



'It shouldn't
be this hard':
children, poverty
and disability

A Child Poverty Action Group Monograph

Donna Wynd

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'It shouldn't be this hard': children, poverty and disability

ISBN: **978-0-9941105-8-9**

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List of abbreviations

CDA	Child Disability Allowance
DCA	Disability Community of Auckland
MSD	Ministry of Social Development
MOH	Ministry of Health
NZCYES	New Zealand Child and Youth Epidemiology Service
ORS	Ongoing resourcing scheme
SENCO	Special Education Needs Coordinators
WHO	World Health Organisation

Acknowledgements

This report is the result of a great deal of effort by a number of people. As ever, I'd also like to thank my other CPAG colleagues for their feedback and comments. Special thanks are due to Jill Gilbert and Janine Thompson for their invaluable feedback on an early draft of this report. Any remaining errors are my own.

CPAG gratefully acknowledges the funding assistance from the Charles Rupert Stead Trust and a bequest from the estate of Neil and Jean Smith.

I would like to extend a huge thank you to all the parents, advocates, those working within the sector and others who so generously gave of their time to be interviewed. This report would not have been possible without you.

A single report cannot possibly hope to solve all the problems faced by disabled children living in hardship; however I hope it highlights some of the key issues they face, and opens the way for future discussions.

Executive summary

Disability is something many of our policies and institutions do not address well. New Zealand has come a long way from the days when many of those with physical and intellectual impairments were housed in institutions out of public view. However, disabled persons still face discrimination in education, health, housing, employment and access to social services.

Internationally, New Zealand is regarded as a leader in disability, and the 2001 Disability Strategy aims for New Zealand to be “a fully inclusive society that continually enhances [disabled person's] full participation”. The government also has an obligation under the Treaty of Waitangi to promote the interests of Māori children who are disproportionately affected by both poverty and disability. Despite these obligations, disabled children are more likely to live in poverty, and barriers to disabled children's inclusion and full participation remain.

Disabled children are at greater risk of living in low-income households.¹ The 2013 *Disability Survey*² shows that of the 95,000 disabled children aged 0-14 years,³ 15% lived in households with incomes under \$30,000. This compares with 10% of 0-14 year olds in all households. Ministry of Social Development data shows that in 2012 (the last year for which data is available) over 13,500 children receiving a Child Disability Allowance lived in households supported by a main income support benefit other than a Veteran's Pension or New Zealand Superannuation. This suggests that around 14% of disabled children live in benefit-dependent households.

Although the *Disability Strategy* has the stated objective of "involving disabled children and youth in decision-making and giving them greater control over their lives," disabled children are often invisible in discussions about policies that affect them. They barely rated a mention throughout the major welfare reforms that have been implemented since 2010. At the local government level, decisions about the provision of services including public transport are commonly made with minimal regard to disabled children's needs. This invisibility means the rights and interests of disabled children and their caregivers are often overlooked.

Advocates for the disabled cite the lack of data pertaining to disabled children as a key issue for them because the lack of baseline information makes it difficult to advocate for better policies and services. Such data as there is (for example census data) is aggregated and provides no geographic or socioeconomic detail for disabled children. The United Nations Committee on Economic, Social and Cultural Rights has recommended that the New Zealand Government "collect data to monitor the enjoyment of economic, social and cultural rights by persons with disabilities and provide information and statistical data in this respect in the next periodic report." The lack of data also makes it difficult to assess whether financial and other support is going to those with the greatest need, and means it is more difficult for the sector and advocates to hold agencies accountable for service delivery.

Other key issues for disabled children are poverty (especially when parents are on benefits for long periods of time because of their own or a child's disability), and inconsistent and fragmented service provision. Parents interviewed for this report especially noted the lack of flexibility and support from Work and Income, difficulty getting financial support for their children's learning, and the lack of integration between service providers. The Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities notes that the right of the disabled child to receive an education at a state school is not legally enforceable, and that "education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission."

The inconsistent support for disabled children is evidenced by the dramatic decrease in the number of Child Disability Allowances (CDA) granted by Work and Income since 2008. The CDA is a non-income-tested allowance available to parents to help compensate for the time and expense of caring for a disabled child. In 2008 about 11,000 CDAs were granted. This had fallen to 6,500 in 2013, during which time the number of disabled children increased from 92,000 in 2001 to 95,000 in 2013. The Office of the Children's Commissioner has noted that: "There is particular concern about the potential low take-up and the level and operation of the Child Disability Allowance amongst poorer families," and recommended "that the government commission research to clarify: how many children are

1 All relevant references are in the main body of the report.

2 The 2013 Disability Survey collected details on 23,000 disabled and non-disabled children and adults living in private households as well as 1,000 adults living in residential care facilities.

3 For children aged 0-14 years, an adult (parent, guardian, or caregiver) answered the survey questions on behalf of the selected child.

living with a disability or are being cared for by a parent with a disability; how many of those children are living in poverty; and what the effects of poverty are on these children.”

It is clear from the interviews that for parents, greater access to carer support, and an individualised programme that wrap around the child and family, along with specialist support if required, would be of the greatest help to them. For caregivers, acknowledgement of the difficult work they do would also be welcome. One caregiver summed it up thus:⁴

It makes you want to shake politicians and tell them that the real heroes in this country are the parents who have daily struggles to get their children up, fed, clothed, accepted at school, resourced, included in their community (all of it) and then do all the other things expected of them - work, home family, be a daughter, sister, wife, [and] mother to all their children.

CPAG would like to acknowledge the parents and advocates spoken to for this project. Many of the interviews took a considerable amount of time, and parents were not only generous with their time but in most instances invited follow-up questions should they be necessary. The overwhelming desire of parents to do the best for their children shone through the interviews despite what, in some cases, were trying circumstances. It was a privilege to be invited into people’s homes to hear their stories, and I hope this report does them justice.

Recommendations

- That the government collect and disseminate better quality, disaggregated, publicly available data on the number, location and socioeconomic and other (including cultural) status of disabled children, their educational and health outcomes, and indicators to assess whether their outcomes are improving over time.
- That the government acknowledge the role of Special Education Needs Coordinators in schools and accordingly fund a staffing entitlement directly through school budgets.
- That the funding and allocation of services for disabled children be reviewed in partnership with the disability sector to identify shortfalls and find ways to improve service delivery in ways that are child-focused.
- That the Office of Disability Issues or other appropriate body investigate ways to ensure that government agencies and staff recognise and take account of the ongoing needs of disabled children and their families when engaging with them.
- That eligibility criteria for the Supported Living Payment be revised for parents with disabled children, or that some other provision be made so that the needs of their children prevail over parents’ job-seeking and work preparation obligations unless parents request otherwise.

⁴ Colleen Brown, pers comm, August 2014.

- That the Ministry of Social Development:
 - Investigates why there has been a sharp reduction in the number of Child Disability Allowance (CDAs) granted;
 - analyses census data to ascertain if there is a socioeconomic, geographical or ethnic variance in respect of the number and proportions of CDAs granted and declined;
 - works with the sector to assess the role of Regional Health Advisors and determine whether they are overriding medical professionals' advice;
 - works with the sector to identify barriers to the granting of CDA where eligibility criteria appear to be met, and considers strategies to minimise these;
 - undertakes a similar process with respect to the Disability Allowance.
- That an individualised funding model be further investigated to provide, where appropriate, tailored programmes and services, including housing, to disabled children and their families. One model that could be trialled is a key worker and advocate for families.
- That an independent fully-funded Commissioner and advocacy service for disabled persons, children and their parents be established that would work with the sector and help parents to deal with state and other agencies, and provide support and advice for families.

Introduction

Disability is something many of our policies and institutions do not address well. New Zealand has come a long way from the days when many of those with physical and intellectual impairments were housed in institutions out of public view. However, social progress has been much slower, with disabled persons facing discrimination in education, health, housing, employment and access to social services (Expert Advisory Group on Solutions to Child Poverty, 2012b, p. 8).⁵

New Zealand is regarded internationally as being a leader in disability issues. The New Zealand Disability Strategy (Ministry of Health, 2001) (*Disability Strategy*) was published in 2001, and New Zealand was active in drafting the United Nations Convention on the Rights of Persons with Disabilities (*Disability Convention*) which it signed in 2007 and ratified in 2008. In recognition of this Governor-General Sir Anand Satyanand was awarded the Franklin D. Roosevelt Disability Award on behalf of his country in 2008.

With regard to the rights of children, Article 7 of the UN convention states:

Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children and that in all actions concerning disabled children, the best interest of the child shall be a primary consideration.

⁵ I acknowledge the extensive academic debate on the respective meanings of 'impairment' and 'disability'. The 2001 New Zealand Disability Strategy describes the social model of disability: "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" (Ministry of Health, 2001, p. 1). This report will mostly use the generic term 'disability'.

Similarly, the UN Convention on the Rights of the Child (Article 23) also enshrines the rights of disabled children:

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

These international obligations have been captured in the *Disability Strategy*, which aims for New Zealand to be “a fully inclusive society [that] continually enhances our full participation (Ministry of Health, 2001, p. 1).” However, while New Zealand’s credentials appear sound, the Disability Convention Independent Monitoring Mechanism’s 2014 Report outlined serious concerns with respect to New Zealand’s implementation of the *Disability Convention*. These included the lack of an enforceable right to education for students, housing affordability and accessibility (especially in Canterbury), and social exclusion and poverty particularly among disabled Māori and Pacific children (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014).

This project began as an investigation into the significant decline in the number of Child Disability Allowances (CDA) granted annually by Work and Income. The number of new or updated CDAs granted has almost halved since 2008 yet the number of disabled children has increased, from 92,000 in 2001 to 95,000 in 2013 (Statistics New Zealand, 2014, p. 3).⁶ It became clear there was no single explanation for this decline although administrative changes to the CDA that commenced in 2007 are clearly having a major impact.

It also became clear that CPAG would be unable to analyse the factors associated with the decline in the number of CDAs granted due to a lack of sufficiently disaggregated data. This lack of data on the number, whereabouts and socioeconomic and other status of disabled children is a major issue as the CDA is potentially an important component of income support for disabled children in poverty. In conversations with caregivers, it was also clear that the lack of financial support available through Work and Income was but one of a number of issues they face. Despite our good intentions New Zealand’s implementation of the *Disability Convention* is neither comprehensive nor well resourced.

A comprehensive review and identification of services and support for disabled children in New Zealand is beyond the scope of this report. The first part of this report reviews what data is available about disabled children and the services provided for them. It then moves to the results of interviews with parents. These highlight parents’ perspectives of raising a disabled child. A key recommendation is that support for disabled children across all sectors needs to be assessed to identify shortfalls and find ways to improve service delivery in ways that are child-focused. While CPAG has made some recommendations it stresses that changes must be done in consultation with those in the sector familiar with the issues.

The title for this report comes from a comment that is often made by parents of disabled children when describing their experiences. Whether negotiating with government agencies, or applying for education funding, or trying to get support from Work and Income, the process is often slow and difficult. Not surprisingly, parents often feel aggrieved that the needs of their children are so easily overlooked.

⁶ Statistics New Zealand uses 2001 as the comparator year. They note that the 2006 data is significantly different from that of other surveys, although it is not clear why this is the case. See http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey2006_HOTP06/Technical%20Notes.aspx.

CPAG would like to acknowledge the parents and advocates spoken to for this project. Many of the interviews took a considerable amount of time, and parents were not only generous with their time but in most instances invited follow-up questions should they be necessary.

While researchers often feign emotional distance from their interview subjects, this proved impossible for this project. The experiences of parents and their overwhelming desire to do the best for their children made it difficult to be a neutral observer. Instead, I hope I have accurately reflected the experiences and concerns of parents, some of whom were living in very trying circumstances. It was a privilege to be invited into people's homes to hear their stories, and I hope this report does them justice.

The invisible disabled child

There has been little research available on disabled children, in large part because of the paucity of relevant data. It is hoped this project will make disabled children less invisible to policymakers, and encourage debate around how to better support disabled children and coordinate the services they use.

The *Disability Strategy* has the stated objective of “involving disabled children and youth in decision-making and giving them greater control over their lives” (Ministry of Health, 2001, p. 27). In reality disabled children are often invisible in the design of policies that affect them. They barely rated a mention throughout the major welfare reforms that have been implemented since 2010. At the local government level, decisions about the provision of services including public transport are commonly made with minimal regard to disabled children's needs.

It is possible that some children do not get the help they need because they are not identified as disabled, or their parents may not want to acknowledge the disability. While disability should be identified before school, parents and pre-school providers may not have the training or experience to identify a problem. Moreover, their parents may be unaware of the need for those services (Porterfield & McBride, 2007), or may not wish to acknowledge the disability. In addition, parents may not give informed consent for data to be shared between pre-school and other agencies.

Services for disabled children are often bolted on to existing policy structures, with delivery being inconsistent. For example, Ongoing Resourcing Scheme (ORS) funding for special needs children is difficult to obtain; and there is no publicly available data on how many children receive ORS funding. Similarly, there is a lack of information about how many disabled children attend mainstream or special schools (Higgins, MacArthur, & Morton, 2008, p. 155).

Disabled children are also largely invisible in discussions about child poverty. The Children's Commissioner notes that having a disabled child is associated with higher levels of divorce, lower rates of parental employment, and greater reliance on welfare benefits – all factors that increase the risk of poverty (Expert Advisory Group on Solutions to Child Poverty, 2012b, p. 8). Despite higher rates of poverty among disabled children, their needs are usually overlooked during the formation and implementation of social assistance policies.

This report uses the term ‘caregivers’ to refer to those looking after disabled children. This is because while most caregivers are parents, many others are grandparents or adoptive parents. Unfortunately we have little idea how many grandparents or other family members are caring for disabled children, with one grandparent suggesting many others were in a “similar situation” [to her] but were under the radar because they were too busy to be active in groups such as Grandparents Raising Grandchildren.

What is meant by disability?

‘Disability’ is a term with no universally agreed meaning – indeed the academic literature on disability is preoccupied with what constitutes a disability and what does not (see World Health Organisation, 2011, pp. 7-8). Disabilities may be physical or intellectual; short/medium-term or permanent; present at birth or developing later through injury or ill health; and they may be mild, to the extent that people live normal lives, or multiple and severe. Then there is the question of whether chronic health conditions such as obesity are a ‘disability’, or whether, for example, diabetes is a disability requiring additional support. Also at issue is whether the disability identified is one that is permanent or one rehabilitation can mitigate or remediate. This distinction is especially important for children where the opportunity for rehabilitation may be short-lived.

Similarly, there does not appear to be a generally accepted method of categorising disability in children. Statistics New Zealand’s *Disability Survey* breaks the data down into impairment *types* (hearing, visual, physical, intellectual, psychological/psychiatric, and other) and by *cause* of impairment (disease or illness, accident/injury, present at birth, ageing, and other). Thus, there is not one spectrum of disability, there are multiple, overlapping spectra. This diversity means policies for services funding and delivery must be sufficiently flexible to meet a range of individual needs and circumstances.

The *Disability Survey* found that impairments that existed at birth are the most common cause of disability in children (49%). The next most common cause (33%) included conditions on the autism spectrum, attention deficit hyperactivity disorder, and developmental delay. It should be noted that while conditions such as autism spectrum, attention deficit hyperactivity disorder, and developmental delay, as well as dyslexia and dyspraxia, may have existed at birth they are not usually identified until later, and may be regarded by parents or caregivers as not having been present at birth. (Statistics New Zealand, 2014, p. 8). Overall approximately 4% of children have a disability they were born with. These figures appear to be consistent with data from other developed countries (Craig et al., 2011, p. 20).

The New Zealand Child and Youth Epidemiology Service (NZCYES) categorises the indicators of chronic conditions and disability by conditions detectable at antenatal or neonatal screening; other disabilities (e.g. autism); other chronic medical conditions (e.g. diabetes, epilepsy); and obesity, nutrition and physical activity (including iron deficiency anaemia) (Craig et al., 2011, pp. 3-4). The NZCYES’ inclusion of chronic conditions such as asthma and obesity on the disability spectrum highlights the difficulty in identifying what constitutes a disability, and what level of disability justifies additional support.

Key disability issues in New Zealand

Lack of data

Advocates for the disabled cite the lack of data as a key issue for them because the lack of baseline information makes it difficult to advocate for better policies and services (see Expert Advisory Group on Solutions to Child Poverty, 2012a, p. 4). Although there is a question about disability in the census, this data is aggregated into simple statistics about place of residence (i.e. in care or at home), age (broken into broad age groups), sex, ethnicity, type of disability, and unmet need for healthcare.⁷ Information on numbers of disabled children is not published for District Health Board or local authority areas. There is no central register of disabled children and no reliable mechanism for transferring information from one agency to the next (for example from early childhood centres to schools). A 2010 report on disabled children observed “it remains very difficult to access useful information on the nature and prevalence of disabilities amongst New Zealand children and young people” (Craig et al., 2011, p. 3). There is little doubt there is a case for significantly improved collaboration and sharing of demographic data, including census data, to map trends including socioeconomic status and ethnicity (which is a significant factor in the Auckland context).

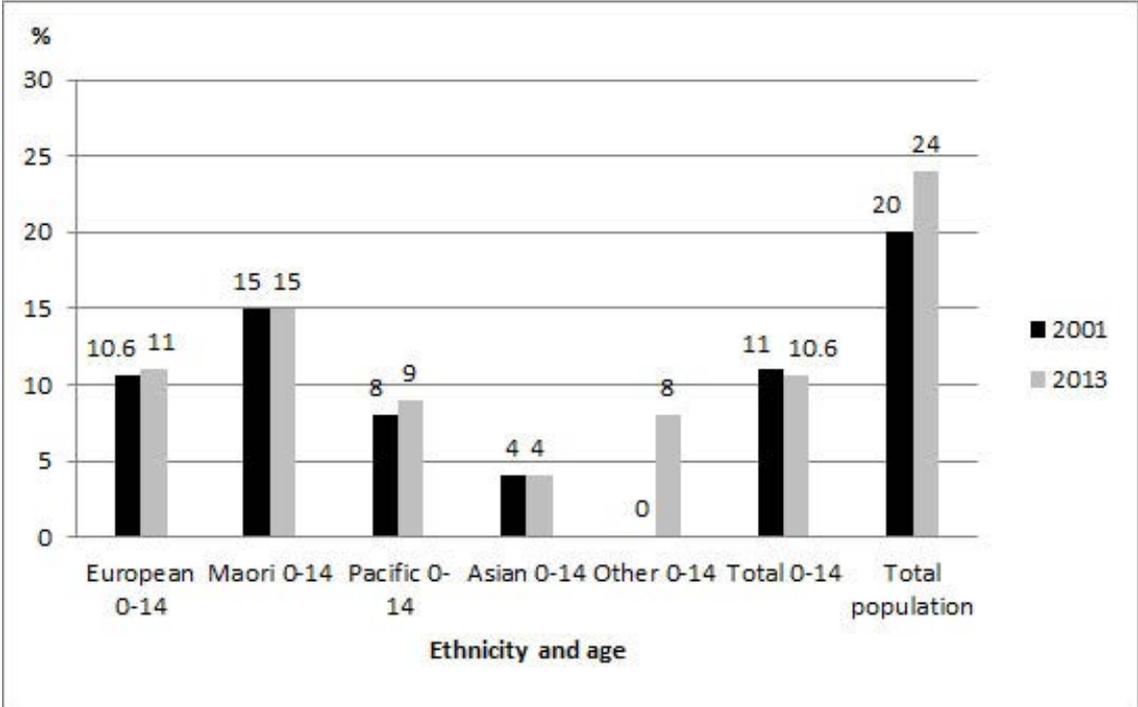
The *Disability Survey* is a post-enumeration survey conducted after each census which involved 23,000 children and adults who were living with disabilities. While this Survey has additional information it, too, aggregates data, in part because of privacy concerns around what is a relatively small sample (similar concerns pertain to disaggregated census data). It does not include data on children with disabilities who live in low socio-economic circumstances or on children who live in low income households where either a parent or other adult has a disability. In recent years, government has commissioned studies to enable better-informed decision-making to monitor compliance with the *Disability Strategy*, policy development, service planning, and allocation of resources to support people with disabilities. While welcomed, these studies focused on individuals with disabilities, rather than children and family units.

The 2013 *Disability Survey* shows there are 95,000 disabled children in New Zealand, and that 11% of children under the age of 15 years have a disability (Statistics New Zealand, 2014, p. 3). This rate is unchanged from 2001.⁸ Disability varies by sex and ethnic group: Māori children have higher rates of disability than average while Pacific children have lower rates (see Figure 1). Males under 15 years have higher rates of disability (13%) than females under 15 years (8%). Overall rates of disability have risen due to New Zealand’s ageing population.

⁷ See <http://nzdotstat.stats.govt.nz/wbos/Index.aspx>.

⁸ Note that although the number of disabled children has increased, the rate of disability remains the same.

Figure 1: Rates of disability for children 0-14 years, 2001 and 2013⁹



Refugee and migrant children can have an impact on the need for specialist disability services, including special education. This is a growing group, often with limited family support.

The New Zealand Child and Youth Epidemiology Service (NZCYES) report on children with disabilities uses hospital admission data but notes: “the data presented primarily reflects secondary health service utilisation, rather than incidence or prevalence estimates for children and young people with chronic conditions and disabilities” (Craig et al., 2011, p. 5). The report states “it is undesirable that a paucity of data should preclude [disabled and chronically ill children] featuring prominently in prioritisation, planning and resource allocation decisions” (Craig et al., 2011, p. 3). This is important as technology improvements and less institutional care mean more children with high needs are living at home (Craig et al., 2011, p. 3) and thus require sometimes significant support.

Overall, the lack of data makes it difficult to assess whether children/caregivers are receiving their benefit and other entitlements, and whether sufficient and appropriate resources are being allocated to local disability health and education services. There is also insufficient data to determine how many disabled children or parents live in poverty, or what resources they need to lift them out of poverty (for example subsidised housing, better access to employment opportunities). The United Nations Committee on Economic, Social and Cultural Rights has recommended that the New Zealand Government “collect data to monitor the enjoyment of economic, social and cultural rights by persons with disabilities and provide information and statistical data in this respect in the next periodic report” (cited in Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, p. 103).

⁹ http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx, http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-counts.aspx.

In its report to the Committee on the Rights of Persons with Disabilities, the Disability Community of Auckland¹⁰ (DCA) recommended that the “Ministry of Social Development...identify whether a child is disabled when reporting on abuse and neglect in its statistical reports” (Disability Community of Auckland, 2014, p. 4; see also Kendall-Tackett, Lyon, Taliaferro, & Little, 2005). CPAG supports this recommendation.

Disabled children and poverty

Most families with a disabled child face financial hardship unless they have established wealth and a sustained high income. It is “rare” for both parents to be working, and many households with a disabled child are reliant on increasingly precarious benefit income. Medical expenses and associated expenses such as transport can be a constant drain on household resources, often with little relief in sight. Normal school services such as after-school care may not be appropriate, and private provision can be very expensive. Working around disabled children can be difficult if parents have to be home after school or during the holidays (many holiday programmes are not open to disabled children, or may not be suitable). In addition, parents are often required to go to appointments with service providers, including schools, during work hours. In practice, many parents end up relying on trusts and private charities for care and provision.

Disability rates not only vary by ethnicity, but also by income with disabled children being more likely to live in low-income households (Expert Advisory Group on Solutions to Child Poverty, 2012a, p. 2; Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, pp. 89-90; also see generally Shahtahmasebi, Emerson, Berridge, & Lanacaster, 2011). *Disability Survey* data shows that of the estimated 95,000 children aged 0-14 years who had a disability, 15% lived in households with incomes under \$30,000.¹¹ This compares with 10% of 0-14 year olds in all households. Ministry of Social Development data shows that in 2012 (the last year for which data is available) 13,500 children receiving a Child Disability Allowance lived in households supported by a main income support benefit other than a Veteran’s Pension or New Zealand Superannuation (Ministry of Social Development, 2013, p. 100); This suggests that a minimum of 14% of disabled children live in benefit-dependent households. Household income data (Perry, 2014, p. 83) shows the real incomes of beneficiary households have fallen since 2009, so these children are very vulnerable to even small changes in the family’s financial circumstances, for example increased prescription charges, or unexpected medical expenses.

The cycle of low income and extra costs can make life very difficult for the caregivers. Perry (2014) notes that being disabled incurs costs in addition to normal household running costs. Disabled children in low-income households are also more likely to live in socioeconomically deprived areas (see also Expert Advisory Group on Solutions to Child Poverty, 2012b, p. 8), with limited access to social services including easily accessible public transport.

¹⁰ A grouping of organisations with an interest in disability issues.

¹¹ It is difficult to make valid comparisons with earlier surveys as the income bands have not been adjusted for inflation.

Also relevant to families facing hardship are the difficulties associated with receiving the Disability Allowance. Children may be eligible for the Disability Allowance. This is means-tested, and often requires families to pay costs up front, retain receipts, and then claim expenses back. Doctors may forget about offering it – the CDA is easier to remember to offer as it is based on children’s disability rather than a family’s circumstances. The Disability Allowance also means disability-specific costs need to be nominated.

This scarcity of disaggregated data makes it difficult to unravel the link between childhood poverty and disability. Does disability impose additional hardships that chip away at family resources over time? Or are disabled children more likely to be born into low-income families, and if so why? It is, however, likely that the situation that holds in the UK is closely mirrored in New Zealand:

There is a two-way relationship between disability and poverty in childhood. Disabled children are among the most likely to experience poverty and poor children are more likely to become disabled than those who are better off. There needs to be a transformation in the quality and accessibility of services for disabled children, young people and their families (cited in Expert Advisory Group on Solutions to Child Poverty, 2012a, p. 2).

Is there a socioeconomic gradient among disabled children?

The relationship between type of disability and socioeconomic status is complex, and highly dependent on the nature of the disability itself. This complexity is evident in the NZCYES data which finds both socioeconomic and ethnic gradients for disabilities. Table 1 below shows the disability and chronic conditions indicators used by the NZCYES and whether they display a socioeconomic or other gradient. While the hospital admissions data is reliable, some of the sample sets are very small, and the data itself only covers the period 2005-2009.

Table 1: Abridged overview of the Health of Children and Young People with Chronic Conditions and Disabilities in New Zealand.¹²

Indicator	New Zealand Distribution
Congenital Anomalies Evident at Birth	Higher rates among older (40+) mothers. The proportion of babies with one or more congenital anomalies identified at birth was significantly higher for males, Asian/Indian and Pacific > European/Other > Māori babies and those from less deprived (NZDep06 deciles 1–2 vs. 5–10) areas.
Congenital Heart Disease	There were no significant ethnic differences in the proportion of babies born with cardiovascular anomalies. Rates were significantly higher however, for babies from the least deprived (NZDep06 deciles 1–2 vs. deciles 5–10) areas, for males, and for those with older (40+ years vs. <20 years) mothers.

¹² Nutrition and physical exercise have been omitted. From NZCYES (2013, pp. 28-34).

Indicator	New Zealand Distribution
Down Syndrome	There were no significant NZDep06, ethnic or gender differences in the proportion of babies identified with Down syndrome at birth. Rates for the babies of mothers aged 40+ years however were 25.7 (95% CI 9.36–70.45) times higher than for teenage mothers.
Neural Tube Defects (NTDs)	There were no significant ethnic, NZDep06 or gender differences in the proportion of babies born with NTDs. The highest rates however, were seen in Pacific babies, the babies of teenage mothers, and those born into the most deprived (NZDep06 deciles 9–10) areas.
Cystic Fibrosis	CF admissions were significantly higher for females and for European/Other > Māori > Pacific and Asian/Indian children and young people.
Developmental Delays and Intellectual Disabilities	Hospitalisations for those with developmental delays were significantly higher for males, Pacific > Māori and European > Asian children and young people and those living in average–more deprived (NZDep deciles 5–10) areas. Hospitalisations for those with intellectual disabilities were significantly higher for males, Pacific and Māori > European > Asian children and young people and those living in average–more deprived (NZDep deciles 5–10) areas.
Cerebral Palsy	CP admissions were significantly higher for males and for Pacific > European/Other > Māori > Asian/Indian children and young people.
Autism Spectrum Disorder	Autism and other pervasive developmental disorders (APDD) were significantly higher for males. Admissions were also significantly higher for European/Other > Māori and Asian/Indian > Pacific children and young people.
Eczema and Dermatitis	Admissions for those with a primary diagnosis of infective eczema, or other eczema and dermatitis were both significantly higher in males than females. Rates were also significantly higher for Māori and Pacific > Asian/Indian > European/Other children. Admissions for both outcomes increased for all ethnic groups during 2000-2012.
Inflammatory Bowel Disease	Admissions for Crohn's were significantly higher for males, although no significant gender differences were evident for ulcerative colitis. Admissions for Crohn's were also significantly higher for European/Other > Asian/Indian > Māori > Pacific children and young people, while rates for ulcerative colitis were significantly higher for European/Other > Asian/Indian > Māori and Pacific children and young people.
Epilepsy	Admissions were significantly higher for males and for Māori and Pacific children and young people, than for European/Other and Asian/Indian children and young people.

Indicator	New Zealand Distribution
Distribution of Overweight and Obesity: NZ Health Surveys	<p>Māori children however were 2.10 (95% CI 1.64–2.68) times more likely to be obese than non-Māori children, while Pacific children were 3.08 (95% CI 2.41–3.93) times more likely to be obese than non-Pacific children, once rates were adjusted for age and gender. There were no significant differences, in obesity rates between Asian and non-Asian children.</p> <p>Children living in the most deprived (NZDep06 deciles 9–10) areas were 2.33 (95% CI 1.37–3.93) times more likely to be obese than children in the least deprived (NZDep06 deciles 1–2) areas, once adjusted for age, sex and ethnic group.</p>
Consequences of Obesity: Type 2 Diabetes	<p>Rates were also significantly higher for females and for Pacific > Māori > Asian/Indian and European/Other children and young people. Similar ethnic differences were seen during 2000–2012, with rates increasing for Pacific and Māori children and young people during this period.</p>
Consequences of Obesity: Slipped Upper Femoral Epiphysis (SUFE)	<p>There were no significant gender differences in SUFE rates, although rates were significantly higher for Pacific and Māori > European/Other > Asian/Indian children and young people.</p>

The classification used here differs from that used by Statistics New Zealand in the Disability Survey (for example the lack of a ‘sensory’ disability category). Craig et al note that (2011, p. 68):

The classifications used in the Household Disability Survey however make it very difficult to determine the aetiology, or likely clinical course of the conditions leading to disabilities in New Zealand children and young people, and as a consequence, provide few insights into potential pathways for prevention, or service requirements over the life course...With prevention and early intervention being critically important for mitigating the significant personal and socioeconomic costs associated with childhood disabilities, a review of these conditions in the New Zealand context may assist the health sector to consider key prevention and early intervention points for each condition, as well as future strategies to reduce disabilities in New Zealand children and young people as a whole.

This data does not necessarily reflect prevalence of disability within the community. For example some disorders (foetal alcohol syndrome, language processing delay) may be unrecognised or undiagnosed learning difficulties and the children’s behaviour interpreted as misbehaviour. Where there are concerns around the child’s learning, the tests required to establish the nature of the disability may be beyond the financial capability of families. Schools can refer children for medical assessments but may not have the funding or expertise to recognise and diagnose learning and behavioural problems.

The socioeconomic and ethnic variation among the different disabilities also suggests that broad-brush one-size-fits-all approaches to providing services for disabled children are unlikely to achieve their aim. We return to this later in the report.

Current services

Support for disabled children comes primarily through the Ministry of Social Development (MSD), the Ministry of Education and the Ministry of Health (MOH); although a total of 11 government agencies fund support for people with long-term disabilities (CCS Disability Action, 2012, p. 8). There is also some individualised funding currently available to a small number of people although this is restricted in its availability (CCS Disability Action, 2012, p. 10).¹³

The NZCYES (2011) sets out current services in some detail (pp. 72-76) so they will only be covered briefly here.

Ministry of Education

The Ministry of Education funds a range of learning-related services for disabled children.¹⁴ There are layers of intervention: individual, school-based (special education grant), and specialist services to which schools can refer students. Funding is accordingly complex (everyone spoken to for this report noted funding complexity in relation to education). Among the specialist services funded by the Ministry of Education¹⁵ are assistive technologies, transport services to get children to and from school, regional health schools for children who are in hospital or unable to go to school; and funding for individual students through the ORS, the school high health needs fund, and Resource Teacher: Learning and Behaviour (RTLb) which provides support within schools for children with learning and behaviour needs.

There is very little information about funding of special education available,¹⁶ and no publicly available data on the numbers of students receiving funding. Special education is bulk funded through the Special Education Grant with schools getting funded to provide special education services, even though some schools actively discourage special needs students, thus requiring caregivers to send children out-of-zone. This appears highly inequitable and leads to a situation where schools are funded “irrespective of how many children with special needs are enrolled. A school with two such children receives the same funding as a school with 20” (Minto, 2008). Special education funding is budgeted to fall in real terms while the number of disabled children is anticipated to rise.¹⁷ This will put further pressure on services for disabled and special needs students.

Ministry of Health

The Ministry of Health provides support for disabled children through Disability Support Services (DSS).¹⁸ Many of the services DSS funds are accessed through Needs Assessment and Service Co-ordination (NASC) organisations which are contracted to the DSS, and work with disabled people to help identify their needs and to outline what disability support services are available. They allocate Ministry-funded support services and assist with accessing other supports. Services include

13 Individualised funding can be described as a portable package of funds allocated for a particular person that facilitates control over how they purchase their disability support needs (Fisher et al., 2010, p. v).

14 <http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/ServicesAndSupport.aspx>.

15 <http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/ServicesAndSupport.aspx>.

16 Funding rates are contained in the just-released school decile rankings, available <http://www.minedu.govt.nz/NZEducation/EducationPolicies/Schools/SchoolOperations/Resourcing/OperationalFunding/Deciles.aspx>.

17 Colleen Brown, pers comm July 2014.

18 <http://www.health.govt.nz/our-work/disability-services/about-disability-support-services>.

home and community support services, respite care, community residential support services, child developmental and other services. The Ministry also assists with equipment such as mobility and communication aids.

The Ministry's website refers to "the development of a broad disability services focused Action Plan for Children and Youth, incorporating strategic priorities and government directions, including the government response to the Select Committee Report on the Inquiry into the Quality of Care and Service Provision for People with Disabilities (2009)," but it appears there has been little change since 2010.¹⁹

Ministry of Social Development

The Ministry of Social Development provides financial support for disabled children and their families. This can be direct support or payment of service providers. Direct financial support includes the Child Disability Allowance, the Disability Allowance and, for adults, a Supported Living Payment. The Supported Living Payment is also available to someone caring for a person (who is not their partner or spouse) who needs hospital-level or residential care. This high threshold means many caregivers of disabled children do not meet the eligibility requirement for this benefit, thus rendering them subject to the job-test requirements of Jobseekers Allowance and Sole Parent Support. Other assistance such as the Community Services Card is also available.

Child Disability Allowance

Some support for disabled children is available through the Child Disability Allowance (CDA). Details of the CDA are in Table 2. The main feature of the CDA that differentiates it from other benefits, including the Disability Allowance, is that it is not income-tested. It is available to caregivers in recognition of the extra care and attention needed for a disabled child where the child has been assessed as needing constant care and attention for at least 12 months. In addition, it confers access to other services.

¹⁹ The Select Committee report is available at http://www.parliament.nz/resource/en-nz/48DBSCH_SCR4194_1/cb220d2e3ba25dc33dec0b28b29b30578d110dd5.

Table 2: Details of Child Disability Allowance

	Child Disability Allowance
Amount per week	\$46.25
Qualifying criteria	Available to caregiver if: <ul style="list-style-type: none"> • they are the main carer of the child (or have care of the child for the time being) • they are a New Zealand citizen or permanent resident • the child has been assessed as needing constant care and attention for at least 12 months because of a serious disability • the child or young person is under 18.
Who paid to	Paid fortnightly to the main carer of a child or young person with a serious disability in recognition of the extra care and attention needed for that child. This payment is not affected by: <ul style="list-style-type: none"> • earnings of caregiver or spouse/partner • any money or assets of caregiver and spouse/partner.
Number of allowances granted²⁰	2008 11,027 (12.1% of disabled children (est)) 2009 10,900 (11.8%) 2010 8,941 (9.6%) 2011 7,112 (7.6%) 2012 6,702 (7.1%) 2013 6,538 (6.9%)
Total number of allowances paid	2008 43,185 (47.2% of disabled children) 2009 45,767 (49.7%) 2010 43,883 (47.2%) 2011 39,253 (41.8%) 2012 36,894 (39.1%) 2013 34,968 (36.8%)

The CDA is only paid to caregivers of children with a serious disability and it is this degree of severity of disability which explains the differences between the availability/pay-out of the CDA and the numbers of children with some level of disability. Section 39A(2) of the Social Security Act 1964 allows for a CDA to be paid to a caregiver where such care is due to

- a) frequent attention in connection with his bodily functions; or
- (b) attention and supervision substantially in excess of that normally required by a child of the same age and sex; or
- (c) regular supervision from another person in order to avoid substantial danger to himself or others.

This definition does not however explain why the availability of the CDA has declined over recent years.

²⁰ Ministry of Social Development *Statistical Report* (2013).

²¹ Estimates extrapolated from 2001 and 2013 *Disability Survey* data.

Administrative changes to the CDA brought in in 2008 mean that case workers can now refer applications for a CDA to a Regional Health Advisor (RHA). In effect the RHA can over-ride the judgment of the child's medical professional and recommend a CDA not be granted. Since the establishment of RHAs the number of new CDAs granted per year has halved, from 11,027 in 2008 to 6,538 in 2013, with the total estimated proportion of disabled children receiving the CDA falling 24% between 2009 and 2013.

The decline in the number of CDAs granted means that a far smaller proportion of caregivers are receiving the CDA. In considering the take-up rates for the CDA, the Office of the Children's Commissioner noted that: "There is particular concern about the potential low take-up and the level and operation of the Child Disability Allowance amongst poorer families" (Expert Advisory Group on Solutions to Child Poverty, 2012b, p. 12). The Children's Commissioner recommended "that the government commission research to clarify: how many children are living with a disability or are being cared for by a parent with a disability; how many of those children are living in poverty; and what the effects of poverty are on these children" (Expert Advisory Group on Solutions to Child Poverty, 2012b, p. 58). CPAG supports this recommendation. However, there is almost no data available on how many children have a disability or where they live. This would make any assessment of benefit, including CDA, take-up rates, and that relationship between take-up and socioeconomic status, very difficult.

Summary

There are a range of supports available for disabled children, ranging from financial support through to equipment and carer support. Despite the *Disability Strategy* setting a goal of fostering an aware and responsive public service, it is questionable whether this is progressing. The Office of Disability Issues (set up under the *Disability Strategy*) concedes that "there is no comprehensive whole-of-government information on how public services actually reach disabled people", and that there are some "important shortfalls...and opportunities" for a more whole-of-government approach to the provision of disability services in New Zealand.²² New Zealand does not yet have an integrated whole-of-government support system for disabled children.

Interviews and results

In trying to give some illustrative perspectives about how well disabled children and parents are supported, CPAG conducted a series of interviews with caregivers with the aim of identifying their common experiences. Interviews were loosely structured and covered demographic information; income and support; experiences with the medical and education systems; and general questions about how families were coping and whether they felt the level of support available was adequate.

Seven interviews were conducted in July-August 2014. Interviews were conducted with a range of respondents with most interviews lasting approximately one hour. Where possible, interviews were conducted face-to-face although several were done over the phone. The socioeconomic and geographic range of the interviews enabled the identification of common experiences rather than just local anomalies.

²² <http://www.odi.govt.nz/nzds/progress-reports/2012/04-progress-report.html>.

It is important to note that most interviewees were recruited through CPAG contacts or through CPAG's Facebook page. Given this, and the small sample size, the interviews do not claim to be fully representative of the experience of all parents of disabled children. Given the predominance of CPAG contacts, this group were more likely to be aware of issues around child poverty than a random sample. Importantly, parents with the fewest resources, including no access to the internet, were (with one exception) not part of this research. Many of the issues faced by this group would be greatly magnified combining as they would low and/or precarious incomes and disability.

Results

Caregivers

A striking feature of all the caregivers spoken to for this report was their motivation to do the best for their child no matter what. This motivation and dedication cut across socioeconomic or other status. While parents are frustrated by lack of household resources and/or support services, many were not merely accepting of their children but had high aspirations for them: "I told them my daughter was going to be a star"; "I have faith that one day my daughter will be able to take care of herself".

This generosity extended to other caregivers with disabled children. After describing their own struggles to get support, parents who were “relatively privileged” were asked about how they thought others with fewer resources would cope. In every case, people expressed concern about the difficulties other families would have including:

- lack of financial ability to get disability-related assessments;
- financial hardship generally, especially in view of the medical and transport costs associated with disability;
- lack of social capital (i.e. networks and family or other support); the impact on other children in the family;
- having English as a second language or facing cultural barriers;
- having no wider family support, for example refugee families; and
- having children with undiagnosed learning or intellectual difficulties. One caregiver observed that “kids with no money are struggling the most – and they [caregivers] often have other children.”

For others, acceptance that their children would never lead a ‘normal’ life came with the discovery of disabilities in addition to that which had been initially diagnosed, and in one case, a series of medical misadventures that compounded the original disability.

One paediatrician also commented on the difficulty in obtaining support for parents without resources. “By that I don’t necessarily mean financial resources, but the ability to work with the system.” One parent also commented on this, noting that she found dealing with Work and Income difficult (“they’re so inflexible”) even though she had previously worked for the Ministry of Social Development.

Financial support

Finances are a struggle for many families. Having a child with a disability, no matter what the nature of that disability, often means incurring costs over and above those normally associated with raising a child. These include medical costs (several parents commented on the hardship caused by increased prescription fees); transport costs to appointments, hospitals and specialist services; education costs; the opportunity cost of not being able to work (for example a severely disabled child requiring full-time care); and costs for specialist services such as learning therapists.

There is a great deal of diversity among families, with some coping well and others less so. For those on benefits who were full-time carers, it became clear that they held little hope of escaping their financial difficulties. Some were struggling to “put food in the cupboard. I’d like to treat the kids sometimes, but I can’t do that.” One caregiver stated the family had recently gone onto a benefit and although they were “lucky” in having paid down debt, they still lived “frugally.” Some respondents were studying in an effort to improve their long-term prospects although this was made difficult by Work and Income requirements that beneficiaries be available for part-time work (one respondent had moved off a benefit as a result). Alarming, one mother stated that despite having a medical certificate stating she had been diagnosed with potentially terminal cancer, the family’s benefits were cut off for three weeks because she had been deemed not to have complied with her job-seeking obligations (she is on a Jobseeker Allowance which has replaced the Sickness Benefit). All the beneficiaries spoken to for this report had at some stage relied on ongoing support from foodbanks, their church or family.

Most caregivers interviewed were receiving the CDA. Most felt that \$46 per week did not come close to covering the costs they incurred as a result of their child's disability. All those on benefit were getting the CDA and this provided some help. One beneficiary was also receiving a Disability Allowance while another stated that although she was eligible for a Disability Allowance, she hadn't applied because it was too difficult assembling all the paperwork. Despite the CDA being universally available to those that fit the criteria, in practice it is difficult to get. Thus one caregiver noted that "parents have to be able to fight [to get the CDA]. If they can't, there's the CDA out the window." This parent "just gave up" trying to get the CDA even though her child appeared to meet the criteria.

There is little indication as to how many children are not receiving the support to which they are entitled. Nor should it be necessary for parents to be skilled at dealing with bureaucracies to get support for their children. With respect to the CDA, the Disability Community of Auckland (DCA) has recommended that "New Zealand increase the uptake of the Child Disability Allowance by clarifying and opening eligibility criteria and promoting the benefit to eligible families" (Disability Community of Auckland, 2014, p. 5). CPAG supports this recommendation.

Comments pertaining to the lack of financial relief included:

- a mother who, reflecting on her daughter's long-term disability, commented that "I can see myself falling down that [financial] hole";
- "We had dreams. We didn't ask for this; we didn't ask to be on a benefit or live in a state house... The future is scary";
- "It's a common theme that children end up going through [foster] homes because parents don't get the support they need."

In an odd quirk of the system of social assistance, parents get less support than grandparents or adoptive/foster parents. One caregiver noted that they got a CDA as well as an Unsupported Child Allowance, something they would not get if their daughter was their biological child.

The need for diagnosis

A clear distinction emerged between children with a medically identified disability and those whose disability required diagnosis by other practitioners – "if children are not diagnosed, nothing happens." Where a child has been identified as having a disability by a medical practitioner, some (although perhaps not sufficient) support kicks in through the health system or, in some cases, through Accident Compensation. A caregiver whose child had been diagnosed with leukaemia stated they were well-supported, but noted the inequity in support for children with cancer as compared to other disabilities.

Far more complex are intellectual and learning disabilities that may be unrecognised or undiagnosed. Several parents described their difficulties in obtaining help for their children because of a lack of assessments of their child's disability (usually a learning-related disability). Where there is uncertainty about the nature of the disability or the appropriate future pathway for the child, parents must fund tests themselves, sometimes at a cost of many thousands of dollars ("my daughter had to have two tests at a cost of [thousands of dollars] each"). Assessments are required in order to prove a child's need for educational and other assistance, for example teacher aides and behavioural therapy. It also became clear that the assessments were necessary to help others understand the nature and extent of their child's problem. Caregivers reported their children were initially considered to just have behavioural problems, with one parent saying her daughter (who has foetal alcohol syndrome and

a learning disability) was described by a medical professional as just needing “a bit of discipline.” Another reported her child (who was later assessed as having a learning difficulty and auditory processing disorder) had been isolated in class for bad behaviour. Even where assessments were made parents stated that they still often struggled to get the assistance to which their children were entitled.

A common concern was that children with unidentified needs could easily have their disabilities interpreted as bad behaviour (autism spectrum disorder, deafness) or inability/unwillingness to learn (sensory processing disorder, intellectual disability). In addition, children with unidentified disability and special education needs are more likely to live in low-decile households that may not know how to access the services to which they are entitled.

Access to services

All the caregivers spoken to talked about the lack of access to appropriate services. The chief concern for parents was difficulty in education, both primary and early childhood. Schooling for disabled children is complex, because of both the wide range of physical, intellectual, and multiple disabilities children may have, and the multiple layers of provision. Reflecting this, the most recent *Disability Convention* monitoring report identified as a key issue facing the disabled. Although the Education Act states that people with special educational needs have “the same rights to enrol and receive education at State schools as people who do not,”²³ the monitoring report notes this right is not legally enforceable. The report also notes: “Exclusion, isolation and bullying remain significant issues for children and youth. Education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission” (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, pp. 9-11). The report notes work by the Education Review Office has made progress towards schools becoming more inclusive, although issues around reporting remain.

Most of the parents spoken to sent their children to mainstream schools, and although this generally worked well, they did raise a number of issues. These included:

- gaining acceptance into the school;
- ensuring their children were accepted for who they were once they were in school;
- being able to access additional funding;
- availability of specialist services such as reader/writers, especially in low-decile schools;
- lack of accountability of schools and the Ministry of Education for failures to provide children with the help to which they are entitled or to implement children’s individual education plans (several parents mentioned their children’s individual education plans “came to nothing”); and
- schools’ failure to recognise and provide services for children with special needs, especially in low-decile schools.

More practically, parents complained that schools did not carry information over from year to year, and that their child’s disability was not noted on their record. Indeed, there can be a gap between a child leaving pre-school, where they are usually well looked after, and services available at school, for example if ORS has not been processed in time. Parents and advocates both described

23 Section 8, Education Act 1989. <http://www.legislation.govt.nz/act/public/1989/0080/latest/DLM175959.html>.

“horrendous” difficulties getting “just a basic level of support” for their children’s education with one parent describing support from her child’s school as “surprisingly useless”. Another described her dealings with the Ministry of Education as “slow, difficult, and they hadn’t read their notes.” While some parents noted the valuable assistance of their school Special Education Needs Coordinators (SENCO), others observed that these were sometimes absent or not sufficiently well resourced to be effective.

There was also a gap with early childhood education providers not being obliged to take on children with disabilities. This is potentially stressful for sole parent beneficiaries with other children who are under pressure from Work and Income to attend job-preparation seminars and comply with social obligations.

ORS funding was perceived as difficult to get, with funding applications being declined when it appeared the child should meet eligibility criteria. Parents and advocates described needing to go to court to get funding decisions reviewed, while one caregiver said her child was presently “just above the level” of disability for funding but “by next year she’ll be far enough behind [from lack of help] that she will be eligible.” And another stated: “Recently I had a father crying on the phone to me about his son, who had complex needs - no ORS funding and [the strain] was wrecking the family.”

Interviews highlighted the differences in schools’ preparedness to cater to disabled and special needs children, and the inequities that remain in the funding of special education. While some schools are committed to their special needs students, others are less committed, with some schools discouraging the enrolment of special needs and disabled students. One caregiver summed it up:

If kiddies can’t perform basic tasks by six, and if programmes are not in place [to help them] then they’re sunk...We had the social capital and ability to advocate [for our child] but some other parents must find it hugely difficult.

Where services were successful, they tended to be self-funded or short-lived. One parent signed her child up for IDEA²⁴ (a service run through IHC) but waited two and a half years before her child could get in. She described it as “fantastic” but pointed out it was a 6 week, one-off service.

A further problem was evident around the lack of services available for disabled children. Although this study was largely conducted in Auckland, interviewees from outside Auckland expressed similar concerns.²⁵ Many services were established decades ago, and have not been expanded to meet population growth. For example, if a child requires deaf education the only available services is in West Auckland, despite the significant problem with hearing impairment in South Auckland. South Auckland (Homai) is home to the only specialist school in the country for visually impaired children and young people, although they offer outreach services nationwide. Several parents talked about needing transport to get to specialist services such as tutors with a couple commenting that for parents without ready access to transport these services would simply be out of reach (it should be noted that some transport services are available for school and access to other services, although these have become more limited in recent years). One mother with a very limited family income stated she was lucky her daughter was able to attend the local school or educating her child would be almost impossible.

24 Intellectual Disability Empowerment in Action.

25 Unfortunately the interviewees did not include anyone from rural areas or small towns although it is likely that similar problems pertain in these areas.

Caregivers were generally grateful for assistance from the health sector although they noted inconsistencies in funding (“very arbitrary”) and services. These included going to court to enforce an entitlement or (as noted above) not being funded for medical assessments. Difficulties also included obtaining assistance for mobility aids and poor follow-up service from agencies. Legal action and following up providers was also time-consuming. Caregivers also commented on the tendency to treat learning and behavioural difficulties with medication, and ignore their concerns, sometimes with severe consequences.

Lastly, caregivers noted the lack of communication and coordination between services. Several described dealing with uncoordinated agencies as “horrendous”; “not working together at all,” and “unstructured.” This included “departments of the same agency”; “every time you want something you have to fill out more forms.” One caregiver was more scathing: “Everyone is trying to get someone else to do the work – there is delegation with no support and minimal information [for caregivers].”

Lack of knowledge

Related to the difficulties in getting equitable access to services, parents also commented on the lack of knowledge about disability in the education and social assistance workforce, and the stigma that remains deeply embedded in the public mind about disability, particularly intellectual disability. Most parents had anecdotes about service providers failing to understand their children’s needs:

- One child’s early childhood centre was focused on child-led learning even though her son would learn nothing because “all he wants to do is play with trains all day. Child-centred learning doesn’t work for [autistic] children like [mine]”;
- “I said if you don’t believe my [7 year-old] son has a learning difficulty, ask him his name. Go on. He won’t be able to tell you”;
- “Work and Income didn’t understand that my daughter often needs to be picked up early from school because she gets disruptive;²⁶
- “they [Housing New Zealand] said ‘tell your daughter she can’t have the dog’. I said you try to tell her. And if she understands, she’ll have forgotten five minutes later”.

What would help

Parents were asked what would be of most help to them. Most said carer support and respite care – more, more easily available, and better quality. One caregiver described the lack of access to, and the administrative difficulties in obtaining, respite care as “a nightmare.” Caring for a disabled child is physically and emotionally exhausting, the financial strain puts significant pressure on relationships, and other children in the family often suffer, perhaps because they care for their siblings, or they don’t get the attention they need (Reichman, Corman, & Noonan, 2008). In addition, children with severe behavioural difficulties may be excluded from respite care (McGill, Tennyson, & Cooper, 2006).

Another recurring theme was the need for individualised services that were relevant to the child and the family. Comments included:

- A support package around the child; support on how to deal with [the disability]; not having to go to court to get “basic support”;

²⁶ This mother was required to work part-time even though her daughter needs full-time care and was receiving a Child Disability Allowance.

- Strengthening Families²⁷ was good because it got everyone around the table;
- An integrated programme of work and an outline of where you are going; someone who walks with the family to coordinate services; help for parents to prioritise; a support mechanism that kicks in at Plunket;
- Hands-on support from someone who understands our situation; someone who understands my daughter not who thinks they know what is best for her;
- Better understanding and greater flexibility from Work and Income; better coordination among service providers;
- A plan of action: “we had nothing, we were given nothing.”

Other services parents commented on were access to specialist teachers and an educational package tailored to the child; a better educated workforce; and greater understanding from the public.

Discussion and the way forward

Disabled children are largely invisible in New Zealand social policy. Where there are policies in place to cater for them (for example in education), from the perspective of the parents spoken to for this project, they are poorly resourced and not well integrated. While agencies dealing with disabled children do the best they can, other factors such as funding and policy frameworks can create problems for parents and service providers.

The provision of services for disabled children comprises but one facet of their overall wellbeing. While this report has focused on those services, there are other aspects that impact on the wellbeing of disabled children including their physical environment (accessibility, mobility); their social environment (discrimination, stigma); the policy environment (does it consider the needs of disabled children?); access to employment; and public health measures to minimise or eliminate the risk of disability (e.g. workplace safety regulations) (see World Health Organisation, 2011). This report has not attempted to consider these.

It should, however, be noted that many of the complexities raised here are exacerbated by the constantly shifting policy and funding environment of services for the disabled. A key difficulty that emerged was the transfer of housing needs assessment from Housing New Zealand to Work and Income. Another is changing service providers (“people lose their places on the waiting list”) which may involve the disruption of established relationships, and the loss of information. It was suggested there needs to be better coordination between service providers in the event that these are changed.

²⁷ <http://www.strengtheningfamilies.govt.nz/>.

Data

The primary shortcoming in New Zealand's care of disabled children is the lack of quality data pertaining to their number, whereabouts, and socioeconomic and family status. This makes it difficult to plan for adequate and appropriate services for disabled children, and to hold service providers to account. It is also difficult to assess whether their position relative to others is improving or not. The *Disability Convention* monitoring report cites lack of data as the first of its five key overarching issues (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014, p. 9), and CPAG supports the report's call for robust, timely and useful data to be regularly collected across a range of sectors. CPAG also considers census data on disabled persons to be made available down to electorate, local council and/or hospital board level.²⁸ While government agencies undoubtedly have access to census and other data for their own purposes, this information needs to be publicly available in order to ensure that resources are equitably distributed, and that children's needs are being met to the greatest extent possible.

CPAG supports the recommendations of the Independent Monitoring Group and the DCA for better quality, disaggregated, publicly available data on disabled children, their educational and health outcomes, their socioeconomic status, and indicators to assess whether their outcomes are improving over time.

One option for identifying children with disability or special needs is through the existing B4 school checks for four year-olds. These are funded by the Ministry of Health²⁹ although they are conducted by pre-school providers.³⁰ They aim to identify any issues that may impact on a child's ability to learn at school. They include screening for visual and hearing impairments. The information is discussed with parents but is not forwarded to the school the child will be attending. Although the checks are voluntary, they offer an opportunity to identify disabilities and organise appropriate support for the child and the family, as well as notify the school the child is likely to attend. One possibility is a central register with the child's details, the nature of the disability and the services they are using. There are a number of issues involved in such a register including security and privacy of information, where such a register would be held, and who would have access to the information. However, the lack of coordination between agencies, including the lack of information between early childhood centres and schools suggests that, at a minimum, information from B4 school checks should be made available to schools where a learning or other disability has been identified.

Recommendation: That the government collect and disseminate better quality, disaggregated, publicly available data on the number, location and socioeconomic and other (including cultural) status of disabled children, their educational and health outcomes, and indicators to assess whether their outcomes are improving over time.

28 We acknowledge privacy concerns with respect to releasing information at the level of Census Area Unit and below.

29 <http://www.health.govt.nz/our-work/life-stages/child-health/b4-school-check>.

30 <http://www.minedu.govt.nz/Parents/EarlyYears/SupportForYourChild.aspx>.

Support

The key issue for parents is the lack of support available for disabled children. Several parents commented to the effect that whereas once disabled children would have been cared for in institutions, they are now most likely to be cared for at home, however adequate support structures to help families and communities care for them have never been established. In its place is a fragmented support system with significant gaps and poor cohesion between the different services. One advocate also pointed out that until relatively recently many disabled children would not have survived past early childhood. However while medical science has advanced so these children are living longer, healthier lives, public policy and social attitudes have lagged behind.

One area that stood out as particularly problematic for parents was education. Parents found the multiple layers of service and intricacies of funding difficult to understand and navigate. The role of school SENCO is important to help ensure children get the services they require, and several parents noted the help they received from their school's SENCO. A 2012 Education Review Office survey of special needs found 80% of schools had a SENCO with small schools being less likely to have a SENCO (Education Review Office, 2012, p. 11). However, among those that do have a SENCO, not all schools have a dedicated SENCO, and the job may be attached to another staff member with few resources to adequately attend to the needs of students.

SENCOs are not given specific funding through school budgets, and this may impact on whether a school has sufficient resources to appoint someone especially for that role. However, if the government is to achieve full inclusion in education for disabled students, then it needs to acknowledge the work involved and provide dedicated funding for school SENCOS through school budgets.

Recommendation: That the government acknowledge the role of Special Education Needs Coordinators in schools and accordingly fund a staffing entitlement directly through school budgets.

A crucial gap is the lack of funding available for disability-related assessments. These are not always publicly funded and the cost can be prohibitive for many low-income families. Tests are used to determine learning and hearing disabilities, intellectual disability, and psychological problems. Given the complexities around funding, it is not obvious which sector should be funding these assessments, with extremely limited resources and often very long wait times. Families who do not have the financial resources to self-fund some of these assessments can be further penalised by long waits to access services. There is no indication of how many children are missing out on assessments and how many of them are falling behind at school because of an intellectual or learning disability.

Recommendation: That the funding and allocation of services for disabled children be reviewed in partnership with the disability sector to identify shortfalls and find ways to improve service delivery in ways that are child-focused.

Recommendation: That the Office of Disability Issues or other appropriate body investigate ways to ensure that government agencies and staff recognise and take account of the ongoing needs of disabled children and their families when engaging with them.

One policy area from which disability has all but vanished is social assistance. Disabled children are disproportionately represented in low-income households, and this includes households reliant on benefit income. Major changes to the system of social assistance since 2010 mean that parents must now be available for part-time work when their youngest child turns six, or full-time work when their youngest child turns 14 (see Wynd, 2013). Those not working part-time must attend job-preparation and other courses. During the drafting of the legislation, and during much of the public discussion, disabled persons, and children in particular, were invisible. There are no specific exemptions for the caregivers of disabled children to be exempt from work obligations, and several parents spoken to for this project reported being under intense pressure from Work and Income to work despite their child's or their own disability or illness.³¹ In Auckland, there are also concerns around migrant and refugee parents with limited understanding of English, and who may face cultural barriers to obtaining assistance.

The interviews strongly suggested that support for disabled children should be reviewed for ease and adequacy of coverage, and that Work and Income urgently review its practices with respect to parents caring for disabled children or who are themselves sick and/or disabled. As well, there is a need for the Disability Allowance be reviewed so that it is less difficult to get for those who fit the criteria, and better reflects the costs of being disabled or caring for a disabled child.

In its *Concluding observations on the initial report of New Zealand*, the UN Committee on the Rights of Persons with Disabilities noted (Committee on the Rights of Persons with Disabilities, 2014, p. 3) said:

17. The Committee is concerned that it is still the case that some children with disabilities, especially Māori children with disabilities, have difficulty in accessing some government services, including health and education services. The Committee notes the recent work undertaken in the Disability Action Plan 2014-2018 to make services more accessible.

18. The Committee recommends that this work be increased to ensure that all children with disabilities are able to access government and related services, including to receive support to express their views.

³¹ This intense pressure on parents with disabled children or who are themselves sick or disabled, and cutting benefits without notice, also comes through strongly in discussions with social service providers.

Recommendation: That eligibility criteria for the Supported Living Payment be revised for parents with disabled children, or that some other provision be made so that the needs of their children prevail over parents' job-seeking and work preparation obligations unless parents request otherwise.

The continuing fall in the number of CDAs granted must be examined. Given the additional time and costs involved in caring for a disabled child, access to the CDA should be far easier for caregivers to obtain and rules for eligibility be made more transparent. Better education of doctors, especially General Practitioners, in criteria for CDA and completions of the application form, also emerged as being critical in whether or not disabled children received the CDA. There appears to be significant variability in doctors' understanding of both the CDA and the Disability Allowance. While the CDA falls short of meaningful compensation, it at least recognises those costs.

Recommendation: That the Ministry of Social Development:

- **Investigates why there has been a sharp reduction in the number of CDAs granted;**
- **analyses census data to ascertain if there is a socioeconomic, geographical or ethnic variance in respect of the number and proportions of CDAs granted and declined;**
- **works with the sector to assess the role of Regional Health Advisors and determine whether they are overriding medical professionals' advice;**
- **works with the sector to identify barriers to the granting of CDA where eligibility criteria appear to be met, and considers strategies to minimise these;**
- **undertakes a similar process with respect to the Disability Allowance.**

The way forward

Support and funding

Clearly there are gaps in the provision of services for disabled children and parents often feel frustrated by the lack of assistance. They also find services are not well integrated, while cost may be a barrier to privately provided tutoring and other services. Service provision is also inconsistent, especially education. Services necessary to enable disabled children to be included at school and in the wider community should be available on the basis of need, not accidents of geography or parents' social capital.

This raises the question of what might be a way forward? How might we think about ways to help all disabled children reach their potential, and enable them and their families to live in some measure of financial security?

The answer is not immediately obvious: there are few examples of support systems for the disabled working well *for the disabled*. Bolted on to existing service structures, services for the disabled appear to have been designed to minimise both the administrative burden and cost to the public sector. It is also clear from the reports on New Zealand's implementation of the *Disability Convention* that the disabled themselves seek to have a greater voice on decisions that affect their lives. Therefore any changes must be made in consultation with the sector: "[That] the New Zealand government provide resources to whānau hauā [Māori disabled people] and their representative groups to work with government to develop and put into effect a kaupapa Māori model of partnership to implement the Convention" (Disability Community of Auckland, 2014, pp. 11-12).

Parents themselves were very clear about what they believed would help: individualised programmes and services that wrapped around families and supported all the family. The model suggested here is therefore one informed by research and interviews with the caregivers spoken to for this project. It is also consistent with the World Health Organisation's 2011 report on disability (World Health Organisation, 2011). In the first instance, and in line with calls New Zealand disability groups, WHO argues changes should include the views of people with disabilities to identify gaps and priorities to reduce health inequalities and plan improvements for access and inclusion (World Health Organisation, 2011, p. 82). While environmental issues (for example access to services and mobility for the disabled) need to be addressed, individualised interventions, as well as targeted interventions for disadvantaged groups, were seen by parents to be the most effective way of assisting their children.

The issues and solutions identified by parents point to an individualised funding and service delivery model, sometimes called the family-centred practice (Hiebert-Murphy, Trute, & Wright, 2011). A key recommendation from the UK's *Final Report on Disability* was "ensuring services are centred on disabled children and their families, not on processes and funding streams"; and in New Zealand: "Provision of holistic person-centred coordination around the person with autism and their family (without ring-fencing) is now urgently required" (Stace, 2011, p. 254). One parent eloquently summed up: "there needs to be a programme of work around children and their families" to ensure they get timely and appropriate services to meet their needs. Every family is unique, and all the parents interviewed commented on the lack of flexibility of existing services, with most noting that "everyone is different."

Clearly, support encompasses income and access to services. Better services to address the health and social inequalities faced by many disabled children may include (Shahtahmasebi et al., 2011, p. 669):

delivering intensive early intervention for pre-school children with, or at risk of, significant disabilities or early cognitive delay; ensuring that sustainable high-quality childcare is available for all disabled children and that benefit regulation ensures that the availability of childcare actively supports opportunities for the parents of disabled children to enter employment; the introduction of health checks for family carers; and reviewing the housing needs of families with disabled children in order to develop specific policies to significantly improve the quality of such housing and develop systems for monitoring progress toward such a goal.

One area of improvement would be to ensure that pre-school providers in low-income areas, or areas with high numbers of migrants, are aware of the services (including culturally appropriate services) available for special needs children and are able to refer them to those services.

Housing is a significant issue for low-income families with disabled children, and must be addressed as part of any review of children's services. Disabled children need safe, adequately fitted-out, permanent housing, and must be a high priority for social housing. The Children's Commissioner notes that not only do many disabled children live in housing that is unsafe, cold, damp and not sufficiently accessible, , but their families may face other problems with housing including:

- lack of appropriate modifications to enable disabled children to be cared for;
- forgoing employment and other opportunities because of inadequate housing;
- lack of accessible exits in the event of an emergency (Expert Advisory Group on Solutions to Child Poverty, 2012a, pp. 10-11).

As well as difficulties finding adequate and appropriate accommodation, low-income families with a disabled child are also faced with very high housing costs in Auckland and Christchurch (Collins, 2014; Johnson, 2014), and often have fewer resources to cope with substantial housing costs.

Practically, one way to do this is through individualised funding, as trialled in Australia and supported by CCS Disability Action (CCS Disability Action, 2012, p. 14). A 2010 review of individualised funding in Australia found that overall "people with disabilities and their families who have individual funding reported a similar or higher level of personal wellbeing compared to the rest of the Australian population"; that people who had changed to individualised funding reported that their current support was better than that which they had had in the past; and, importantly, that their new arrangements had improved the wellbeing of their families (Fisher et al., 2010, p. 53). People on individualised funding also reported higher levels of satisfaction with personal relationships, better community participation, and improved "control, choice, independence and self-determination" (Fisher et al., 2010, pp. 55-58).

Recommendation: That an individualised funding model be further investigated to provide, where appropriate, tailored programmes and services, including housing, to disabled children and their families. One model that could be trialled is a key worker and advocate for families.

Concerns about individualised funding focused chiefly on security of funding; future security and the option to change levels of support in the future; and the ability of individuals to manage their own funding (some relied on family to do this); relationships with service providers; and restrictions within their support packages. Outcomes varied by type of disability (Fisher et al., 2010, pp. 53-58), and there is also the possibility of exploitation of funds by unscrupulous family members or service providers.

Overall, the Australian review points to some problems but generally the outcomes, especially social outcomes and participation, were superior for persons who had individualised funding packages.

Advocacy

At present there is no specialist funded agency to advocate for parents or deal with disputes between providers and parents (or other disabled persons). Some existing advocates, for example the Disability Law Centre in Mangere, do excellent work despite limited resources and the constant threat of closure. However better access to advocates and dispute resolution (for example appeals pursuant to section 10 of the Education Act so parents can get education resourcing for their children) is required.

The DCA has urged the appointment of a dedicated Disability Commissioner (Disability Community of Auckland, 2014, pp. 4, 15). In addition, disabled children's advocate Colleen Brown³² argues there is an urgent need for something akin to a Parents' Advocacy Council to hold state agencies to account in a "public and authoritative" way. The Office for Disability Issues is not perceived as being independent as it receives administrative support from the Ministry of Social Development and is focused primarily on supporting the Minister for Disability Issues and working with other government agencies.³³

CPAG supports both of these suggestions and considers that a stand-alone, fully-funded Commissioner and advocacy service that would work with the sector and help parents to deal with state agencies would provide support and advice for families. Given the statistics around disabled Māori children, a dedicated Māori advocate would need to be part of any Commissioner's office. DCA note "whānau hauā are largely invisible in the government's report [to the UN Committee on the Disability Convention]" (Disability Community of Auckland, 2014, p. 11) even though the Crown has an obligation to protect and nurture disabled Māori children. This need is heightened by the socioeconomic and health disparities that exist between Māori and others. A similar argument pertains to a Pacific advocacy service. While Pacific children have lower rates of disability, they are also more likely to live in low-income households that are overcrowded and/or in poor condition. The Pacific community embraces a diversity of languages, cultures and abilities and this should be recognised as part of the establishment of an advocacy service.

It is clear from the reports, submissions and other publications of the disability groups that disabled people are articulate, capable of speaking up for their own interests, and must be part of any review of support services for disabled children. It is evident there is a great deal of frustration among advocates and disabled parents, and that despite the *Disability Strategy* now being 14 years old, there is much work to do on developing an equitable support system for disabled children.

Recommendation: That an independent fully-funded Commissioner and advocacy service for disabled persons, children and their parents be established that would work with the sector and help parents to deal with state and other agencies, and provide support and advice for families.

³² Pers comm, August 2014.

³³ See <http://www.odi.govt.nz/what-we-do/index.html>.

Conclusion

There are many factors that contribute to the wellbeing of disabled children and their families. They include children's physical and social environment, public health and safety regulations, the broad policy environment, and public attitudes including discrimination (World Health Organisation, 2011). During a discussion about disabled children one advocate stated that "if poor children were the bottom of the pile, poor disabled children are the bottom of the bottom". Given the socioeconomic disparities among disabled children; the gaps in service provision; the difficulties in obtaining financial and other assistance to which disabled children are entitled; and the patchy and uneven distribution of quality education for disabled and special needs children, this claim is difficult to refute.

Few countries do services for disabled children well, and New Zealand is one of many who fall short in this regard. In New Zealand disabled children with complex needs are increasingly cared for at home, yet our financial support and services for families have not caught up with this profound change. This is reflected in part by the lack of coordination among agencies providing services to children. Education stands out as being particularly difficult, with access to special education services being inconsistent and hard to get, with not all schools having the level of expertise required to deal with special needs students or refer them to services.

It is difficult to gauge the extent of disadvantage of disabled children or monitor whether strategies to improve their wellbeing are having a positive impact because there is a lack of data about the number, location and socioeconomic and other status of disabled children. The little data that is available is aggregated and offers little useful information for parents or the general public. This lack of publicly available data makes it difficult to assess whether financial and other support is going to those with the greatest need, and hinders the public's ability to hold agencies accountable for service provision. Lack of data is cited by WHO as a problem in most countries, but in New Zealand there are opportunities through the census and existing mechanisms such as the B4 school checks to improve on the available data. Improved data collection is a necessary pre-requisite to improving support and services for disabled children, and must be a priority (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, 2014).

New Zealand has a good international reputation on disability issues, but, from the perspective of children with disability, is not doing well in delivering appropriate and adequately resourced services. New Zealand was an active participant in the drafting of the *Disability Convention*. It has ratified the UN Convention on the Rights of the Child, which also states that governments shall recognise disabled children should enjoy a full and decent life, and that they will facilitate the child's active participation in the community. The government also has an obligation under the Treaty of Waitangi to promote the interests Māori children who are disproportionately affected by both poverty and disability.

For caregivers, acknowledgement of the difficult work they do, along with appropriate levels of support would be welcome. One caregiver summed it up thus:³⁴

It makes you want to shake politicians and tell them that the real heroes in this country are the parents who have daily struggles to get their children up, fed, clothed, accepted at school, resourced, included in their community (all of it) and then do all the other things expected of them - work, home family, be a daughter, sister, wife, [and] mother to all their children.

New Zealand is a long way from fulfilling its promises to disabled children. Disabled children are more likely to live in poverty, and those that do are likely to miss out on services that are not publicly funded, and live in neighbourhoods and attend schools with limited access to support and services. The independent reports to the UN Committee on Disability show clearly where improvements for children need to be made. It is time New Zealand stood by its disabled children to ensure they can participate in their communities and schools on an equal basis with their peers.

CPAG has referenced the EAG's paper on Child Poverty and disability (Working Paper No.21) extensively in this report, and would like to acknowledge the important work of the Office of the Children's Commissioner on child poverty and disability.

34 Colleen Brone, pers comm, August 2014.

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'It shouldn't be this hard': children, poverty and disability

ISBN: **978-0-9941105-8-9**

© February 2015

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