

Proactive Release

Submissions on the Child and Youth Wellbeing Strategy

August 2019

The Department of the Prime Minister and Cabinet has released the following submission received during its public consultation on the child and youth wellbeing strategy.

Some of the information contained within this release is considered to not be appropriate to release and, if requested, would be withheld under the Official Information Act 1982 (the Act).

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child & youth **wellbeing**



DEPARTMENT OF THE PRIME MINISTER AND CABINET TE TARI O TE PIRIMIA ME TE KOMITI MATUA

Child and Youth Wellbeing Strategy – Submission Template

This document is intended for individuals or groups who wish to make a formal submission on the child and youth wellbeing strategy.

Please complete this template and email it to: childandyouthwellbeing@dpmc.govt.nz

A guide to making a submission is available on the DPMC website <u>https://dpmc.govt.nz/our-programmes/child-and-youth-wellbeing-strategy</u>

Submissions will close on Wednesday 5 December.

Please provide details for a contact person in case we have some follow up questions.

Contact Name:	Sam Murray
Email Address:	9(2)□(a)
Phone Number:	
Organisation Name:	CCS Disability Action
Organisation description: (tell us about your organisation	CCS Disability Action is a community organisation that has been advocating for disabled people to be included in the community
 – i.e. who do you represent? How many members do you have? Are you a local or national organisation?) 	since 1935. 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.
Executive Summary:	Recommendations
(Please provide a short summary of the key points of your Submission - 200 words)	 Focus Area 1 explicitly states that disabled children will live in loving homes and be free from abuse, neglect and family violence.
	 Remove from Focus Area 2 the statement that: "the particular vulnerability of disabled children and young people to accidental injury is addressed".
	 Focus Area 11 states the need to remove physical, informational and attitudinal barriers that prevent disabled children from having equal opportunities in society.
	4. In the title of Focus Area 11 the word "improved" should

	be replaced with "equal".
5.	Focus Area 11 states that parents and carers of disabled children will be supported to feel comfortable with their disabled child taking risks to the same extent as other children.
6.	The last statement of Focus Area 11 is strengthened by adding "to enable full and equitable participation" after "quality services and support".
7.	Focus Area 12 has a provision recognising the need for increased mental wellbeing support for disabled children and young people.

Submission Content

Recommendation for Focus Area 1

1. Focus Area 1 explicitly states that disabled children will live in loving homes and be free from abuse, neglect and family violence.

Why we recommend this:

Disabled children and their whānau are diverse and have many strengths. Yet they face large systematic barriers in society from a lack of accessible services and infrastructure to negative public and professional attitudes towards disability. As a result, children with disabilities and their whānau are more likely to live in poverty. Disabled children are also at higher risk of abuse and neglect, by both their whānau as well as formal services.

Out of people receiving Ministry of Health funded disability support services, 19% of those aged between 19 to 28 and 15% of young people aged below 16 have had a finding of abuse or neglect. This is much higher than for the population as a whole (Office for Disability Issues, 2016). For this reason, we feel it is important that Focus Area 1 explicitly states that disabled children will live in loving homes and be free from abuse, neglect and family violence.

Recommendation for Focus Area 2

2. Remove from Focus Area 2 the statement that: "the particular vulnerability of disabled children and young people to accidental injury is addressed".

Why we recommend this:

While well-intentioned, the statement in Focus Area 2 that the particularly vulnerability of disabled children and young people to accidental injury needs to be addressed, could have negative unintended consequences. Disabled children and young people already report being excluded from activities based on perceived, or claimed, health and safety concerns, including crucial activities such as school camps, afterschool activities, and potential workplaces. This statement risks further limiting the opportunities available to disabled children and further increasing social isolation (Koller, Pouesard, & Rummens, 2018). We recommend this statement is removed.

First recommendation for Focus Area 11

3. Focus Area 11 states the need to remove physical, informational and attitudinal barriers that prevent disabled children from having equal opportunities in society

Why we recommend this:

Disabled children are more likely to live in low-income households and experience serious discrimination and barriers in access to education and other services. Often these barriers are caused by society itself, such as the poor physical accessibility of buildings, transport and infrastructure. This can include facilities designed specifically for children, such as playgrounds and afterschool care (Spink, 2016).

Negative attitudes towards disability can also be a prevalent barrier, preventing disabled children from accessing the same opportunities as non-disabled children. 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).

The Focus Area 11 for disabled children notes the importance of quality support and services. Disabled children and their whānau need more than this, however, to have equal opportunities. They need societal and environmental barriers removed. The Focus Area should note the need to remove physical, informational and attitudinal barriers.

Second recommendation for Focus Area 11

4. In the title of Focus Area 11 the word "improved" should be replaced with "equal".

Why we recommend this:

Given the aspiration nature of the Strategy, it seems odd that the goal is just to improve opportunities and outcomes, not aim for equal opportunities and outcomes. This is especially odd, given the Focus Area also states that disabled children should have access to quality support and services in order to enable full and equitable participation

Third recommendation for Focus Area 11

5. Focus Area 11 states that parents and carers of disabled children will be supported to feel comfortable with their disabled child taking risks to the same extent as other children.

Why we recommend this:

Parents and carers of disabled children often do an incredible job, especially considering the barriers they face. Parent and carers, inadvertently, can, however limit the opportunities available to disabled children by being overly risk-adverse. In overseas research about disabled children, parents frequently over-protected their child and this resulted in negative outcomes for the child (Chandramuki, Shastry, & Vranda, 2012, p. 64). It is important that we support parents and carers to feel comfortable with their disabled child taking risks to the same extent as other children (Banks, Maitre, McCoy, & Watson, 2016; Chandramuki, Shastry, & Vranda, 2012).

Fourth recommendation for Focus Area 11

6. The last statement of Focus Area 11 is strengthened by adding "to enable full and equitable participation" after "quality services and support".

Why we recommend this:

We are pleased to see the statement on neurodisability and neurodiversity. We recommend the statement is strengthened to match the one preceding it. It should state "quality services and support to enable full and equitable participation".

Recommendation for Focus Area 12

7. Focus Area 12 has a provision recognising the need for increased mental wellbeing support for disabled children and young people.

Why we recommend this:

Disabled children and young people are 35% more likely to require mental wellbeing support compared to non-disabled children and young people ((McLeod, Ball, Tumen, & Crichton, 2015). There are multiple reasons for this, disabled children and young people are at risk of low levels of social integration, and high risks of bullying and social isolation (Koller, Pouesard, & Rummens, 2018).

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Please note that your submission will become official information. This means that the Department of the Prime Minister and Cabinet may be required to release all or part of the information contained in your submission in response to a request under the Official Information Act 1982.

The Department of the Prime Minister and Cabinet may withhold all or parts of your submission if it is necessary to protect your privacy or if it has been supplied subject to an obligation of confidence.

Please tell us if you don't want all or specific parts of your submission released, and the reasons why. Your views will be taken into account in deciding whether to withhold or release any information requested under the Official Information Act and in deciding if, and how, to refer to your submission in any possible subsequent paper prepared by the Department.



TE HUNGA HAUĀ MAURI MÕ NGÃ TĀNGATA KATOA

Submission on the Child Poverty Reduction Bill

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4 April 2018

Sam Murray National Policy Coordinator

Contents

Executive summary	
Recommendation	
Introduction	
About us	
The norm is to exclude disabled children and disabled parents/carers from child	
poverty data and policy-development	3
There are no sources of data on disabled children that could meet the	
requirements of the Bill	4
Breaking the norm and including disability	
Recommendation	6
Conclusion	
Appendix 1 data and research on disabled children and their families	
The number of disabled children	8
Carers of disabled children	
Household income	
Higher costs, discrimination and inaccessible mainstream services	
Disability and disabled children are often invisible within research generally	
Bibliography	14

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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

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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.

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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.

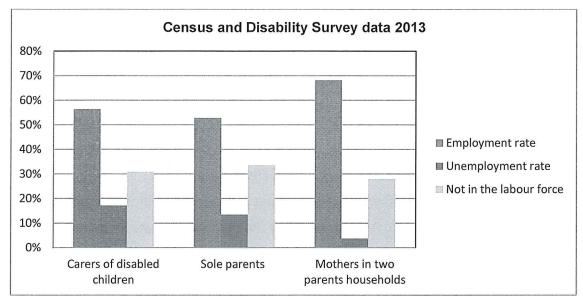
Further working may be more difficult because often the parent is a sole parent. In the 2013 Disability Survey, 30% of disabled children lived in one parent households. 23% in just one parent households and 7% in one parent with other people (but not a couple) households. By comparison, 17% of non-disabled 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

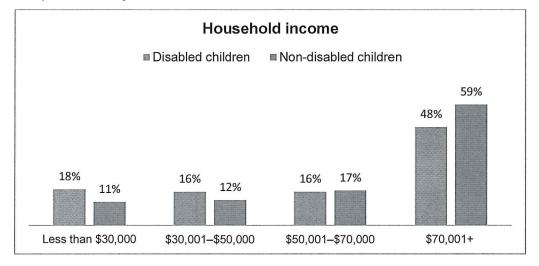
that found almost 26% of people on the Domestic Purpose Benefits had children with disabilities (O'Donovan, McMillan, & Worth, 2004).

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.



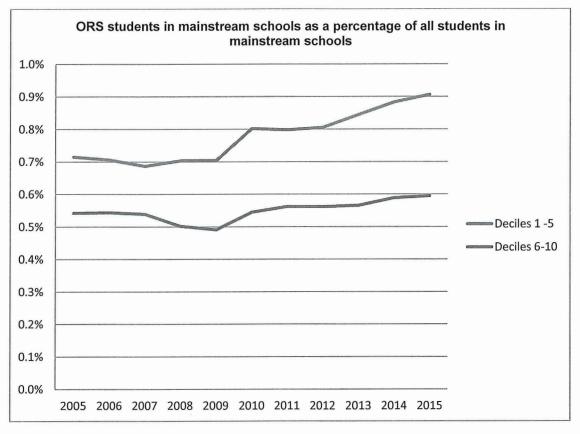
Household income

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

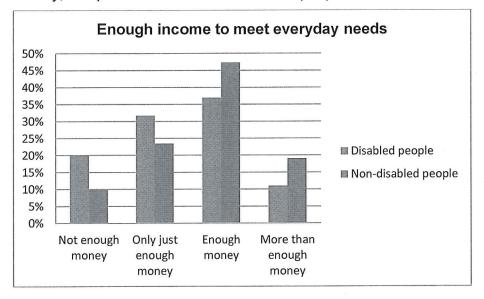
There are often significant extra costs involved in raising children with disabilities (Browne, 2010, p. 65). These costs are because of barriers in society, such as the poor physical accessibility of buildings, transport and infrastructure as well as negative attitudes towards disability. This can include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

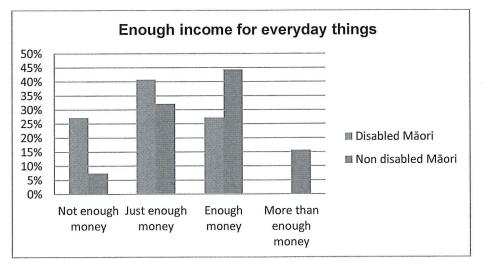
⁶ Information sourced from the Ministry of Education. All students attending special schools have been taken out, both out of the Ongoing Resourcing Scheme students and out of the all students groups. This gives a better picture of the decile ratings as special school are not evenly spread out across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

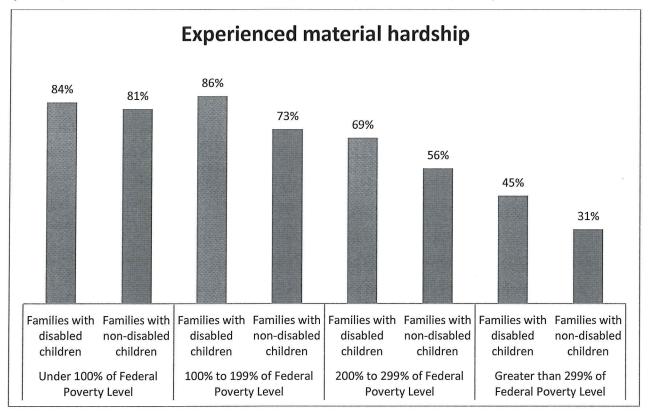
Unfortunately, we do not have specific data on the extra costs disabled children and their whānau face. We do have some New Zealand data and research on adults (Wilkinson-Meyersa, et al., 2014). The 2016 General Social Survey found that 20% of disabled people reported not having enough income to meet 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.

13

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