



CCS
disability action
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOĀ

Submission on the Child Poverty Reduction Bill

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Executive summary

- Disabled children are more likely to live in sole parent and low income households.
- Carers of disabled children are more likely to be unemployed.
- Disabled children and their whānau are more likely to face extra costs, resulting in greater rates of material hardship.
- Neither the Child Poverty Monitor: Technical Report or the Household Incomes in New Zealand Report include any data at all on disabled children or disabled parents/carers.
- The norm in New Zealand has been for data collection on child poverty to not include disabled children and disabled parents/carers.
- There was no consultation with any disability expert or related groups in the development of the Child Poverty Reduction Bill. The Departmental Disclosure Statement also failed to identify the Convention on the Rights of Persons with Disabilities as relevant to the Bill.
- The Census now includes the Washington Group Short Set of Questions on Disability. The Short Set is not designed to identify disability status in children, however, and can miss a significant number of children with developmental or psychosocial conditions. The Census also happens on a five-year cycle, which is not regular enough.
- Administrative data cannot provide reliable information on unmet need and disability prevalence as well as social and economic outcomes for the whole disability population.
- Because there are no sources of data on disability that could meet the Bill's requirements, we are deeply concerned that disabled children and disabled parents/carers will be left out of the Government's targets and the Statistician's reports.
- The Bill needs to make it explicit that disabled children and the children of disabled parents/carers are to be included in the Government's targets and the Statistician's reports.

Recommendation

- The Bill requires reporting on the number of disabled children as well as children who have disabled parents/carers in each of the primary and supplementary measures.

Introduction

Requiring the publishing of regular statistics on child poverty is a positive step.

Unfortunately, the current norm in New Zealand is to not collect data on the rate of child poverty amongst disabled children or the children of disabled parents/carers. As a result, we are concerned that disabled children as well as the children of disabled parents/carers will be invisible within the statistics required by this Bill. This in turn will result in policies that do not take into account the experiences of disabled children as well as whānau with disabled parents/carers.

We strongly believe that the Bill should explicitly require the inclusion of disabled children as well as the children of disabled parents/carers in reporting and target-setting.

About us

CCS Disability Action is a community organisation that has since 1935, supported disabled people and advocated for their inclusion in the community. As of May 31 2017, we were providing support to around 4,000 children, young people and adults through our 17 branches, which operate from Northland to Invercargill. Our support focuses on breaking down barriers to participation. We receive a mixture of government and private funding.

The norm is to exclude disabled children and disabled parents/carers from child poverty data and policy-development

Disabled children are more likely to live in sole parent and low income households (Statistics New Zealand, 2016, p. 4; Statistics New Zealand, 2014). Carers of disabled children are more likely to be unemployed¹. Disabled children and their whānau are more likely to face extra costs, resulting in greater rates of material hardship (Parish, Rose, Andrews, Grinstein-Weiss, Richman, & Dababnah, 2009; Browne, 2010, p. 65). Despite all this, both disabled children and disabled parents/carers have often been absent in research and data collection on child poverty.

For example, neither the Child Poverty Monitor: Technical Report or the Household Incomes in New Zealand Report include any data at all on disabled children or disabled parents/carers (Duncanson, Oben, Wicken, Morris, & McGee, 2017; Perry, 2017). The

¹ Unpublished data from the 2013 Disability Survey, available on request.

norm in New Zealand has been for data collection on child poverty to not include disabled children and disabled parents/carers. Unless this Bill explicitly makes it a requirement that data on poverty amongst disabled children and disabled parents/carers is collected and published, we are simply not confident that they will be included.

We note that there was no consultation with any disability expert or related groups in the development of the Child Poverty Reduction Bill. The Departmental Disclosure Statement also failed to identify the Convention on the Rights of Persons with Disabilities as relevant to the Bill (Ministry of Social Development & Department of the Prime Minister and Cabinet, 2018, pp. 8, 12). In our view, the Convention on the Rights of Persons with Disabilities has a number of relevant articles.

Article 7 of the Convention on the Rights of Persons with Disabilities requires the government to ensure disabled children have the same freedoms as other children. Article 28 of the Convention requires the government to ensure access by disabled people to poverty reduction programmes, especially woman and girls with disabilities. Article 28 also requires the government to ensure disabled people and their families living in poverty have access to assistance with disability-related expenses. Article 31 of the Convention requires the Government to collect appropriate data to enable them to formulate and implement policies to achieve the Articles of the Convention (Convention on the Rights of Persons with Disabilities). It is difficult to see how any of these articles can be fully realised, unless reliable data is regularly collected on the number of disabled children, their whānau and disabled parents/carers who live in poverty, especially data that can then be used to measure progress against targets.

There are no sources of data on disabled children that could meet the requirements of the Bill

The best current data on poverty amongst disabled children and whānau comes from the post census Disability Survey. Unfortunately, in 2012, the Government reduced funding for the disability survey. As a result, the disability survey has gone from a five-year cycle to a ten-year cycle. The next disability survey is now not due until 2023 (Statistics New Zealand, 2015, p. 7; Office for Disability Issues, 2016). This means the disability survey will not happen regularly enough to meet the requirements in the Bill.

The Census now includes the Washington Group Short Set of Questions on Disability. As Statistics New Zealand has acknowledged, however, the Short Set is not designed to identify disability status in children (Statistics New Zealand, 2015, pp. 10, 15). In particular, the Short-Set can miss a significant number of children with developmental or psychosocial conditions (Washington Group on Disability Statistics, 2018). The Census could be used to measure poverty amongst disabled parents and carers, although the Short-Set also struggles to identify adults with learning disabilities and/or experience of mental health conditions (Grondin, 2016, p. 10). The Census also happens on a five-year cycle, which is not regular enough.

Administrative data while useful should never be the main source of data on poverty amongst disabled children and their whānau. Administrative data only provides information on people who are eligible for and who access disability-related support. The eligibility criteria for disability-related support varies greatly across government, even within the same Act of Parliament². A lack of awareness about what support is available and barriers to applying for support can also result in lower numbers of people accessing support. For example, research by the Child Poverty Action Group has found that awareness of the Child Disability Allowance is low and that people found it difficult to apply for (Suri & Johnson, 2016, pp. 17-18).

As a result, administrative data cannot provide reliable information on unmet need and disability prevalence as well as social and economic outcomes for the whole disability population (Statistics New Zealand, 2015, p. 6). Further, it is well noted in disability literature that eligibility criteria for disability-related support are inconsistent and vulnerable to political considerations (Reisine & Fifield, 1993, p. 164; Barnes & Mercer, 2010, pp. 39-40; Bickenbach, 2008; Roulstonea, 2015, pp. 673-674).

As an example of the instability of administrative data, in 2007 the Ministry of Social Development redesigned medical certificate for the Child Disability Allowance, published a

² In the Social Security Act, the meaning of disability for the Disability Allowance is explicitly linked in the Act to the Human Rights Act definition. By comparison, the definition of disability in the Child Disability Allowance is not explicitly linked to the Human Rights Act definition. Further, the definition for the Disability Allowance requires the disability to last more than six months, for the Child Disability Allowance the disability has to last longer than twelve months.

new guide for doctors and issued new guidelines for Work and Income case managers (Ministry of Social Development, 2007). As a result, the number of children receiving the Child Disability Allowance dropped by almost 20% between 2008 and 2012 (Ministry of Social Development, 2012, p. 99).

Because there are no sources of data on disability that could meet the Bill's requirements, we are deeply concerned that disabled children and disabled parents/carers will be left out of the Government's targets and the Statistician's reports.

Breaking the norm and including disability

The Bill needs to make it explicit that disabled children and children who have disabled parents/carers are to be included in the Government's targets and the Statistician's reports. In particular, there should be data produced on the number of disabled children as well as children who have disabled parents/carers in each of the primary and supplementary measures.

Child poverty is really about family/whānau poverty and household income. The key is therefore identifying the disability status of the children and adults in the household. Simply identifying a single disabled child will allow comparisons between households with and without disabled children. This is the simple comparison that data from the Disability Survey allows (Statistics New Zealand, 2014). Of course vastly more insight would come from being able to compare households with different numbers and percentages of disabled children as well as households with disabled parents/carers.

Statistics New Zealand has the expertise to collect quality data on the poverty rate amongst households with disabled children and disabled parents/carers. What Statistics New Zealand needs is the mandate, and therefore access to resources, which this Bill can give.

Recommendation

- The Bill requires reporting on the number of disabled children as well as children who have disabled parents/carers in each of the primary and supplementary measures.

Conclusion

Thank you for the opportunity to submit on this important Bill. We believe it is vital that this Bill breaks the current norm around excluding disability in child poverty statistics. We need to make the experiences of disabled children as well as whānau with disabled parents/carers visible to policy makers. Otherwise, we risk leaving these groups further behind. The attached appendix outlines some of the information we currently know about disabled children and their families.

Appendix 1 data and research on disabled children and their families

The number of disabled children

The 2013 Disability Survey estimated that there are around 95,000 disabled children aged between 0 and 14. This is 11% of the total population of children (Statistics New Zealand, 2014). The Disability Survey uses a series of questions about what tasks the child has difficulty with to determine if they have a disability (Statistics New Zealand, 2015, p. 23). As a result, some of these children may not access or qualify for disability services. Some of these children may not identify as having a disability. The Disability Survey provides an estimate of the number of children who have difficulty with everyday activities.

A smaller number of children access disability-related support. For example, as of September 2016, 12,876 children and young people under 20 were receiving Ministry of Health funded disability support services (Ministry of Health, 2017, p. 8). As of July 2016, 8,753 students were receiving the Ongoing Resourcing Scheme (Indicators & Reporting Team, Ministry of Education, 2017). As of June 2015, 34,589 children were receiving the Child Disability Allowance³.

Carers of disabled children

As of June 2015, 50.9% of carers receiving the Child Disability Allowance (which is not means tested) are on a main benefit or superannuation⁴. This indicates that a large number of whānau with disabled children are not working. Often one or both parents have to give up their jobs because of their child's support requirements.

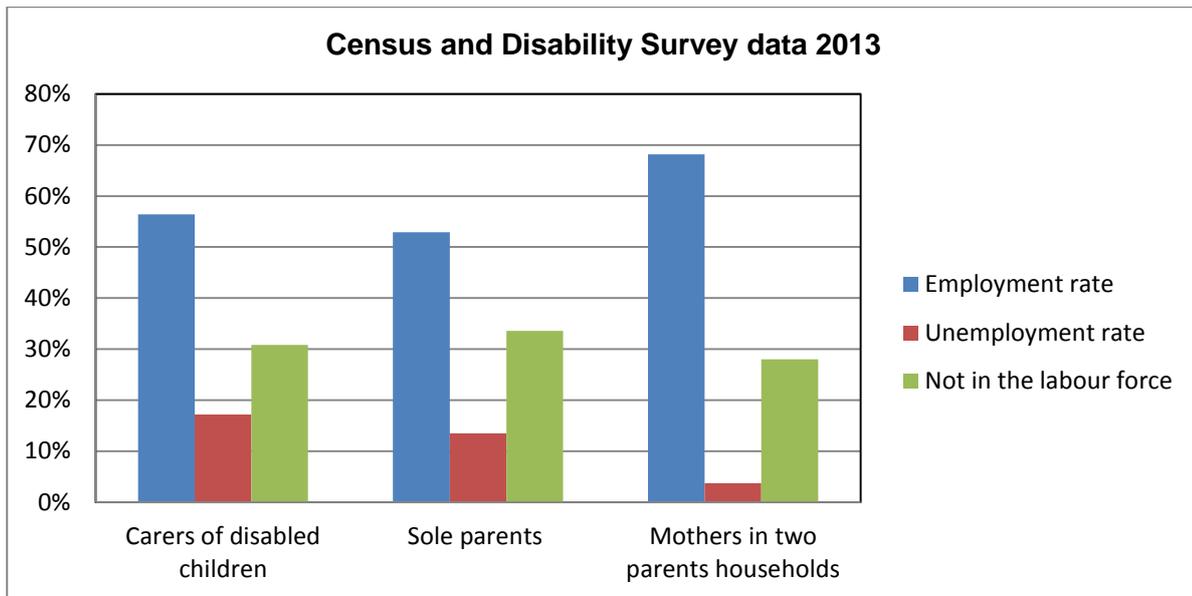
Further working may be more difficult because often the parent is a sole parent. In the 2013 Disability Survey, 30% of disabled children lived in one parent households. 23% in just one parent households and 7% in one parent with other people (but not a couple) households. By comparison, 17% of non-disabled children lived in one parent households. 14% in just one parent households and 3% in one parent with other people (but not a couple) households (Statistics New Zealand, 2016, p. 4). This matches previous research

³ Unfortunately, since the Ministry of Social Development stopped releasing the Statistical Report, this information is only available through Official Information Act requests.

⁴ Data sourced through Official Information Act request

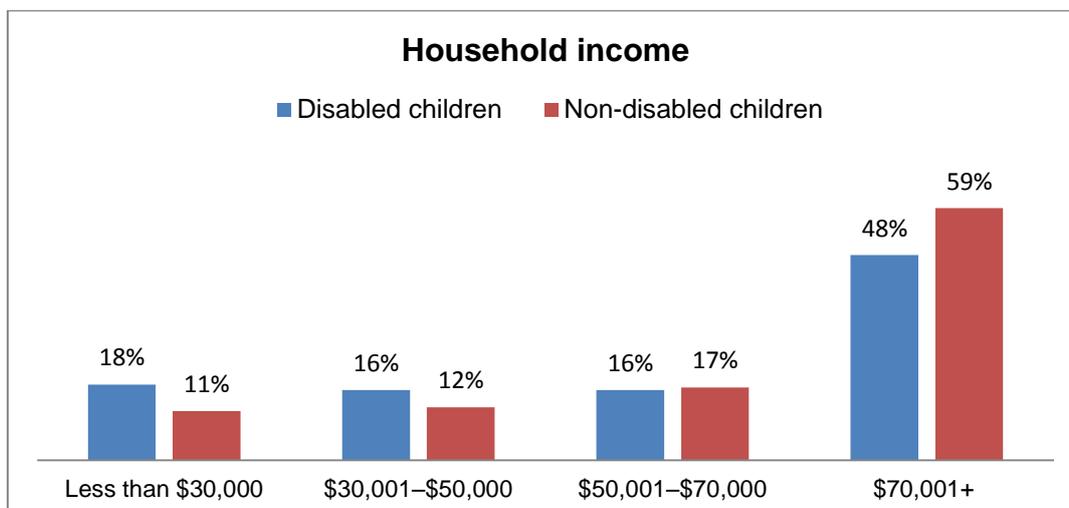
that found almost 26% of people on the Domestic Purpose Benefits had children with disabilities (O'Donovan, McMillan, & Worth, 2004).

In the 2013 Disability Survey, an estimated 17% of primary carers of disabled children were unemployed⁵. This is higher than for sole parents in general or mothers in two-parent households.



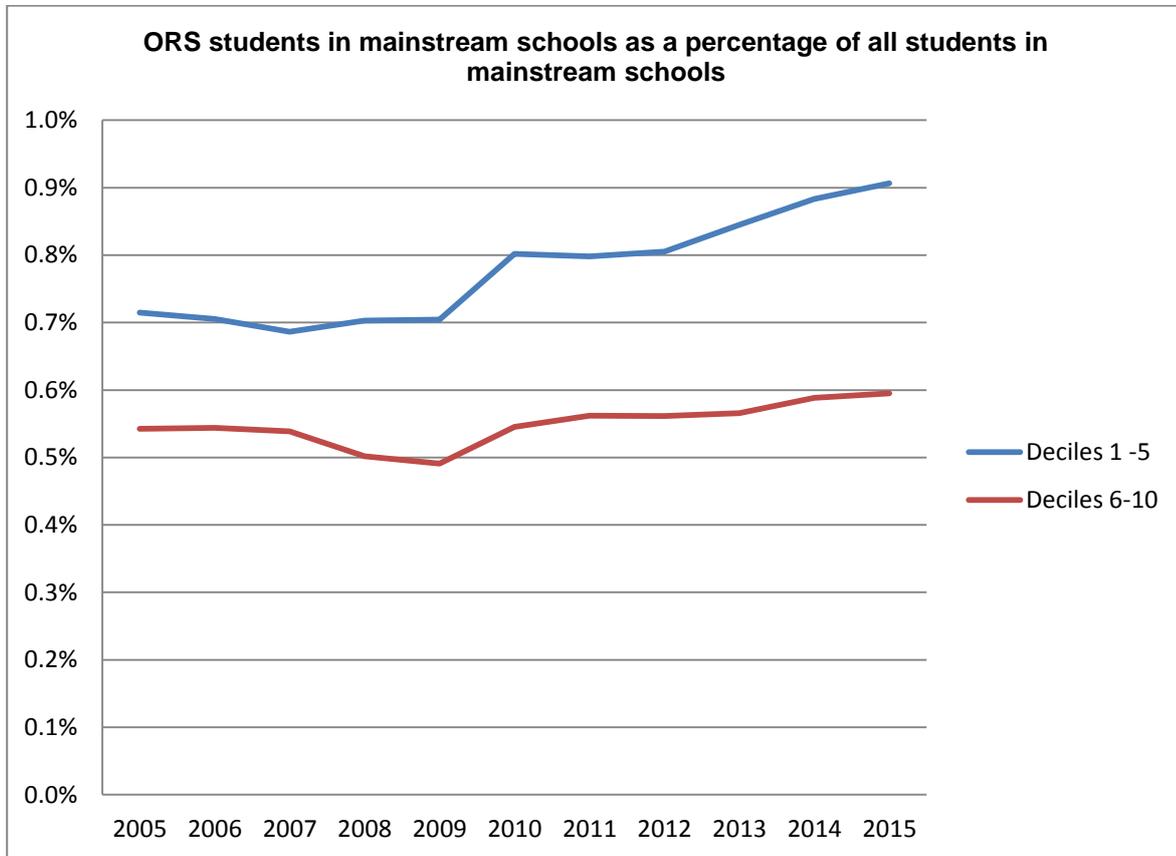
Household income

Disabled children are more likely to live in low income families. The 2013 Disability Survey found that 34% of disabled children live in families that earn under \$50,000 a year, compared to only 24% of non-disabled children.



⁵ Unpublished data from the 2013 Disability Survey, available on request.

Students with disabilities are also more likely to be attending a low decile school. Ongoing Resourcing Scheme students are becoming an increasingly large percentage of students at lower decile schools⁶.



Higher costs, discrimination and inaccessible mainstream services

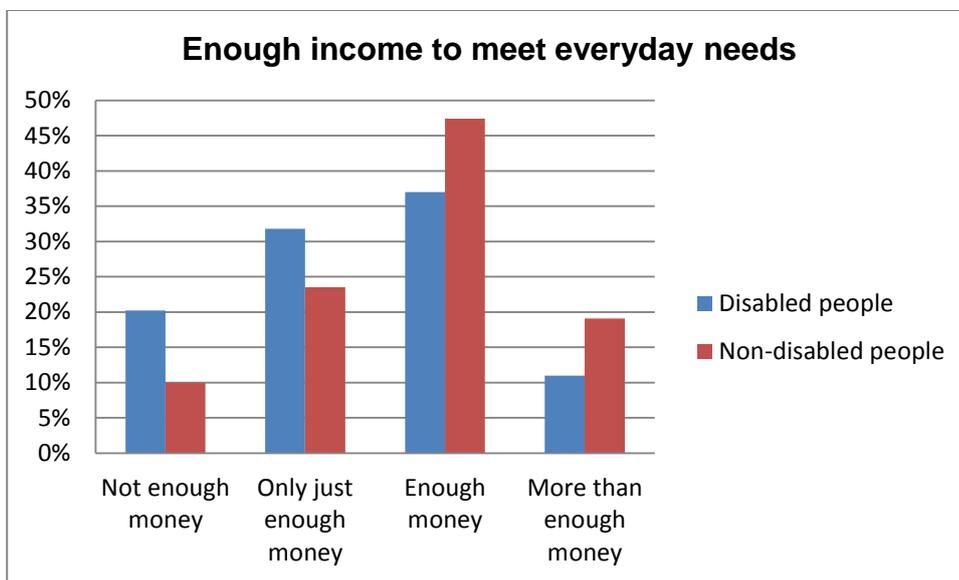
There are often significant extra costs involved in raising children with disabilities (Browne, 2010, p. 65). These costs are because of barriers in society, such as the poor physical accessibility of buildings, transport and infrastructure as well as negative attitudes towards disability. This can include facilities designed specifically for children, such as playgrounds and afterschool care (Spink, 2016).

Mainstream services are often reluctant to accept children with disabilities because of perceived hassle and resourcing challenges. This is especially apparent in education (Wills & Rosenbaum, 2013, pp. 34-35). Public attitude can prevent children with disabilities

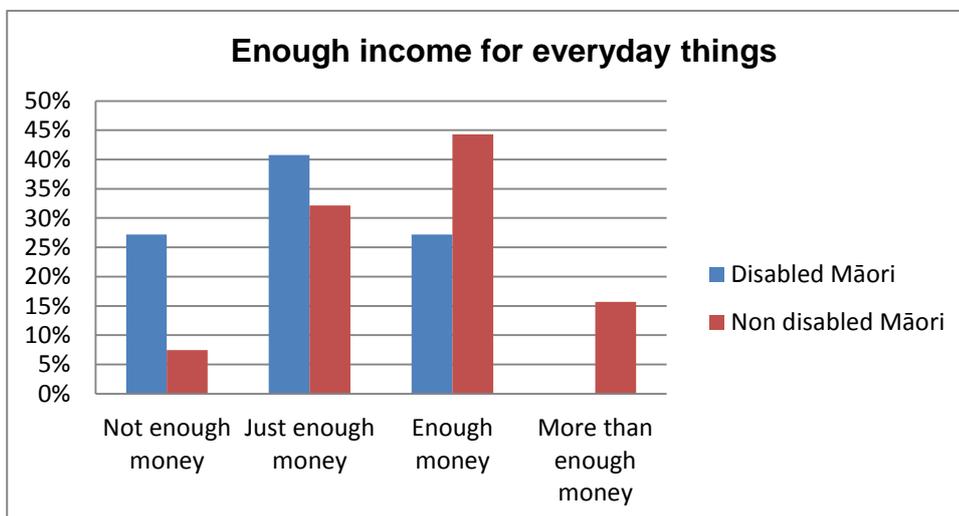
⁶ Information sourced from the Ministry of Education. All students attending special schools have been taken out, both out of the Ongoing Resourcing Scheme students and out of the all students groups. This gives a better picture of the decile ratings as special school are not evenly spread out across deciles (and they do not match the shifting of decile ratings in mainstream schools).

from accessing services. New Zealand Research has found cases of Parents planning to petition early childhood centres for the removal of children with disabilities (Stark, Gordon-Burns, Purdue, Rarere-Briggs, & Turnock, 2011, pp. 11-12)

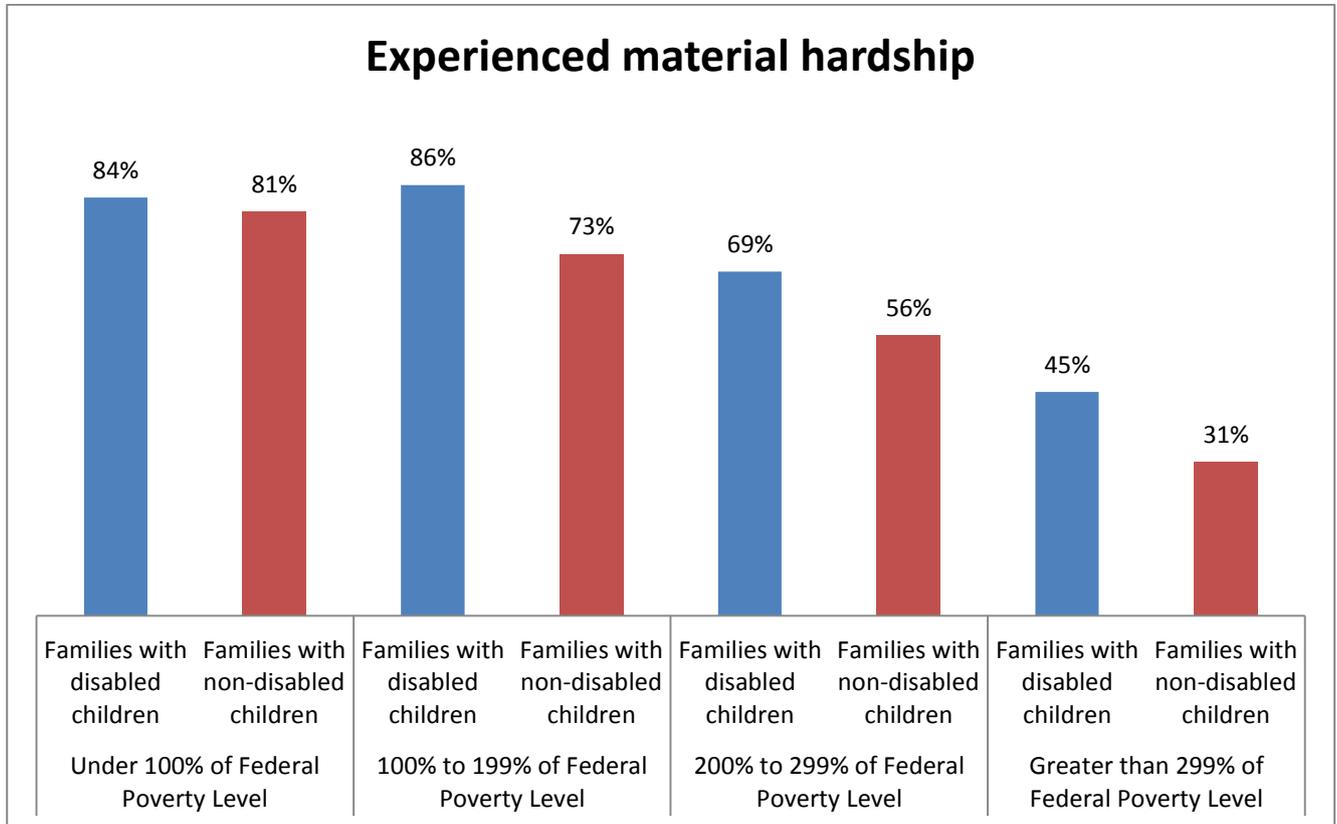
Unfortunately, we do not have specific data on the extra costs disabled children and their whānau face. We do have some New Zealand data and research on adults (Wilkinson-Meyersa, et al., 2014). The 2016 General Social Survey found that 20% of disabled people reported not having enough income to meet everyday needs, compared to 10% of non-disabled people. 52% of disabled people either had not enough or only just enough money, compared to 34% of non-disabled people.



The 2013 Disability Survey using a similar question, found that 27% disabled Māori reported not having enough income to buy everyday things, compared to just 7% of non-disabled Māori.



United States research has found that families with disabled children tend to experience greater rates of material hardship even at higher income levels. The Federal Poverty Level is a poverty threshold based on three times the annual cost of a basic food budget (Parish, Rose, Andrews, Grinstein-Weiss, Richman, & Dababnah, 2009).



We spend a large amount of time advocating for children with disabilities to receive mainstream services or for infrastructure to be made accessible. For example, last year we surveyed our coordinators about the work they are doing under our flagship Supported Lifestyles service. We got data back on the work we have done with 611 child/young people and their whānau that we are currently supporting. Out of these 611 child/young people, 499 (82%) had received some sort of advocacy support from us. This demand for advocacy support is driven by how inaccessible, and sometimes even hostile, mainstream services are for disabled children and their whānau.

Disability and disabled children are often invisible within research generally

There is a general trend for research to exclude disability. Public health researchers have noted that there appears to be a reluctance to address disability in public health (Sherlaw, Lucas, Jourdain, & Monaghan, 2014, p. 447). One study of 533 child development articles found that only 54 studies actually included children with disabilities. 89.9% of articles did

not include disabled children and 69.6% did not even mention children with disabilities. Only 32% of studies provided an explicit reason for excluding disabled children (Feldman, Battin, Shaw, & Luckasson, 2012, p. 1002). Child poverty researchers have also told us that disability-related inequalities are seen as a less interesting or “sexy” research area compared to areas such as ethnic or gender inequalities.

The invisibility of disabled children is due to two reasons. First, a failure to identify or disaggregate disabled children within research results and datasets. This means we cannot be sure disabled children were included or what their unique results might be. This makes the experiences of disabled children and their whānau invisible as well as prevents comparisons between disabled and non-disabled children, which is essential for identifying, and addressing, inequalities. The second issue is that disabled children can be explicitly excluded from participating in research and data collection. This is usually because of perceived concerns about disabled children’s vulnerability to exploitation and their ability to give informed consent as well as inaccessible and non-accommodating research methods (Feldman, Battin, Shaw, & Luckasson, 2012, pp. 999-1000). We need to systematically address both issues.

Bibliography

- Barnes, C., & Mercer, G. (2010). *Exploring Disability Second Edition*. Cambridge: Polity Press.
- Bickenbach, J. E. (2008). Disability, non-talent and distributive justice . In K. Kristiansen, S. Vehmas , & T. Shakespeare, *Arguing about Disability Philosophical perspectives* (pp. 105-123). Taylor & Francis e-Library.
- Browne, N. J. (2010). *Quality of Life for Caregivers of a Child aged 6 - 16 years with Autistic Spectrum Disorder and/or an Intellectual Disability: A Comparative Study*. Massey University.
- Convention on the Rights of Persons with Disabilities. (n.d.).
- Duncanson, M., Oben, G., Wicken, A., Morris, S., & McGee, M. (2017). *Child Poverty Monitor: Technical Report 2017*. Otago: New Zealand Child and Youth Epidemiology Service.
- Feldman, M. A., Battin, S. M., Shaw, O. A., & Luckasson, R. (2012). Inclusion of children with disabilities in mainstream child development research. *Disability & Society*, 997-1011.
- Grondin, C. (2016). *A New Survey Measure of Disability: the Disability Screening Questions (DSQ)*. Statistics Canada.
- Indicators & Reporting Team, Ministry of Education. (2017). *Number of ORS Students by Ethnic Group & Ethnicity as at 1 July 2005-2016*.
- Ministry of Health. (2017). *Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services*.
- Ministry of Social Development . (2012). *The Statistical Report: for the year ending June 2012*. Wellington: Ministry of Social Development.
- Ministry of Social Development & Department of the Prime Minister and Cabinet . (2018). *Departmental Disclosure Statement Child Poverty Reduction Bill*. New Zealand Government.
- Ministry of Social Development. (2007). *Comparison of the Child Disability Allowance with comparable allowances in other countries including the involvement of health professionals to determine eligibility*. Retrieved from New Zealand Parliament: https://www.parliament.nz/resource/en-nz/49SCSS_EVI_49DBHOH_PET3016_1_A142954/79bfb7ba535ac78cb7c0c6613e61803c2a604fbe
- O'Donovan, T., McMillan, K., & Worth, H. (2004). An Employment Barrier: The Health Status of DPB Recipients' Children. *Social policy journal of NZ Te Puna Whakaaro*.
- Office for Disability Issues. (2016). *Disability Survey - update*. Retrieved from Office for Disability Issues: <http://www.odi.govt.nz/what-we-do/better-evidence/update-on-the-disability-survey.html>

- Parish, S. L., Rose, R. A., Andrews, M., Grinstein-Weiss, M., Richman, E. L., & Dababnah, S. (2009). *Material Hardship in US Families Raising Children with Disabilities: Research Summary & Policy Implications*. UNC School of Social Work.
- Perry, B. (2017). *Household incomes in New Zealand: Trends in indicators of inequality and hardship 1982 to 2016*. Ministry of Social Development.
- Reisine, S., & Fifield, J. (1993). Expanding the Definition of Disability: Implications for Planning, Policy, and Research. In M. Nagler, *Perspectives on disability* (pp. 163-172). Palo Alto: Health Markets Research.
- Roulstonea, A. (2015). Personal Independence Payments, welfare reform and the shrinking disability category. *Disability & Society*, 673-688.
- Sherlaw, W., Lucas, B., Jourdain, A., & Monaghan, N. (2014). Disabled people, inclusion and policy: better outcomes through a public health approach? *Disability and Society*, 444-459.
- Spink, E. (2016, January 13). *Mahy playground 'misses the mark' for children with special needs - advocate*. Retrieved from Stuff.co.nz: <http://www.stuff.co.nz/the-press/business/the-rebuild/75817624/margaret-mahy-misses-the-mark-for-children-with-special-needs--advocate>
- Stark, R., Gordon-Burns, D., Purdue, K., Rarere-Briggs, B., & Turnock, K. (2011). Other parents' perceptions of disability and inclusion in early childhood education: Implications for the teachers' role in creating inclusive communities. *He Kupa eJournal*, 4-18.
- Statistics New Zealand. (2014). *2013 Disability Survey: Social and economic outcome tables*.
- Statistics New Zealand. (2014). *Disability Survey: 2013*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (2015). *Measuring disability in New Zealand: Current status and issues: A discussion document for the Working Group on Disability Data and Evidence*. Wellington: Statistics New Zealand.
- Statistics New Zealand. (2016). *Disability and housing conditions: 2013*.
- Suri, J., & Johnson, A. (2016). *Child disability and barriers to support Uptake of the Child Disability Allowance in Otago*. Child Poverty Action Group.
- Washington Group on Disability Statistics. (2018). *Short Set of Disability Questions*. Retrieved March 5, 2018, from Washington Group on Disability Statistics: <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/>
- Wilkinson-Meyers, L., Brown, P., Reeve, J., McNeill, R., Patston, P., Dylan, S., et al. (2014). Reducing disablement with adequate and appropriate resources: a New Zealand perspective. *Disability and Society*, 1540-1553.

Wills, R., & Rosenbaum, S. A. (2013). Parental Advocacy and the Safeguards Necessary for Inclusive Education: New Zealand Lessons for Pacific-Asian Education. *Pacific-Asian Education*, 27-40.