for before and after school care and up to 50 hours a week for school holiday programmes. Families can get this subsidy when their family income is below a certain limit and the child's main caregiver is seriously ill or disabled.

Supporting Disabled Parents within the Education System
Options for supporting disabled parents within the education system (outlined by the USA taskforce of parents referred to above) include the following. These practices may already be occurring in New Zealand, but not yet documented in research literature.

> Disabled parents becoming more visible and more active in their children's early childhood centres and/or schools. For example, participating in classroom presentations; getting involved with the PTA; demystifying and normalising disability.
> Allowing parents to request materials distributed to all parents be sent ahead of time, to allow sufficient time for material to be studied.
> Educating early childhood centre and school personnel about options for communicating with disabled parents (eg text-messaging, large print) and summarising these options on a website so parents can access and share this information.

The taskforce also notes the importance of educating teachers (including student teachers) about diverse impairments.

Guidelines for supporting disabled parents' involvement in their children's education have also been developed in the United Kingdom, based on research findings (Brunner et al, 2009).[81] The resource includes disabled parents' descriptions of good practices in schools that have helped them to be involved in their children's education. The guidelines suggest "proactive but unobtrusive support can make a difference" (p11).

Suggestions included:

> Teachers explaining children's homework to parents verbally, to benefit parents with learning disabilities
> Providing disabled parents with opportunities to volunteer; this requires flexibility from the school and trust between the school and the disabled parent. Volunteering can also help to reduce social isolation.

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80   Families meeting other criteria may also be eligible; see http://www.workandincome.govt.nz/individuals/a-z-benefits/out-of-school-care-and-recreation-oscar-subsidy.html

81   http://www.leeds.ac.uk/disability-studies/archiveuk/maguire/2500_Guidance_5.pdf

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My approach has always been that I'm a mother before I'm a person with a disability. I tried really hard to be part of the children's lives. I went on the kindergarten committee to make the kindergarten wheelchair accessible, and I did fruit duty and reading. I've done spinal injury awareness talks at the children's schools and have been as much a part of my children's recreational activities as I could – the calisthenics committee, and racing around the three phases of dressage, show jumping and cross-country in my three-wheel motorbike. Now one son is an Olympic athlete and my daughter is getting there in equestrian events.'
(Mother, wheelchair user)[82]

> Representative bodies (eg Boards of Governors) can include disabled parents by sending information in accessible formats and in advance…and by recognising some parents will need support to become involved and to stay involved.
> Adjustments to enable disabled parents to attend school events or parent evenings; eg by ensuring space is made available for a wheelchair amongst other seating, by checking with parents with visual impairments where they and their family need to sit, ensuring events held off school premises are also accessible to disabled parents.

We've got the new school….They've thought about things like lighting, acoustics …and it's actually a pleasure. They've got automatic doors and things like this, very easily moveable furniture. …everything has been designed so a disabled child [and a] disabled parent has got total access to every part of the building. (p.13)

> Schools working flexibly with external support agencies (eg social workers, carers, parent/family support groups, young carers' organisations and the voluntary sector) to support disabled parents and their families.
> Being sensitive to timing, taking the needs of disabled parents into account, and easing the stress of meetings "by being flexible about time and venue, conducting meetings more informally, keeping meetings as small as possible and making sure the parent has support to participate fully" (p. 17).

Flexibility was key. She [parent] could have good days, bad days et cetera. It was basically around ensuring she had access to information, that her meetings were scheduled in such a way that she could access them and come along and also for parents' nights as well, ensuring she had an earlier slot (p.15).

> Consistency amongst staff, and across time. For example, continuing with agreed methods of communication between parent/s and school as the child progresses from class to class.

The underlying ethos…rather than specific policies, seem to make the difference. Making life as rich and fruitful as possible is usually about communication and openness. You can have everything in a policy but it can stay in the filing cabinet. An ethos is 'alive' and out there and we hope it encompasses staff, students and parents and is all-encompassing for any disabilities within those groups.'
(Assistant Principal, p. 19)

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[82] http://raisingchildren.net.au/articles/parents_with_physical_disability.html

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> > Every-one associated with a school – including the principal, teachers, classroom assistants, non-teaching staff, and other parents and children – working to overcome attitudinal barriers.

In terms of parents' willingness to disclose their disability, Brunner et al's study found parents are more likely to disclose impairments if they believe support will be provided to benefit their child's education. Brunner et al recommend disclosures should be voluntary and handled sensitively.

> *Schools could send a form to all parents asking how they would prefer the school to communicate with them (e.g. in writing, orally, by email) or asking if parents had any particular support needs. This could be sent out annually in the general contact information required of parents, enabling identification of both changing impairment related support needs and newly disabled parents.* (Brunner et al, 2009, p.26)

However, the guidelines emphasise that if schools become 'disclosure-friendly' and encourage parents to disclose, there must be resources in place at the school to support the parents.

Social/Recreational Opportunities

Raffensperger et al (2012) found spending time together having fun helps to build family resilience. Yet disabled parents are not always able to take advantage of opportunities to participate in recreational, sporting, or other leisure activities with their families.

Transportation may present a challenge, particularly if a disabled parent has to arrange and coordinate transportation for their child(ren) as well as for themselves. Vehicles such as hoist vans in which the whole family can travel are not always available. Coordinating and waiting for transportation can consume a considerable amount of time. Modifications to transport or equipment are not always affordable.

> *All people have the right to seek and gain fulfilment in life through participation in arts, recreation, leisure and sporting activities in their community.* DPA (New Zealand) Inc Vision 2009-2012[83]

> *I got a mobility scooter last year and that is great. I can now take my son to the park, go and see friends, and do the things I could not do before.* (Couch poll respondent)

The DPA and CCS (2010) *Inclusive Communities* report describes key principles and action areas for local authorities and DHBs to work on in partnership with disabled people, their families and friends to identify and address barriers, and ensure disabled people can participate.

In New Zealand, there are a number of initiatives aimed at increasing accessibility for disabled people to recreation, sports and leisure activities. Wellington and Christchurch City Councils focus on raising awareness of disability issues, reducing attitudinal

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[83] http://www.dpa.org.nz/downloads/our_vision_2009-2012.doc

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barriers, and increasing accessibility. Some city councils provide a concession pass for leisure activities for disabled people or for those on benefits (Gravitas, 2006).

In Christchurch, the Inclusive Communities Programme is based within the Recreation & Sports Unit and is funded by the Christchurch City Council and The Canterbury Community Trust[84].

The vision of the Inclusive Communities Programme is to increase opportunities for inclusive recreation participation for disabled people. An Inclusive Communities Coordinator is employed to oversee this, associated with the KiwiAble brand. Increasing such opportunities will also make it easier for disabled parents to participate in recreational activities with their children, eg visits to the swimming pool.

Amongst other activities, KiwiAble administers the KiwiAble Leisure Card that provides discounted recreational opportunities to over thirty facilities. To be eligible for the card, individuals must meet certain criteria[85].

The Christchurch City Council's Inclusive Communities Co-ordinator r[86] confirmed that although they do not specifically develop programmes for disabled parents, council facilities, such as swimming programmes, are regularly used by disabled parents. Swimming pools have water wheelchairs with incline access, and hoists are also available. Council staff encourage family-focused participation in events and activities for families with disabled members, and advocate for caregivers and support people to have free or reduced entry fees to activities such as the movies, gondola etc. Many of the programmes the Council offers are described as mixed-ability, such as performing arts programmes, meaning they are inclusive and anyone can join in. Participants are not required to identify as disabled so it is possible there may be disabled parents taking part in some of these activities.

Wellington City Council (WCC) has an Accessibility Advisory Group that provides the Council with feedback and advice from disabled people living in Wellington city; disabled parents are represented on the group. The group responds to issues raised by the Council and to concerns expressed by disabled people. The annual Accessibility Forum also provides an opportunity for the disability community and the Council to share ideas. Discussion groups focus on specific themes and make recommendations for improvements.

The WCC website identifies accessible facilities within the city and notes whether mobility parking, wheelchair access, accessible toilets and/or hearing loops are available at each facility. Other material provided on the website includes information about mobility parking permits, and various forms of transportation available for disabled people wishing to explore the city (eg free mobility scooters). A downloadable accessibility map includes information about facilities with disabled access within Wellington City, including playgrounds and wheelchair access to the beach – all of which can make it easier for disabled parents to participate in leisure activities with children and other family members.

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[84] http://www.ccc.govt.nz/cityleisure/communityservices/kiwiable/index.aspx
[85] http://www.ccc.govt.nz/cityleisure/communityservices/kiwiable/leisurecard.aspx
[86] Personal correspondence, 4/11/2011

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Sport New Zealand's No Exceptions Strategy
One of the goals of Sport New Zealand's[87] No Exceptions Strategy[88] is that "all people have access to a range of physical recreation and sport opportunities of their own choice in environments that enable full participation. Accessibility includes physical, attitudinal, resources, information and communication".

The Strategy is intended "to guide the strategies and actions of all agencies involved in the provision of physical recreation and sport opportunities for disabled people. It is intended to provide leadership and strategic coordination in the sector". A wide range of organisations have identified the strategies and actions they will commit to implementing. Although specific outcomes for disabled parents are not identified, they are likely to benefit from the strategy's implementation.

Increasing accessibility and affordability
The report of the (USA) Bay Area Parents with Disabilities and Deaf Parents Task force[89] makes a number of recommendations in relation to the provision of more accessible, affordable recreational opportunities that would allow disabled parents and their families to participate together as a family, including:

> > More parent advocacy, training and education about the benefits and opportunities for family recreation (ie playing together)
> > Encouraging existing recreational programmes for disabled children and disabled adults to expand opportunities for the whole family to participate.

The Taskforce notes the need to make public recreation sites such as playgrounds, parks and pools accessible and affordable, describing the cost of many recreational activities (eg tickets) as problematic for low income families. They also note a lack of information about the accessible activities that are available.

Wellington and Christchurch City Councils are committed to facilitating access to recreational opportunities for disabled people. Further exploration would determine the extent to which recreational opportunities for disabled parents, their families and whānau are being developed and promoted in other areas of New Zealand.

Opportunities are also provided by individual organisations. For example, the Deaf Sports Federation of New Zealand (DSFNZ) offers opportunities for Deaf athletes (such as participation in the New Zealand Deaf Games), as well as developing youth initiatives, coaching, and training for officials.[90]

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[87] Previously known as SPARC.
[88] http://www.sportnz.org.nz/Documents/Funding/No_Exceptions_Strategy_June_05.pdf

[89] http://www.lookingglass.org/announcements/67-news/100-report-task-force-on-bay-area-parents-with-disabilities-and-deaf-parents

[90] http://www.deafsports.co.nz/?page=about

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Housing

The physical environment within a home, associated with a lack of suitable equipment, can cause practical difficulties for disabled parents who have identified a need to have funding and support to secure their sections and make their homes child safe.

Saville-Smith et al (2007), in a report prepared for the Centre for Housing Research, Aotearoa New Zealand - Kainga Tipu (CHRANZ), state the impact of inaccessible and inadequate housing is "very personal and profound for disabled people and their families" (p.ii). Although the report primarily focuses on the needs of disabled individuals and the parents of disabled children and young people, several examples of issues for disabled parents are identified. For example, disabled parents being told housing modifications (widening a doorway to a child's bedroom to enable parental access) were not necessary, affecting their ability to care for their children.

The Gravitas (2006) report notes for blind people renting the need to accommodate seeing-eye dogs may limit rental accommodation choices (citing Newbold, 1987) as well as potentially adding further costs, for example, erecting and maintaining fences. Vision impaired parents may also need to have fenced properties so their children can play safely outdoors.

In addition to general housing needs, a need has been identified for refuges to be more accessible to disabled people, particularly disabled women experiencing violence (CCS, 2006).

Greater availability of suitable housing would make a positive difference to the lives of disabled parents and their families. As the New Zealand Disability Strategy points out, although New Zealand has standards for accessibility, houses (and schools, workplaces, supermarkets, banks, movie theatres, marae, churches and so on) are, in the main, still designed and built by non-disabled people for non-disabled users.

CCS Disability Action advocates for application of the Universal Design philosophy, which ensures consideration of the access needs of all users early in the planning process for any alterations, new buildings, or public amenities, including parks.

Universal Design (also known as Lifetime Design) means making safe, accessible homes that people can live in and enjoy regardless of their age, mobility or stage of life. [91] This philosophy recognises that at some time in life, through accident, illness, or old age, everyone will experience (some degree of) impairment.

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[91] http://www.ageconcern.org.nz/my-home/home-choices/lifetime-design

Young Carers

… I have managed very well until now. I don't want to be dependent on my children to do anything for me. [Couch poll respondent.]

I am the oldest of five children who became young carers for my Mum, when the youngest of us was just three. To this day I am mystified no one questioned us about how we were coping, how my mother who was paralysed was being dressed and fed and toileted each day, or for that matter how her young family were being dressed and fed and getting to school each day. [Pania Tulia, former young carer and Young Carers New Zealand Leader][92]

'Young carers' is a term often used to describe children and young people under the age of 18 who provide care, assistance or support to a family member (who may be a parent, sibling, grandparent, or other relative).

Participants at a Young Carers workshop held in Wellington in 2005[93] identified reasons why New Zealand children and young people become young carers, categorised as: cultural expectations (expectations of support from family members, rather than government), nature of disability, awareness and acceptance of services (or lack thereof), and answers relating to the family unit ("*If I don't care for my parent, nobody else will. I need my parents' support, so I have to support them.*" "*No other adults in the family are aware of what is happening or see it as their responsibility.*")

Balancing Parents' and Children's Rights

The rights of disabled parents and the rights of young carers must be balanced. It is important not to minimise the needs and rights of young carers, but to recognise that they can co-exist with the needs and rights of their parents. The SCIE (2007) principles (Appendix D) underpinning "the development of good practice in the support of families affected by parental disability or ill health", include:

> Children's needs are usually best met by supporting their parents to look after them
> Inappropriate tasks and responsibilities undertaken by a child or young person which adversely affect their emotional, physical, educational or social development should be prevented, by providing adequate and appropriate support to the parent(s) and their family.

Johnston et al (2007) also describe a need to balance the rights of the child (to experience "good enough" parenting) and the rights of the parent to care for their children. They note the importance of carrying out an individual assessment of the "unique and particular circumstances" of each family, to ensure appropriate, well-informed decisions are made.

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[92] http://www.carers.net.nz/files/pdf/YCNZFinalReport.pdf
[93] Unpublished paper following Young Carers workshop, Wellington, 2005

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Gaffney (2007) undertook a research project to explore anecdotal concerns about children who take on a significant caring role within their family or household, often because parents have a disability or illness. Gaffney notes that identifying young carers can be a challenge because social service systems are not set up to recognise young carers and children and adults do not acknowledge the situation. Goodhead and McDonald (2007) also point to the difficulties of determining the number of young carers in New Zealand, in part because of a previous lack of recognition of young carers as a separate group – meaning there are no robust statistics available. Gaffney's recommendations include raising the profiles of young carers with social service agencies.

Boyd and Sigglekow (2011) undertook a small-scale study of mental health services in the Nelson Marlborough area of New Zealand to learn about the perspectives and priorities of family members and mental health services staff. They report being told by two staff members that sometimes young children had become the main caregiver to parents with mental illness while the children still required care and support themselves. Staff believed if a family receives earlier support, staff may be less likely to inappropriately view children as the main caregivers of their parents.

The Young Carers section of the Carers New Zealand website identifies links and reports relevant to young carers.[94]

The Need for a "Whole Family Approach"

Gaffney (2007) advises "understanding of the role of young carers requires not only an assessment of the child or young person, but also an understanding of the whole family and the balance of care within before interventions can occur" (p.6). Gaffney suggests when family assessments take place an evaluation is conducted to determine the impact of interventions on young carers. This would enable evaluators to learn about what challenges children face even when the family member with disability or illness is supported.

Frank (2002) also emphasises assessment of family circumstances is essential, taking into consideration both children's and parents' needs, rights, feelings, and perspectives.

> Legislation, guidance and good practice all direct practitioners to consider the needs of the child within the context of the family. A holistic approach is always advocated, meeting the needs of the person who is ill or disabled, recognising family strengths as well as any difficulties or problems and being careful not to undermine parenting skills. (Frank, 2002, p.15)

Frank and McLarnon (2008) have developed Key Principles of Practice[95] for practitioners supporting young carers, parents, and their families in the United Kingdom, complemented by the Whole Family Pathway resource.[96] The principles are intended to

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[94]   http://www.carers.net.nz/carer_community/young_carers_nz

[95]

   http://www.nzfamilies.org.nz/sites/default/files/Key%20Principles%20of%20Practice%20with%20
cover.pdf

[96]   http://www.nzfamilies.org.nz/sites/default/files/Whole%20Family%20Pathway.pdf

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be used alongside existing legislation and guidance. Each principle outlined has associated standards, performance indicators and outcomes.

1. Children's welfare should be promoted and safeguarded by working towards the prevention of any child undertaking inappropriate levels of care and responsibility for any family member.
2. The key to change is the development of a whole family approach and for all agencies to work together, including children's and adults' services, to offer co-ordinated assessments and services to the child and the whole family.
3. Young carers and their families are the experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.
4. Young carers will have the same access to education and career choices as their peers.
5. It is essential to continue to raise awareness of young carers and to support and influence change effectively. Work with young carers and their families must be monitored and evaluated regularly.
6. Local young carers projects or other targeted services should be available to provide safe, quality support to those children who continue to be affected by any caring role within their family.

The emphasis is on ensuring the best use of resources to deliver support to the whole family, including supporting disabled parents' entitlements to assessments and services, and consideration of parenting support needs. Citing Morris (2003) the resource emphasises the positive influence of early support, delivered in a non-judgemental and empowering way, on a disabled parent's ability to look after their child/ren.

Previously Morris (1997) challenged the notion of 'care' and its allusions to burden and dependency, as well as the 'young carers' terminology. She argued people needing support in their daily lives had been constructed as 'dependent people', with their voices overlooked. She expressed concern the focus on young carers had been based on prejudicial assumptions about disabled parents, and "a failure to tackle the real problem – which is that many disabled parents are not getting the assistance to which they are entitled" (p. 55).

There is still much to be learned about the circumstances and needs of young carers. A 2005 report[97] focusing on the needs of young carers in the USA suggests research, practice and policy questions deserving exploration. These include questions which are also applicable to young carers in New Zealand.

> What is the best way to distinguish child caregiving from the ordinary chores that children in most families are expected to perform?
> Are there some caregiving tasks or levels of responsibilities that are inappropriate for children?
> What are the special needs of child caregivers in households where they act as interpreters for care recipients in their dealings with the health care system?

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[97] http://www.caregiving.org/data/youngcaregivers.pdf

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> What are the special needs of child caregivers when the care recipient has a mental illness or is addicted to drugs or alcohol?
> How can teachers and schools recognise children who need assistance and provide referrals without violating parental rights?
> As child caregivers age beyond adolescence, how can educational, social and career opportunities be encouraged in the context of caregiving?

The report concludes by noting more information is needed to understand which characteristics of children, their families, and their environment potentially lead to problems and which support a positive outcome. Olsen and Wates (2003) suggest future research agendas should encompass exploration of effective methods of preventing children's involvement in inappropriate roles, and a focus on "emerging practice and service provision for disabled parents with greater attention to the implications for choice and independence in the way in which assistance is provided" (p.29). Gaffney (2007) recommends case study research including children, parents and whānau and agencies be undertaken in New Zealand to provide a more complete picture of family life where young carers are involved – including exploration of the outcomes for young carers as they make the transition to adulthood.

The New Zealand Carers' Strategy

"My daughter and husband both have psychological and mental problems, as the carer I can get very stressed at times. It would be nice to be able to access some holiday time away to recharge my own batteries – but money is the problem."
(Couch poll respondent)

Disabled parents, as well as those supporting disabled parents (including family and whānau) may need support to fulfil their roles as carers. The New Zealand Carers' Strategy and Five-year Action Plan[98] was published in 2008 to begin addressing some of the issues that impact the lives of people who assist friends and family members needing help with everyday living because of ill health, disability or old age. The Strategy was developed in a partnership between government agencies and the New Zealand Carers Alliance.

The Strategy provides a framework of principles to guide policy development and the delivery of services by government agencies and non-government organisations (NGOs) that work with carers.

> **Recognise diversity**: acknowledge and respond to the diversity of needs and aspirations of carers
> **Be proactive:** enable family focused support to be in place for carers when they need it
> **Enable carers**: enable carers to have choices and the autonomy to develop, grow and sustain their personal, family and community support systems; and ensure formal supports are reliable and are able to provide real support to carers

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[98] http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/

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> **Be inclusive**: acknowledge the needs of carers, family, whānau, or aiga and the person being supported are often intertwined.

The Government is developing a monitoring framework to measure the progress of the Strategy and Five-year Action Plan. Monitoring, research and evaluation will keep carers and other stakeholders informed about how well the Strategy is doing. Links to the Strategy and related documents are shown in Appendix E.

Conclusions

This overview of the support needs of disabled parents, and the barriers and challenges they may face accessing support for themselves and for their families and whānau, has also described parents' strengths and resiliencies. Opportunities for improvement have been identified and we have outlined the reasons why more consideration should be given to the support needs of disabled parents in New Zealand, to benefit both parents and children.

Although more national and international research is emerging, there remains a shortage of information about the experiences of disabled parents in New Zealand. The experiences of disabled parents – fathers as well as mothers, and across ethnic groups – need to be better documented, and knowledge about factors contributing to positive outcomes for disabled parents, their families and whānau shared across sectors.

Parenthood is a realistic expectation for many disabled adults. The transition to parenthood can be eased by the provision of appropriate support and information pre-parenthood, during pregnancy, labour and delivery, and the postnatal period. Support providers and others who work with and for disabled parents - particularly those in the health, family services, and education sectors – will benefit from regular professional development to ensure they are well-informed about existing and emerging best practices.

Parents can play a role in educating people about their impairments by using contact with professionals as an opportunity to increase their knowledge. Such education will help to challenge assumptions – and misperceptions – about disabled parenthood, and in turn lead to the reduction of attitudinal barriers. Structural barriers in the home and wider environments (such as schools and communities) also need to be dealt with. Involving disabled parents in service development, monitoring and evaluation can help to identify and address both attitudinal and structural barriers.

Needs for support may fluctuate, and not all disabled parents will need, seek or welcome support. For those parents who do, this should be offered proactively, rather than waiting until the child of a disabled parent is identified as being 'at risk', or when a crisis occurs within the family.

In addition to the needs of the disabled parent, the needs of the whole family and whānau must be taken into account, including those of children and young people. Their needs should be considered alongside parental strengths, capacities and resources; for children's needs to be met, any support their parents need must also be in place. Some children and young people have significant caring responsibilities and their rights, needs

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and perspectives should be recognised. Partners, too, must have their needs considered.

National and international literature outlining the experiences and expectations of disabled parents supports our belief families and whānau will do best when surrounded by supportive, well-connected communities. Individual, family, and whānau values, practices and beliefs should be respected, acknowledging experiences and perspectives of disability are influenced by culture and ethnicity. Recognising parental strengths and resiliencies, valuing family and whānau diversity, and allowing parents to identify their changing needs and priorities, will contribute to positive outcomes for disabled parents, their families and whānau.

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Appendix A: Conceptual Approaches to Disability

The World Health Organisation (2002) summarises the medical and social models of disability:

> The *medical model* views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to 'correct' the problem with the individual.

> The *social model* of disability…sees disability as a socially created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment.

The WHO/World Bank "World Report on Disability" (2011) suggests although the medical model and the social model are often presented separately, disability should not be seen as purely medical nor as purely social, with a balanced approach needed. For example, the report notes disabled people frequently have problems stemming from a health condition. Similarly, an earlier WHO report (2004) notes disability is an interaction between individual characteristics and features of the overall context in which a person lives, with both medical and social responses appropriate to the challenges associated with disability.

An alternative model proposed within the WHO (2002) ICF[100] framework is the the *biopsychosocial model.* This model incorporates elements of both the medical and the social model to broaden the perspective of disability and allows medical, individual, social, and environmental influences on functioning and disability to be taken into account.

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[100] ICF = International Classification of Functioning, Disability and Health

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Appendix B: (United Nations) Convention on the Rights of Persons with Disabilities

(United Nations) Convention on the Rights of Persons with Disabilities
http://www.un.org/disabilities/convention/conventionfull.shtml

The Office for Disability Issues reports that New Zealand ratified the Convention on 26 September 2008 and is progressively implementing its obligations. The Government has established a framework to promote, protect and monitor implementation of the Convention, which involves participants within government and independent of government.

Extract from the Convention on the Rights of Persons with Disabilities[101]
Article 23 - Respect for home and the family

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure :
The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

Persons with disabilities, including children, retain their fertility on an equal basis with others. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

States Parties shall ensure a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

States Parties shall, where the immediate family is unable to care for a child with

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[101]   http://www.un.org/disabilities/convention/

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disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Appendix C: Disabled Adults with Parenting Responsibilities: A Checklist for Good Practice

Source: Olsen, R. and Wates, M. (2003) Disabled parents – examining research assumptions. Research in Practice www.rip.org.uk
http://lx.iriss.org.uk/sites/default/files/resources/disabled%20parents.pdf

Olsen and Wates suggest local authorities and other relevant agencies may find this checklist useful as a basis for enquiring into existing practices in their own area. The list is intended to prompt reflection across a range of agencies and services. Although it includes references to British legislation, many of the questions raised would also be applicable to New Zealand agencies.

1. Are disabled adults (including parents with physical and sensory impairments, Deaf parents, parents with learning difficulties, those who are users of mental health system and those with drugs and alcohol issues) recognised as service users with support needs in relation to parenting?

2. Is there clear agreement about how Community Care legislation, in combination with children's legislation where appropriate, is to be used to support disabled parents and families?

3. Where policies/protocols/procedures exist, are they in use and are all staff and relevant bodies aware of what they say?

4. Are parenting tasks and responsibilities included in eligibility criteria and covered in assessment procedures for adult services and benefits?

5. Is the meeting of needs associated with parenting responsibilities regarded as a priority for access to assessment and service allocation?

6. Are mechanisms in place that ensure timely and effective cross-referencing between different agencies and across organisational divisions to ensure disabled adults with parenting responsibilities are effectively keyed in to mainstream and specialist supports?

7. Do support systems have the flexibility and responsiveness to respond quickly and appropriately to changing family needs?

8. Do policies and protocols ensure no disabled parents should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks?

9. Do policies and protocols make it clear the children of disabled parents are not automatically regarded as vulnerable?

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10. Can disabled adults access the parenting support they need without their children first having to be 'children in need' or 'young carers'?

11. In cases where there are child protection concerns, how is the ongoing involvement of both children's and adult specialist workers guaranteed and co-ordinated?

12. Do all parents have access to advocacy services?

13. Are cases in which child protection measures are taken, monitored to make sure this is the most appropriate response?

14. Does the local authority record how many children whose parents are disabled are in long-term foster care, or in line for adoption?

15. Do agencies have procedures and staff appointed to support the development of joint working and inter-agency training across relevant statutory agencies and voluntary bodies?

16. Are clear arrangements in place across divisions of social services departments and between agencies for pooling budgets and sharing costs, where appropriate?

17. Might charging policies for parenting tasks be waived in line with a preventative approach to family support, regardless of which budget the support is funded from?

18. Are direct payments promoted to meet parenting support needs? Since this is possible both under Community Care legislation and under the Children Act 1989, are there arrangements for joint direct payments packages (which might also include health services) to be made where appropriate?

19. How many parents are receiving direct payments to assist them in their parenting role?

20. Are disabled parents consulted on their access to, and experience of, services intended to support them in their parenting role?

21. Is service information provided to disabled parents that explains what services they are entitled to and how to go about getting hold of them?

22. Is any service user information provided to disabled parents appropriate and accessible to parents from minority ethnic communities, parents with learning difficulties and Deaf parents, as well as to disabled parents generally?

23. Do agencies regularly monitor their practice, procedures and communication with disabled parents, to determine whether these are consistent with their supportive intentions?

24. Do disabled parents have full access to (including access to information about) local maternity services, primary health care, parent education and

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family facilities, including shops, sports, leisure, playgrounds, playgroups, schools etc.?

25. Do disabled parents have full access to (including access to information about) supports and volunteering opportunities for parents and families in the voluntary sector?

26. Are disabled parents' perceptions of services and agencies evaluated?

27. What steps have been taken to allay disabled parents' fears in relation to approaching service providers and to ensure services are welcoming?

28. Are disabled parents involved in the development, monitoring and evaluation of services?

Appendix D: Principles of Good Practice – Supporting Families Affected by Parental Disability or Ill Health

Source: Morris, J. and Wates, M. (2007) Working together to support disabled Parents – Adults' Services Resource Guide 9, page 9. London: Social Care Institute for Excellence

The following principles underpin the development of good practice in the support of families affected by parental disability or ill health:

> Local authorities and all other agencies working or in contact with children have a responsibility to safeguard and promote children's welfare.
> Children's needs are usually best met by supporting their parents to look after them.
> Professionals should respect and support the private and family lives of parents who have additional support needs associated with physical and/or sensory impairment, learning disabilities, mental health problems, long-term illness or drug and/or alcohol problems.
> Support needs should be addressed by enabling parents to access universal and community services wherever possible and appropriate.
> Additional support needs should be met by the timely provision of specialist assessments and services.
> Agency responses should be needs-led, aim to support family and private life and prevent unnecessary problems from arising.
> Agency responses should address the needs of parents and children in the context of the whole family and not as individuals in isolation from one another.
> Inappropriate tasks and responsibilities undertaken by a child or young person which adversely affect their emotional, physical, educational or social development should be prevented by providing adequate and appropriate support to the parent(s) and their family.
> Diversity should be valued and fully considered in agency responses.

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Appendix E: Resources/Links

This list identifies a range of disability-related resources and websites; it is not intended to be comprehensive.

New Zealand

ACC Support for Disabled Parents

ACC can provide support to people who need help because of an injury. The help provided will depend on the individual's needs. If the client is a parent who is having difficulty as a result of their injury, ACC may be able to provide childcare, equipment and/or home help.

How the process works:
> The client must have a claim accepted by ACC
> The client contacts ACC to request support
> ACC staff receive this request and arrange for the client to be assessed
> The assessor works with the client to find out about their injury-related support needs. The assessment may look at a number of areas of the client's life, for example, their ability to look after themselves and their family and their ability to go to work.
> The client and the assessor talk about different ways to meet the identified injury-related needs
> The assessor reports back to ACC
> ACC staff use the information from the assessment to provide appropriate support to the client.

http://www.acc.co.nz
ACC claims helpline on 0800 101 996.

Attitude Pictures Ltd

Attitude Pictures Ltd is an Auckland-based documentary and television programme maker; their catalogue includes a wide range of content relating to disability, including 280 episodes of their specialised disability series.

Their team has a strong relationship with Special Olympics (worldwide) and Paralympics New Zealand and the staff includes people who live with disability.
http://www.attitudepictures.com/attitude-tv/

Attitude's Facebook page: http://www.facebook.com/pages/Attitude-TV/61281423185

Carers New Zealand

Carers New Zealand provides information, advice and resources for carers and their families and whānau. Their Resource Library includes articles, fact sheets, Emergency Planning Tools, and research.
http://www.carers.net.nz/home

Young Carers NZ is a special interest group for children and young people who help to support ill, elderly, and disabled friends and family members, including people who have an addiction.
http://www.carers.net.nz/carer_community/young_carers_nz

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CCS
The CCS Disability Action Library and Information Service provides access to articles, books, magazines and DVDs on disability-related topics, including parenting with a disability. Anyone can borrow from the library and loans are free of charge.
http://www.ccsdisabilityaction.org.nz/

Disability Clothesline Project
The Disability Clothesline project is run by DCAV, the Disability Coalition against Violence. "The Project is a way of breaking the silence about domestic and all forms of violence and abuse experienced by disabled people, enabling victims to give creative expression to their experiences as they use clothing as a canvas."

Disabled people experience abuse and violence at extremely high levels, but this is in effect invisible because it is not acknowledged. "The Disability Clothesline Project gathers stories and experiences to 'bring the invisible into the light'.
http://www.disabilityclothesline.org.nz/

Diversity Works
Diversityworks Trust was incorporated in 2005 with the following exclusively charitable purposes in New Zealand:

> The advancement of social and community welfare including the support of disabled people and other disenfranchised groups and individuals, together with their families and dependants, and the promotion of their value, inclusion and participation within the community;
> The establishment of community based projects promoting community development to enhance social and economic participation, with an emphasis on artistic and creative processes;
> The advancement of culture and heritage, including the promotion and fostering of the New Zealand heritage, and the practice and development of Tikanga Māori and Te Reo Māori.

http://www.diversityworks.org.nz

Diversityworks Peer Support Network
Diversityworks Peer Support Network aims to develop a flexible, multi-faceted and sustainable network for disabled people, young people, whānau/families and others who could benefit from peer support.

The network is an informal collective of people committed to shared support and learning in a social environment. It provides a means for people to share, discuss and celebrate unusual, challenging or difficult situations. It aims to create bonds and bridges between people with unique and common experiences, with a focus on building healthy relationships and good communication.

Peers are diverse and from a wide range of backgrounds. They join to get support about unique function or disability, unique mental experience or mental distress, sexual diversity, being young, parenting, learning new skills, being creative, making changes in their lives or finding new friendships and connections.

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To keep people in touch with each other, the network uses a mix of online chats, social networking, Skype, phone and face-to-face gatherings.
www.dpsn.net.nz

'Domestic Violence and Disabled People' - a resource booklet produced for the 'It's not OK' campaign. It identifies barriers for disabled people that may make it difficult to talk about abuse, including:

> fear of losing a caregiver
> fear of being institutionalised
> being unable to communicate without help or technological aids
> being unable to access support in mainstream ways
> social isolation
> lack of access to transport

The resource identifies ways in which disabled people can increase their safety and how and where to get help.
http://www.areyouok.org.nz/files/disability-booklet-newest.pdf

Families Commission
The Families Commission provides a voice for New Zealand families and whānau. The Commission speaks out for all families to promote a better understanding of family issues and needs among government agencies and the wider community. A number of reports published by the Commission have focused on families with members living with disability.
http://www.nzfamilies.org.nz/

Health and Disability Commissioner
The Health and Disability Commissioner is an independent agency set up to:
> promote and protect the rights of consumers who use health and disability services
> help resolve problems between consumers and providers of health and disability services.
http://www.hdc.org.nz/

Human Rights Commission
The Commission works for a fair, safe and just society, where diversity is valued and human rights are respected.
http://www.hrc.co.nz/

Reports and resources focusing on disability, and links to disability news and issues:
http://www.hrc.co.nz/disabled-people

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IHC

IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. IHC advocates for the rights of people with an intellectual disability and is committed to including everyone with intellectual disability in their local communities. The IHC library shares information (books, DVDs and other resources) with families, people with intellectual disability, educators and others.
http://www.ihc.org.nz/resources/our-library/

Inclusive Communities: Guidelines about Disability for Councils and District Health Boards (2004) DPA (NZ) and New Zealand CCS

This resource is "a tool for producing more effective regional relationships between disabled people and their families/whānau and Councils and DHBs. It describes the collective views and aspirations of disabled people and their families/whānau throughout New Zealand". It was created by the Disabled Persons Assembly of New Zealand (DPA) as a partnership initiative with New Zealand CCS.
http://www.dpa.org.nz/downloads/inclusive_communities_2004-09.pdf

KITES

Kites helps families to develop plans for children whose parents experience mental illness and become unwell. Additional resources can also be found on the Kites website.

http://www.kites.org.nz/kites/pdf/kites-kids-plan-v3.pdf

'Me' Relationship Resources

'Me' educational resources were developed in New Zealand for people with intellectual and learning disabilities, from adolescence to adulthood. The resources were designed to be easy to use and were developed "to teach people with learning difficulties to master basic skills essential for having safe relationships." The range of topics covered in the 'Me' CD Rom includes: understanding boundaries, dating, breaking up, and how to ask for help when inappropriate things (such as bullying and other forms of abuse) are happening.
http://www.menow.co.nz/

Mental Health Foundation of New Zealand

The foundation provides free information and training, and advocates for policies and services that support people with experience of mental illness, and also their families/whānau and friends. The website has links to reports and resources for parents with experience of mental illness.
http://www.mentalhealth.org.nz

Ministry of Health

The Ministry of Health is the Government's principal advisor on health and disability.

> **Disability services overview** including information about Needs Assessment and Service Coordination services, Equipment and Modification Services, and Respite Services and Carer Support.
http://www.health.govt.nz/yourhealth-topics/disability-services

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> Video Stories
  The videos feature stories about living with a disability and the difference getting support can make. Several of the videos feature disabled parents.
  http://www.health.govt.nz/yourhealth-topics/disability-services/video-stories

New Zealand Carers' Strategy and Five-year Action Plan
The New Zealand Carers' Strategy and Five-year Action Plan (2008) address some of the issues affecting the many New Zealanders who assist friends and family members that need help with everyday living because of ill health, disability or old age.

The Government has committed to:

> monitoring the progress of the implementation of the Strategy
> readjusting the Strategy's objectives to adapt to changing circumstances
> being accountable to carers and their families for delivering what the Strategy says it will deliver in the Five-year Action Plan

There are actions to achieve the following objectives:

> Provide information
> Protect the health and wellbeing of carers
> Enable carers to take a break
> Provide financial support for carers
> Provide training and pathways to employment for carers.

http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/

The associated resource *A Guide for Carers - He Aratohu mā ngā Kaitiaki* outlines financial and other forms of support available to carers.
http://www.msd.govt.nz/documents/what-we-can-do/community/carers/carers-brochure-english.pdf

New Zealand Disability Support Network
The New Zealand Disability Support Network is an association of disability support service providers.

http://www.nzdsn.org.nz/

New Zealand Family Violence Clearinghouse
The New Zealand Family Violence Clearinghouse (NZFVC) is the national centre for collating and disseminating information about domestic and family violence in Aotearoa New Zealand. It provides information and resources for people working towards the elimination of family violence, including disability-related material.

The NZFVC is based at the School of Population Health, The University of Auckland.
http://www.nzfvc.org.nz/

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New Zealand Federation of Disability Information Centres
The Federation nationally promotes and supports the local provision of generic disability information and referral services. Federation members provide information relevant to their own communities.
http://www.nzfdic.org.nz/

Pacific Disability Forum
A partnership of Pacific organisations of and for people with disabilities; it includes New Zealand members as well as members from other Pacific nations. It was established in 2002 and promotes and facilitates Pacific regional cooperation on disability-related concerns. http://www.pacificdisability.org/default.aspx

People First New Zealand
People First New Zealand is a self-advocacy organisation run by and for people with learning/intellectual disability. People First New Zealand is part of an international self-advocacy movement.
http://www.peoplefirst.org.nz

SKIP (Strategies with Kids, Information for Parents)
SKIP supports parents to raise their children in a positive way. It does this through a nationwide network of individuals, community groups, government agencies, workplaces and national NGOs. SKIP is administered by a small team in the Ministry of Social Development, who support the development of positive parenting initiatives.

SKIP resources have been developed to help parents manage difficult times, such as tantrums and sibling rivalry, as well as how to be a positive parent.

The Royal New Zealand Foundation of The Blind and SKIP have partnered together to produce a small selection of SKIP booklets in accessible formats, including DAISY audio, e-text and Braille.

The booklets available in accessible formats include:

> Ages & stages
> Tantrums
> Supermarket survival
> Temperament
> Kids and safety
> Jealousy and fighting
> Managing behaviour
> Tips on stress
> Children with special needs
> Kids and car seat safety
> Helping each other after the Earthquake

http://www.rnzfb.org.nz/members/useful-resources/skip-programme-in-accessible-formats

A positive parenting resource has also been developed for Deaf parents. The *Parenting – It's in Our Hands* DVD and booklet are the result of a collaboration between SKIP and Cambridge-based filmmakers Stretch Productions.

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http://www.skip.org.nz/news-and-events/news/2012/its-in-our-hands.html

http://www.skip.org.nz/

Statistics New Zealand
Statistics New Zealand collect, compile, analyse and communicate information on a wide range of topics, including disability. Statistics about New Zealanders with disabilities are available from 1996, 2001, and 2006 surveys. These surveys collected information on the prevalence, nature, duration, and cause of disability, as well as on the barriers people with disability encounter in everyday life. The next Disability Survey will take place in 2013.

http://www.stats.govt.nz/browse_for_stats/health/disabilities.aspx#latest

WEKA
The WEKA website provides disability information for disabled people, their families, whānau and caregivers, health professionals and disability information providers. It includes information about equipment, education, support, transport, housing, travel and self-advocacy.
www.weka.net.nz

Selected International Resources

Australian Institute of Family Studies
Parents with disabilities bibliography
http://www.aifs.gov.au/cfca/topics/subtopics/disabilityparent.php

Disabled Parents Network, United Kingdom
A national organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters. Links to publications and reports:
http://disabledparentsnetwork.org.uk/publications/
http://disabledparentsnetwork.org.uk/reports-guidance/

Disability, Pregnancy & Parenthood international (DPPi)
A UK based registered charity, promoting better awareness and support for disabled people considering parenthood, during pregnancy, and as parents. Their website and online journal provide information on a broad range of topics. In October 2010 they held a conference that provided an opportunity for delegates to discuss what empowers disabled parents to make choices about pregnancy, childbirth and caring for their new baby.[102]
http://www.dppi.org.uk/

Healthy Start (Australia)
Healthy Start is a national capacity building strategy which aims to improve health and wellbeing outcomes for children whose parents have learning difficulties. Healthy Start works with practitioners, managers, researchers, and policy makers to access and

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[102]   http://www.dppi.org.uk/projects/conference2010.php

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exchange knowledge, information, resources and expertise about how best to support parents with learning difficulties and their children.
http://www.healthystart.net.au/

Inclusion International
Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide.
http://www.inclusion-international.org/about-us/who-we-are/

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