



# The state of wellbeing and equality for disabled people, their families, and whānau

Sam Murray, 4 December 2019



**ccs**  
**disability action**  
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA

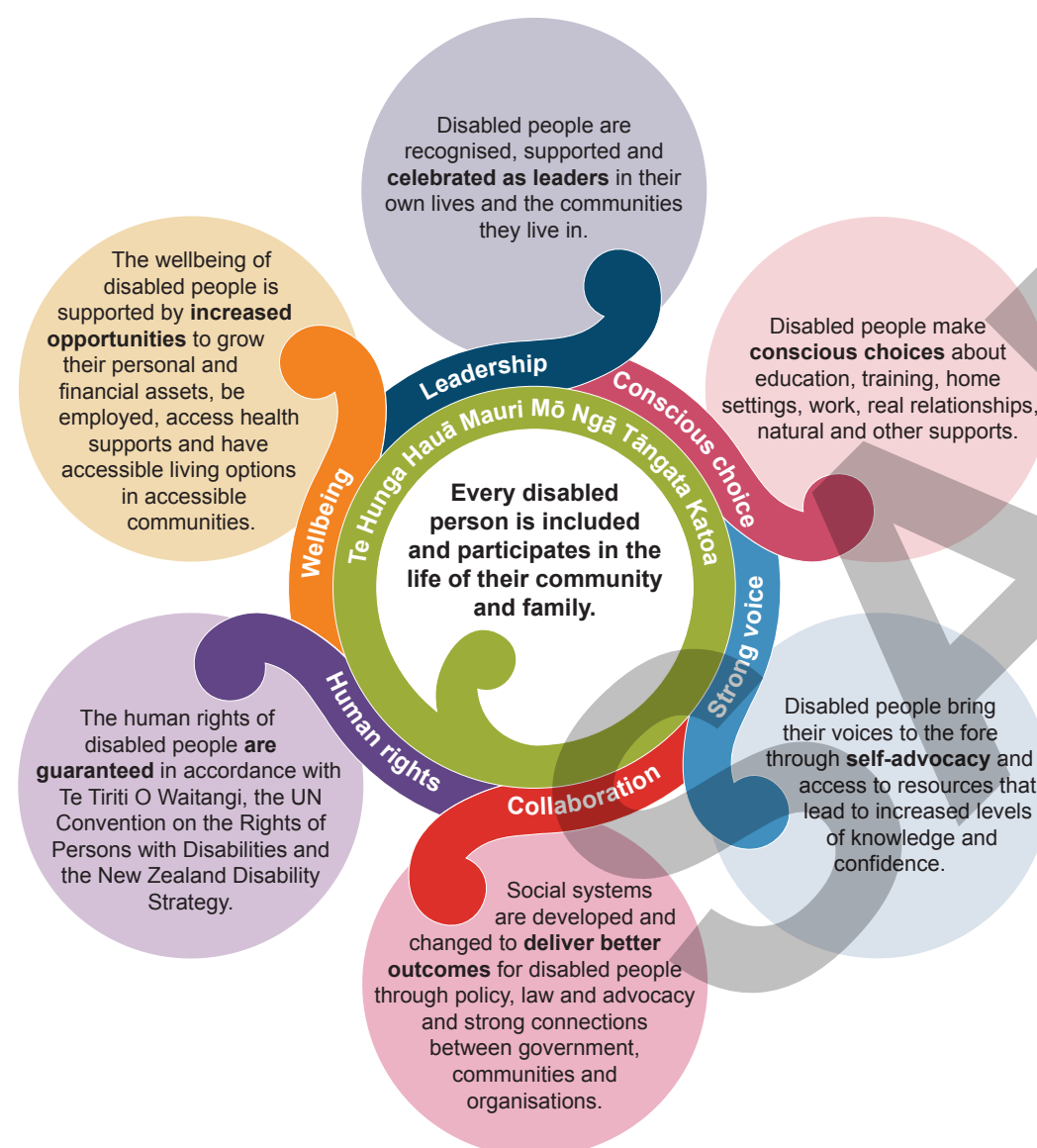
# Welcome to this report

Tena koutou katoa

Te Puawaitanga - the vision of CCS Disability Action holds fast to the principle that every disabled person should be included and free to participate in the life of their communities, families and whānau, as they choose. To achieve this, change is required, and crucial data is needed to ensure barriers are removed and inequality for disabled people is reduced and eliminated so disabled people are truly valued and included.

This will require all New Zealanders to connect and unite, in order to be bold in upholding rights and policies, as well as in the changes we need to make for society, communities, families and whānau.

CCS Disability Action works within a human rights framework and this is reflected in everything we do and in our Strategic Priorities of:



<b>Leadership</b> More disabled people are recognised, supported and celebrated as leaders in their own lives, the community and business.	<b>Conscious choice</b> More disabled people can make conscious choices about education, training, home, work, real relationships and natural supports.	<b>Strong voice</b> More disabled people will grow their self-advocacy skills, confidence, knowledge and personal resources to bring their voices to the fore.
<b>Collaboration</b> Social systems will deliver better outcomes for disabled people through changes in policies, laws and regulations because of advocacy and connections made with and between Government, communities and businesses.	<b>Human rights</b> Human rights will take more of a centre stage in Aotearoa/ New Zealand supported by the foundation documents of Te Tiriti, the UN Convention on the Rights of Persons with Disabilities and the NZ Disability Strategy.	<b>Wellbeing</b> The wellbeing of disabled people is supported by increased opportunities to grow their personal and financial assets, be employed, access health supports and have accessible living options in accessible communities.

The needs of disabled people and our organisation's Strategic Priorities are confirmed, supported and backed by the data in this wellbeing report. There is an ongoing and glaringly obvious need for change to occur to ensure disabled people are included and can function as full citizens in their communities.

I leave with you with a thought to ponder on:

**“Te hunga hauā mauri mo ngā tāngata katoa”**

All people have Mauri, unique life force, and that we value every person equally.

What a fantastic environment Aotearoa New Zealand would be if we all embraced this and brought it to life as citizens.

There is much to be done together.

I wish you well with this ongoing journey we all must take to ensure equality and inclusion of disabled people and I hope this wellbeing report serves you well in achieving this end.

Mauri ora

Mā te wā

**Dairne Kirton**

National President CCS Disability Action



# Shining a light on inequality

Amartya Sen is a famous Nobel-Prize winning economist and philosopher. Sen thought that addressing disability-related disadvantage should be central to work on wellbeing and creating a fairer society. Yet he was amazed that it often was not. Disability is treated as a side topic or ignored entirely. I find this is often the case in New Zealand. In many non-disability specific initiatives, there is just a mention or two of disability without any wider context.

The excuse is frequently because there is a lack of data on disability. This is only partially true. We do lack data in plenty of areas, but there is a considerable amount of New Zealand disability data that is unpublished and/or under analysed. This report uses this data to shine a light on some of the inequality disabled people and their family and whānau experience.

Crucially, this data also shows that this inequality can be reduced. Inequality is significantly lower amongst disabled people over 65 in key areas. Many disabled people over 65 would not have faced disability-related barriers for much of their life. As a result, they are likely to have more financial assets as well as higher social and human capital. This means if we can remove barriers and provide more support, inequality for disabled people under 65 can be lowered to the same amount.

The end goal should be the full elimination of the inequality disabled people experience. As a first step, a measurable and achievable short-term goal is the reduction of inequality amongst disabled people under 65 to the same level as disabled people over 65.

**Sam Murray**  
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CCS Disability Action

## Table of Contents

Welcome to this report	2
Shining a light on inequality	4
About us	6
Ideas that guide this document	7
Who is this report for?	7
Where does this data come from?	8
The number of disabled people	8
Wellbeing data on adults	10
Material hardship barriers	10
Attitudinal barriers	14
Overall wellbeing measures	18
The data shows change is possible	22
Data on disabled children	24
Child, family and whānau poverty	24
The changing demographics of disabled children and young people	30
We need change	36
Conclusion	37
What is data good for?	37
Statistics have stories behind them, and they are glimpses of people's stories	38
New Zealand's story with disability statistics	38
Endnotes	39
Acknowledgements	40

## About us

CCS Disability Action is a community based organisation that has been advocating for disabled people to be included in the lives of their families and communities since 1935. We are the largest pan-disability support and advocacy organisation in New Zealand providing direct support to approximately 5,000 children, young people and adults through our 28 work-sites, which operate from Northland to Invercargill. Our support focuses on breaking down barriers to participation. We receive a mixture of government and private funding.



## Ideas that guide this document

This report is guided by Our Vision, Strategic Priorities, and our core documents.

- Our vision is that every disabled person is included and participates in the life of their family and community.
- Our Strategic Priorities focus on leadership, conscious choice, strong voice, collaboration, human rights, and wellbeing.
- Our core documents are the Convention on the Rights of Persons with Disabilities, the New Zealand Disability Strategy and Te Tiriti o Waitangi.

This means, the report will:

- focus on inequalities between disabled people and non-disabled people; and
- focus on areas relevant to our Strategic Priorities.

## Who is this report for?

Hopefully everyone. We did have two audiences in mind though. We want the report to be useful for people in government, political, community, research and advocacy roles who may have not properly considered disability-related inequality before.

We also hope that the report is a useful resource for anyone working in disability advocacy and self-advocacy. This report aims to empower the voices and leadership of disabled people.

We have tried to keep the report as simple as possible.



# Where does this data come from?

Most of the data in this report has been collected through customised data requests to Statistics New Zealand and data requests to the Ministry of Education. Some of the data has not been published before and/or is not readily accessible. The key sources are the 2013 Disability Survey, the 2018 General Social Survey, and the Ongoing Resourcing Scheme (ORS).

# The number of disabled people

Believe it or not, the latest data we have on the number of disabled people is still the 2013 Disability Survey. We are unlikely to get an update until the 2023 Disability Survey.

The current disability questions in the Statistics New Zealand’s surveys and 2018 Census cannot give us estimates on the number of disabled people. This is not their purpose and they do not cover all impairment types.

We can use estimates, however, from a great Statistics New Zealand tool (see endnotes) with the 2018 Census results to get a very rough estimate of the number of disabled people in 2018. Based on the 2013 Disability Survey percentages for each age group, the number of disabled people should have grown by 133,000 people between 2013 and 2018. By comparison, the total population grew by 440,160 people.

The estimated number of disabled people in that tool is different from the initial 2013 Disability Survey releases. So, depending on which one we use the total number of disabled people should be either 1,151,000 or 1,195,000. Rounding up, this is about 1.2 million disabled people, compared to 1.1 million in 2013.

This 1.2 million includes 143,000 disabled children and young people under 20 years old, 593,000 disabled adults aged 20 to 64 years old, and 415,000 disabled people over 65. Disabled people are a broad section of society and very diverse.

This does not consider changes in ethnic and gender demographics or migration or any change in the disability rate. Just a very rough estimate that considers age.

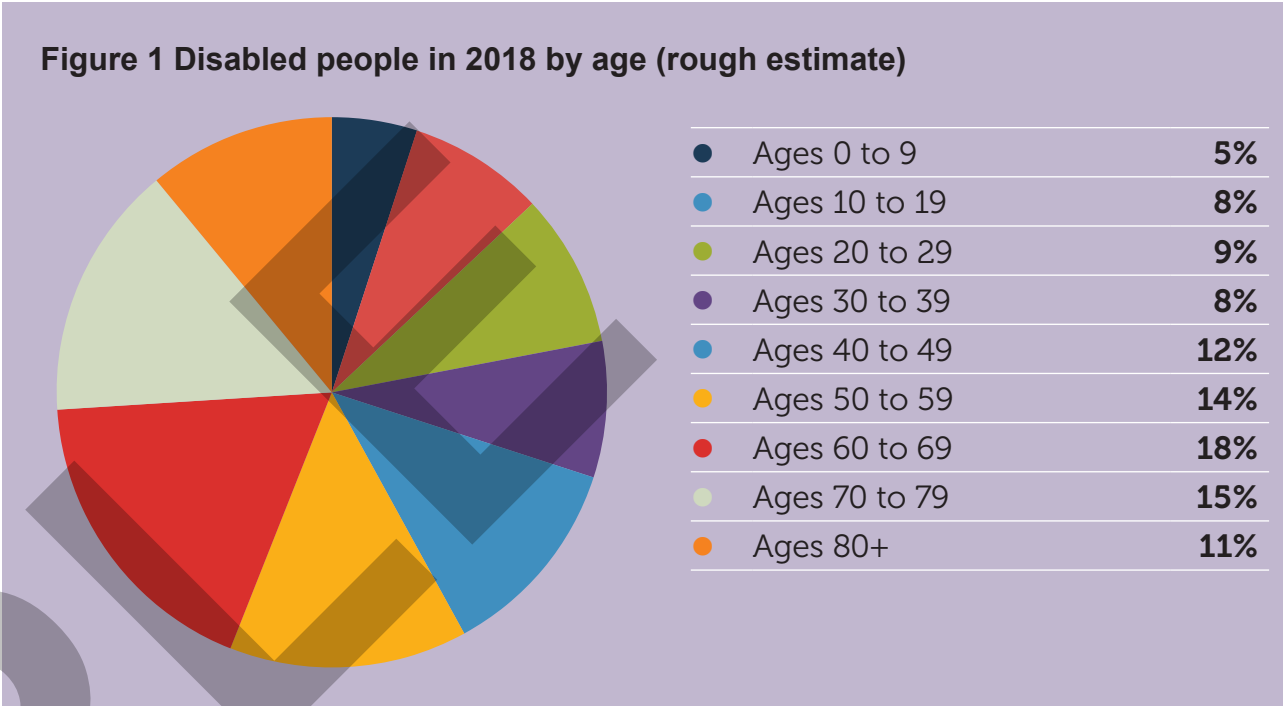


Table 1 Disabled people and non-disabled people in 2018 by age (rough estimate)

	Number of disabled people	Number of non-disabled people
Ages 0 to 9	53,660	566,560
Ages 10 to 19	89,208	525,972
Ages 20 to 29	105,842	576,121
Ages 30 to 39	87,656	536,707
Ages 40 to 49	133,675	485,963
Ages 50 to 59	165,161	458,284
Ages 60 to 69	207,953	302,374
Ages 70 to 79	177,463	149,174
Ages 80+	130,400	41,179

# Wellbeing data on adults

The latest wellbeing data for 2018 shows a wide range of inequalities for disabled people, particularly for disabled adults below 65. Below we look at six areas, broadly divided into three categories; material hardship barriers, attitudinal barriers, and overall wellbeing measures.

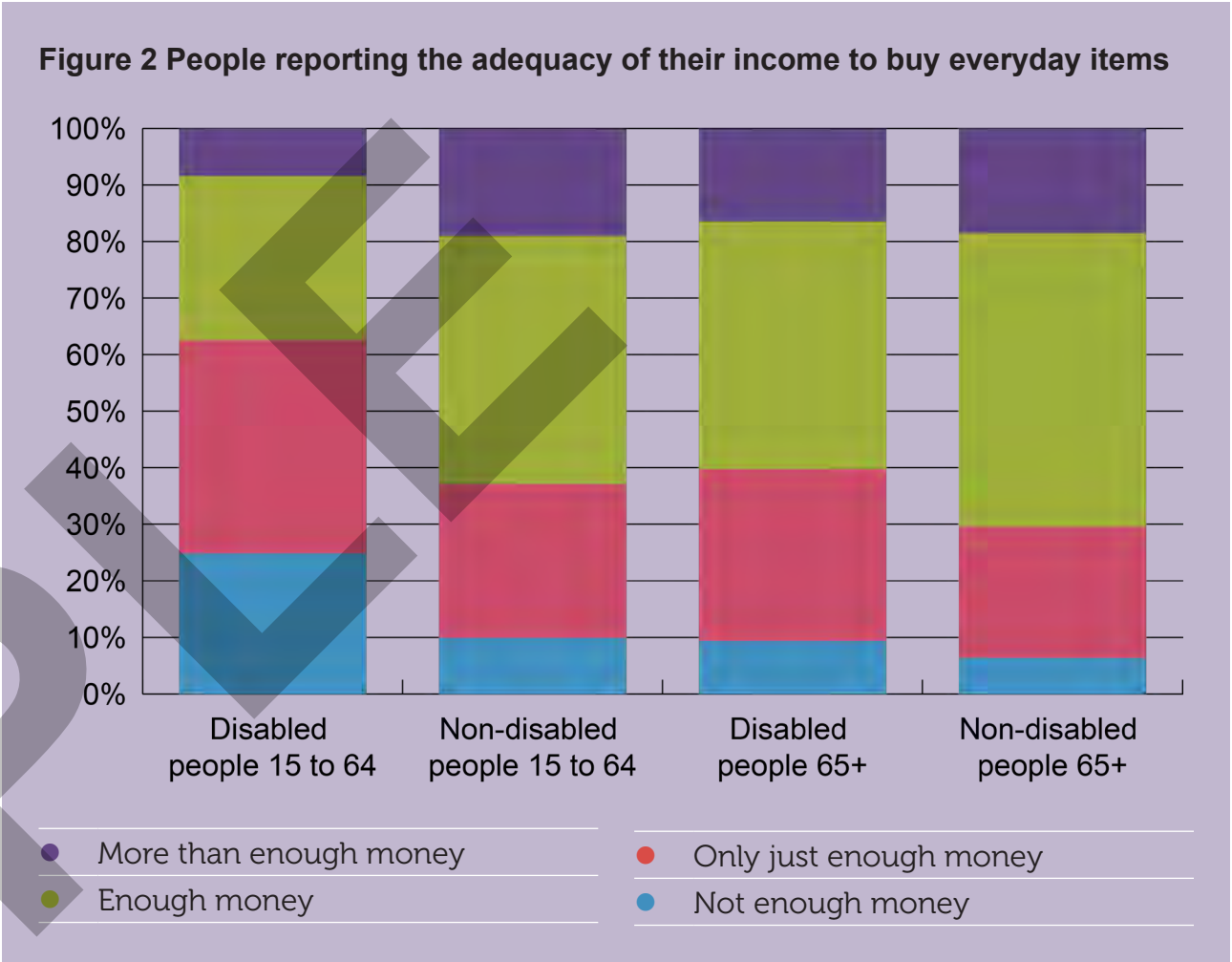
## Material hardship barriers

### Income adequacy

Income adequacy is a very important poverty measure, especially for disabled people. It is based on asking people if they have enough income to buy everyday items. Disabled people tend to have lower income and face extra costs. Because of this asking about people’s ability to buy everyday items gives us better insight into poverty than just asking about income.

Disabled people under 65 are almost 2.5 times more likely to report not having enough income than non-disabled people under 65. This is unacceptably high.

There is some disparity between disabled people over 65 and non-disabled people over 65. Disabled people over 65 are 1.5 times more likely to report not having enough income. There are still income and cost issues with disabled people over 65, but they are less acute.



**Table 2 People reporting the adequacy of their income to buy everyday items**

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
Not enough money	24.9%	10.0%	9.4%	6.4%
Only just enough money	37.7%	27.2%	30.4%	23.2%
Enough money	29.0%	43.8%	43.8%	51.9%
More than enough money	8.5%	19.0%	16.4%	18.6%

Housing affordability

People were asked on a 0 to 10 scale how affordable their house or flat was. 10 was very affordable and 0 was very unaffordable. People were asked to consider housing costs such as rent or mortgage payments, maintenance costs, insurance, power, and rates.

60% of disabled people under 65, put a score of 6 or less, compared to 50.1% of non-disabled people under 65. Disabled people under 65 were also 1.6 times more likely to put a score of 3 or less.

The inequality was much lower for disabled people over 65, but they were still more likely to put a low score for housing affordability than non-disabled people over 65.



Table 3 People rating the affordability of their housing

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
0 to 3	17.2%	10.6%	7.6%	6.4%
4 to 6	42.8%	39.5%	39.4%	35.7%
7 to 8	21.4%	31.1%	27.6%	30.5%
9 to 10	18.7%	18.8%	25.4%	27.3%



Attitudinal barriers

Expressing identity

This question asks people how easy it is to be themselves in New Zealand. Disabled people under 65 are 2.1 times more likely to say it is not easy or very easy to be themselves, compared to non-disabled people under 65. There is some disparity for disabled people over 65, although it is much smaller. Disabled people over 65 are 1.2 times more likely to say it is not easy or very easy to express their identity.

If disabled people find it difficult to express their identity, this may make it more difficult for them to be leaders, have a strong voice, self-advocate, and make conscious choices about their lives. It also means our society has problems with making disabled people feel included, empowered, and comfortable.

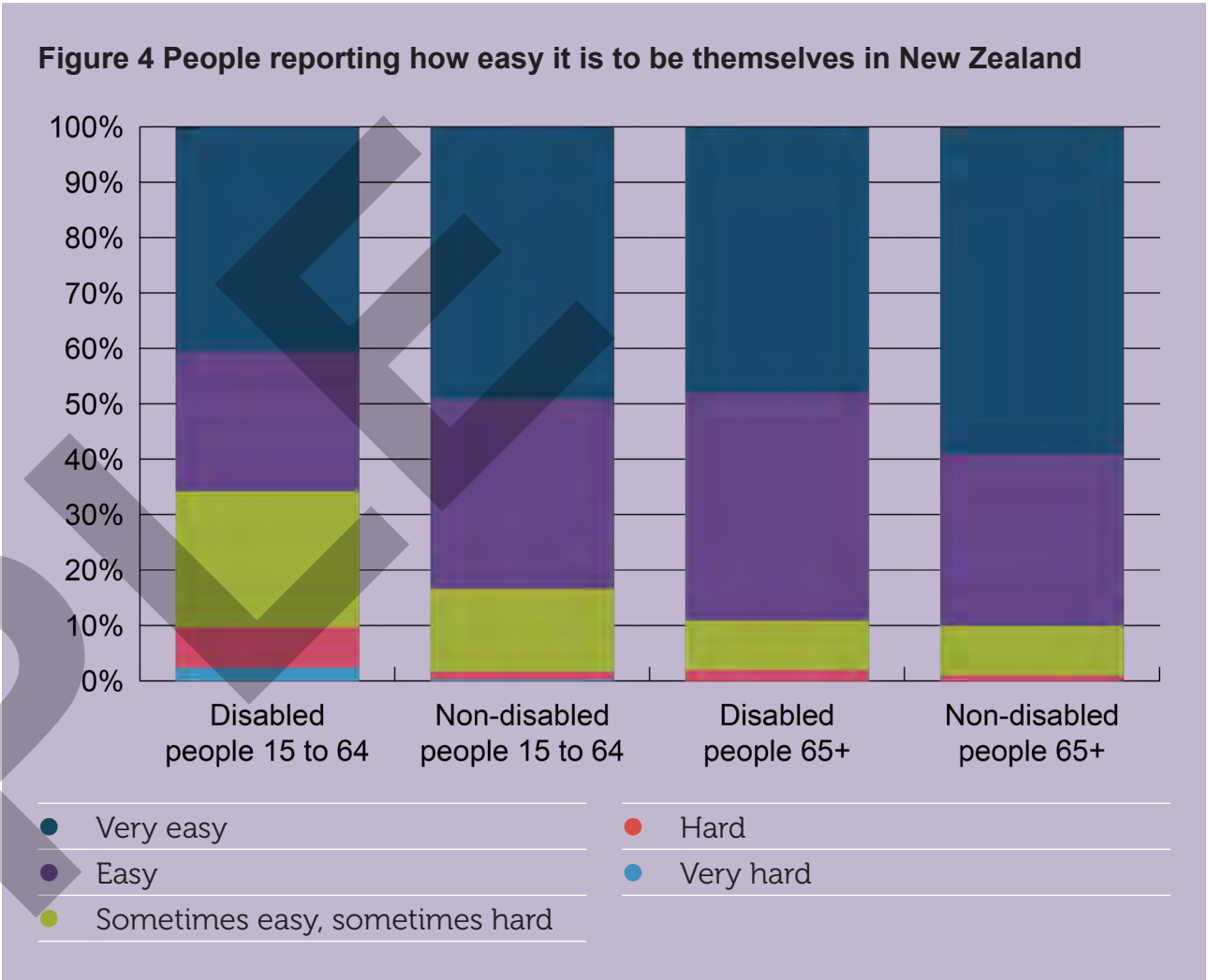


Table 4 People reporting how easy it is to be themselves in New Zealand

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
Very easy	40.6%	49.2%	47.3%	59.2%
Easy	25.1%	34.1%	40.4%	31.2%
Sometimes easy, sometimes hard	24.6%	15.0%	9.1%	8.6%
Hard	7.3%	1.4%	2.0%	0.7%
Very Hard	2.4%	0.3%		



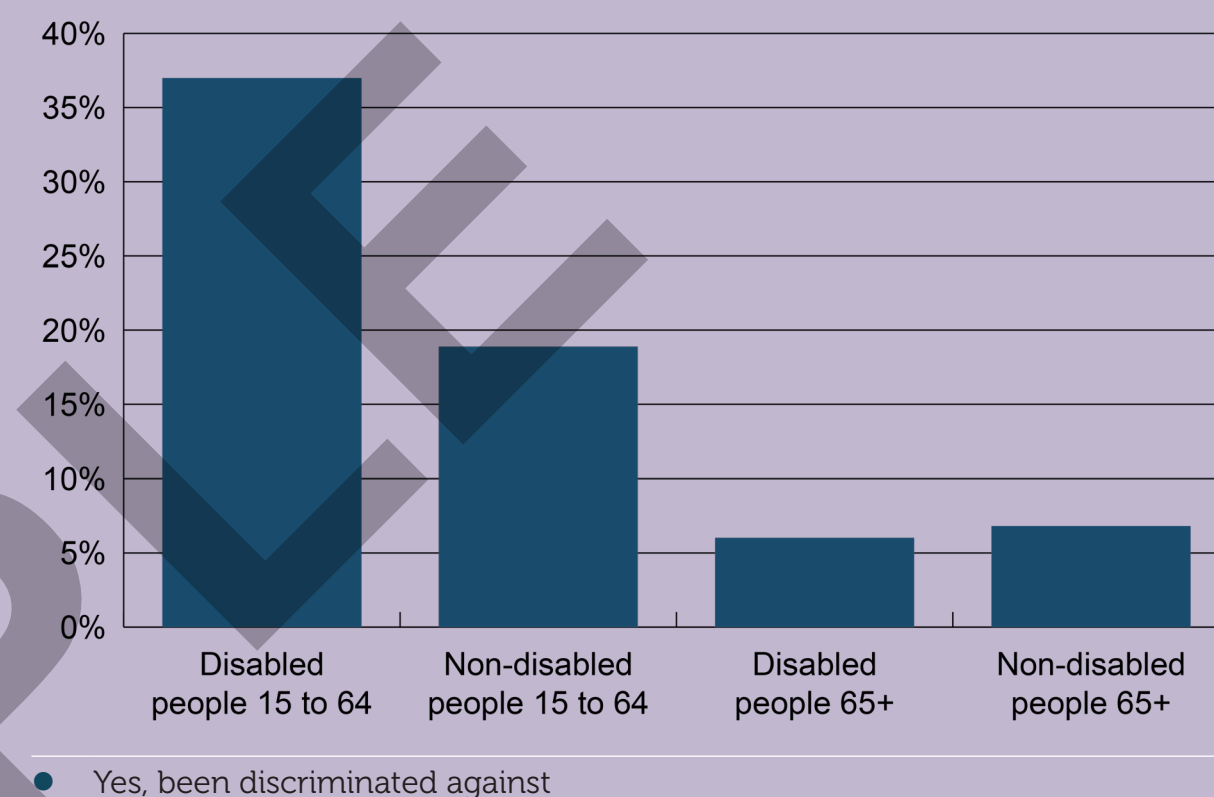
## Discrimination

People were asked if they had been discriminated against in the last twelve months. Discrimination was defined as being treated unfairly or differently compared to other people.

Disabled people under 65 were almost twice as likely to report being discriminated against, compared to non-disabled people under 65. Disabled people over 65 were less likely to report being discriminated against, compared to non-disabled people over 65. This measure shows how different disabled people over and under 65 can be.



**Figure 5 People reporting discrimination in the last twelve months**



**Table 5 People reporting discrimination in the last twelve months**

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
Yes, been discriminated against	37.0%	18.9%	6.0%	6.8%

# Overall wellbeing measures

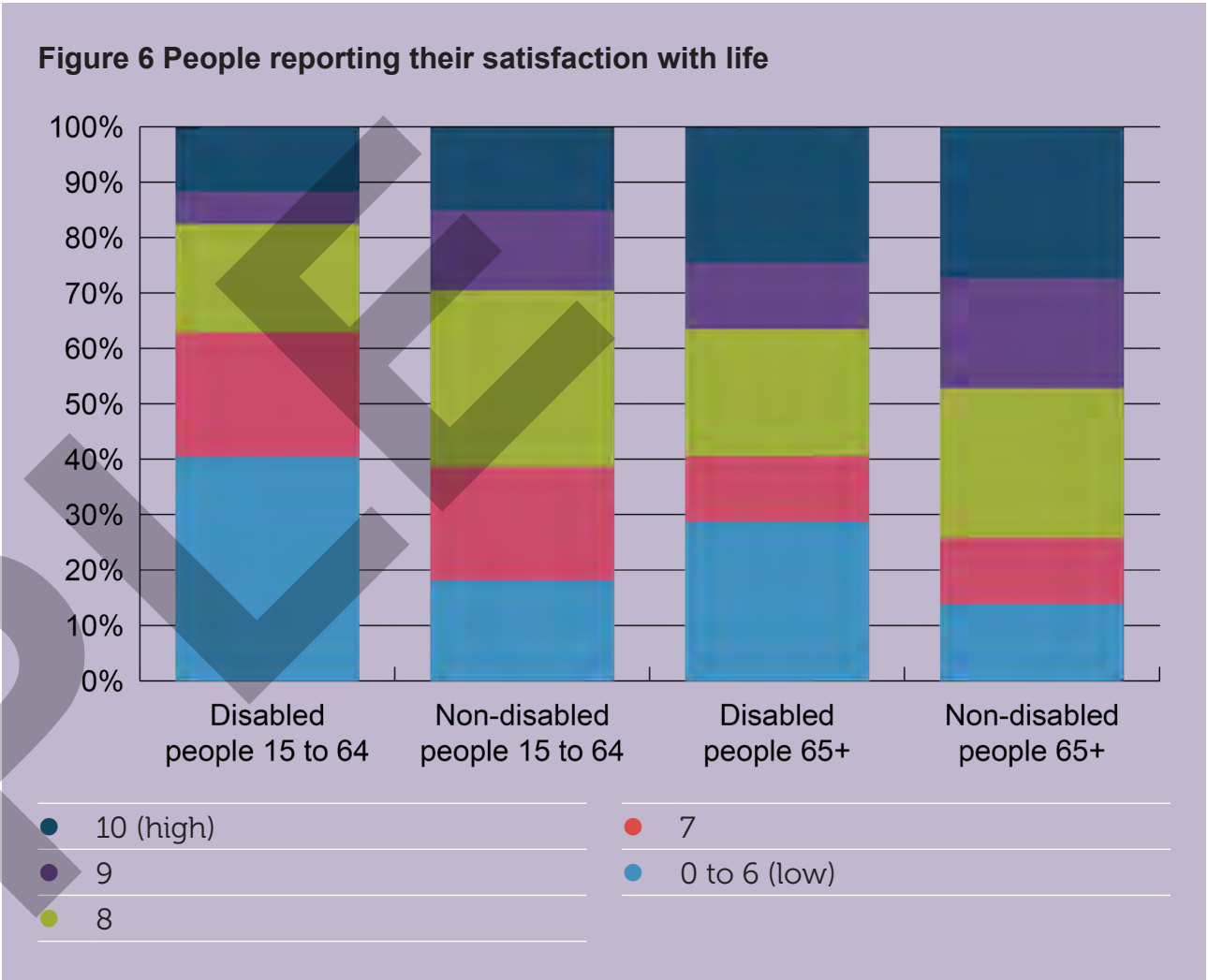
## Life satisfaction

Life satisfaction provides a single measure of how well people think their life is going. People are asked to rate their satisfaction with life on a scale of 0 to 10. 10 is the highest possible satisfaction with life.

There is a high rate of disparity between disabled people and non-disabled people here. Compared to non-disabled people of the same age range:

- disabled people under 65 are 2.2 times more likely to rate their life satisfaction as 6 or below; and
- disabled people over 65 are 2.1 times more likely to rate their life satisfaction as 6 or below.

There is a difference between disabled people under and over 65. Disabled people under 65 are 1.4 times more likely to rate their life satisfaction as 6 or below.



**Table 6 People reporting their satisfaction with life**

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
0 to 6	40.5%	18.2%	28.8%	13.9%
7	22.4%	20.5%	11.8%	12.0%
8	19.6%	31.8%	22.9%	26.9%
9	5.8%	14.5%	12.0%	19.9%
10	11.7%	14.9%	24.5%	27.4%



Family wellbeing

Family wellbeing provides a measure of how well people think their family is doing. The question asks people how well their family is doing in general on a scale of 0 to 10. 10 means extremely well and 0 means extremely badly.

There is still a high level of disparity for disabled people under 65 here, although not as high as for life satisfaction. Compared to non-disabled people of the same age range:

- disabled people under 65 are 1.9 times more likely to rate the wellbeing of their family as 6 or below; and
- disabled people over 65 are 1.3 times more likely to rate the wellbeing of their family as 6 or below.

Disabled people under 65 were also 1.9 times more likely to rate the wellbeing of their family as 6 or below, compared to disabled people over 65.

This measure reminds us that the barriers and disadvantage disabled people face can affect whole families and whānau. Disability-related inequality is not just about individuals, but whole families.

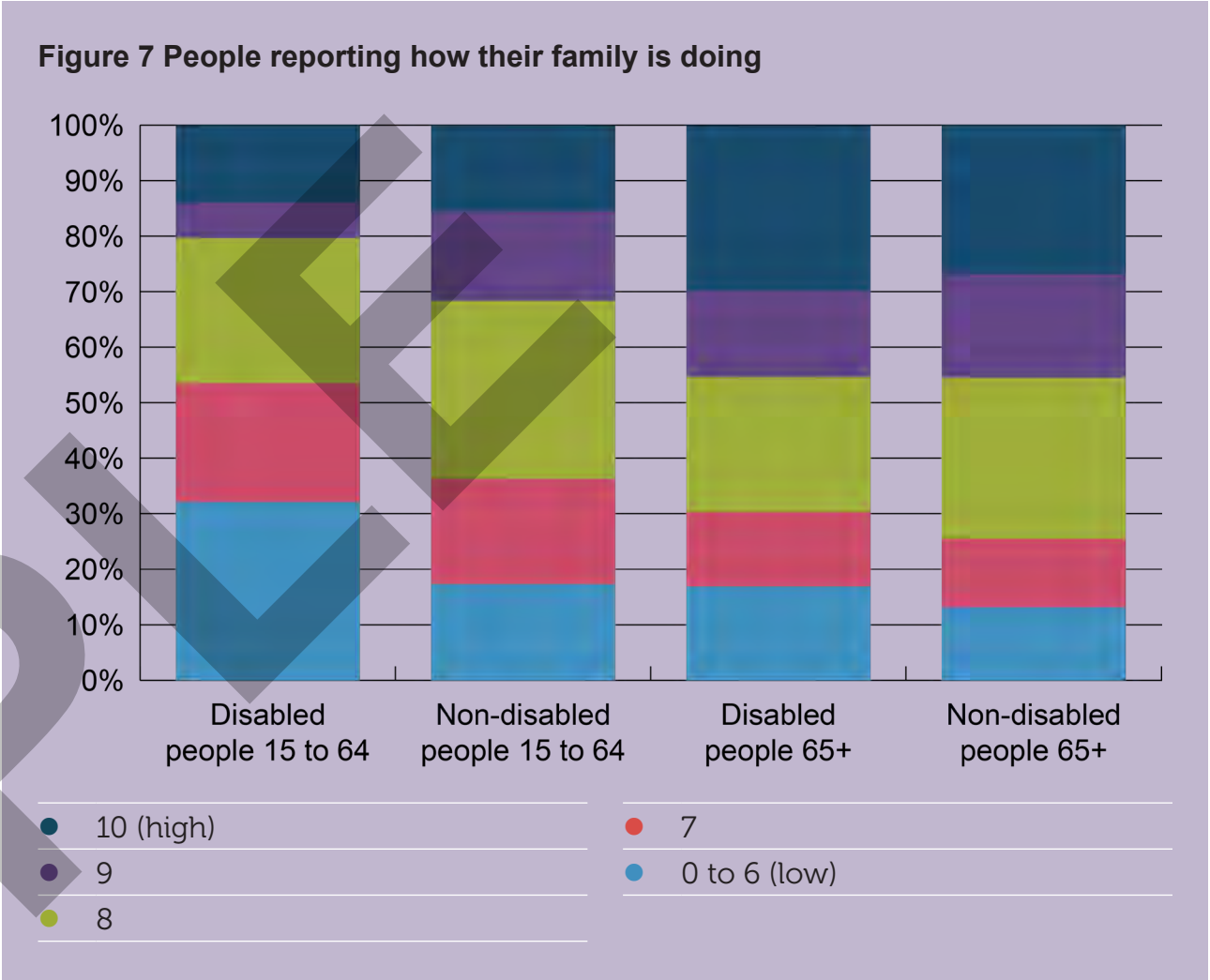


Table 7 People reporting how their family is doing

	Disabled people 15 to 64	Non-disabled people 15 to 64	Disabled people 65+	Non-disabled people 65+
0 to 6	32.2%	17.4%	17.0%	13.2%
7	21.3%	19.0%	13.4%	12.4%
8	26.2%	32.0%	24.2%	28.9%
9	6.4%	16.0%	15.5%	18.7%
10	14.0%	15.6%	29.9%	26.9%



# The data shows change is possible

There are significant differences between disabled people under and over 65. Disabled people over 65 face less inequality than younger disabled people. This is likely to be because disability rates increase sharply over the age of 65. Over 65, a large percentage of disabled people would have acquired their impairment(s) in recent years.

Many disabled people over 65 would not have faced disability-related barriers for much of their life. As a result, they are likely to have more financial assets as well as higher social and human capital than disabled people who have faced barriers for longer. Income support for people over 65, through superannuation, is also higher than forms of income support for people under 65.

This means, if we can increase the financial, social, and human capitals of disabled people under 65, then it is likely their results will look more like those for disabled people over 65.

This would still leave some disparity though. There is one exception to the lower rates of inequality. Disabled people over 65 still have significantly higher rates of low life satisfaction compared to non-disabled people the same age. Disabled people over 65 are still facing some of the same barriers as younger disabled people, especially around the accessibility of the built environment.

This suggests we need a dual approach. We need stronger support that counteracts existing barriers, especially for younger disabled people. We also need to remove barriers both around physical and information access as well as attitudinal barriers.

Support includes direct financial support, such as the disability allowance, as well as support services, such as those available through the Ministry of Health. As the recent Welfare Expert Advisory Group recommended, the Ministries of Health and Social Development need to sit down and come up with a comprehensive system that meets people's disability related-costs.

The current system has been developed in an ad-hoc way with little attention given to whether it is enough to meet disability-related costs. This data is clear, it is insufficient. We need to keep increasing levels of support until disabled people are no more likely to report material hardship than non-disabled people.

For the removal of barriers, as a member of the Access Alliance, we fully support a new law aimed at setting mandatory standards for a wide range of areas from housing to employment to streetscapes to transport. Crucially this law would also set a clear timeframe for all areas to be made fully accessible. That would address the accessibility of the built environment.

Increasing the number of disabled people in leadership roles as well as increasing the voice of disabled people in society may reduce attitudinal barriers. There is good qualitative research on attitudinal barriers (see endnotes for one piece of research).





# Data on disabled children

There has not been any Statistics New Zealand data available on disabled children since the 2013 Disability Survey. This is because Statistics New Zealand has been using disability questions aimed at adults.

This will hopefully change next year. The Household Economic Survey is beginning to collect data on disabled children and their households. Some data may also be available from the 2018 Census, but that is based on the adult questions so will not be very accurate.

We can get some insight from further analysis of the 2013 Disability Survey and from looking at data from the Ongoing Resourcing Scheme (ORS).

## Child, family and whānau poverty

Disabled children are significantly more likely to live in poverty in New Zealand. On the opposite page is data from the 2013 Disability Survey looking at three different poverty thresholds. Households with disabled children are between 1.4 and 1.6 times more likely to be below all three poverty thresholds than households that only had non-disabled children.



**Table 8 Households earning under three poverty thresholds**

Household income	Households with disabled children	Households with only non-disabled children
Less than \$25,001	13.9%	9.6%
Less than \$30,000	17.7%	10.8%
Less than \$40,000	27.8%	18.3%

The impact of this is larger than it may initially seem. This is because if disabled children are more likely to live in poverty, it follows that their siblings and parents are also more likely to live in poverty. Likewise, because disabled adults are more likely to live in poverty, then their children will also be more likely to live in poverty.

We currently lack New Zealand data on family composition and disability, but we can look at data from the United Kingdom, which should be broadly similar. In the 2017/18 Family Resources Survey, 8% of all children were disabled children, however, 31% of children lived in a family where at least one member was a disabled person. This included 23% of children who had a disabled parent. Disabled parents are an often-overlooked group with limited support available. The definition of family used here was only immediate family; a single adult or a married or cohabiting couple and any dependent children.

The United Kingdom data shows that almost a third of all children may be affected by disability-related inequalities. This shows the wide reach of disability-related inequalities and barriers.

Income adequacy

The 2013 Disability Survey also asked about income adequacy. As mentioned, income adequacy can be a better measure of poverty than just income, especially for disabled people. The table below compares this data with data from the 2012 General Social Survey. Note the comparison is a bit different from the ones above. This comparison is between the carers of disabled children and all parents. This will underestimate the level of inequality because carers with disabled children are included in the all parents' data too.

The carers of disabled children are 1.5 times more likely to report not having enough income than all parents. 63% of carers of disabled children say they do not have enough money or only just enough money, compared to 46% of all parents.

Compared to disabled people age 15 to 64, the carers of disabled children are slightly less likely to report not having enough income (20.2% compared to 24.9%) but are slightly more likely to report having only just enough money (42.6% compared to 37.7%). Both sets of data are relevant for child poverty measurement because some disabled adults are parents.

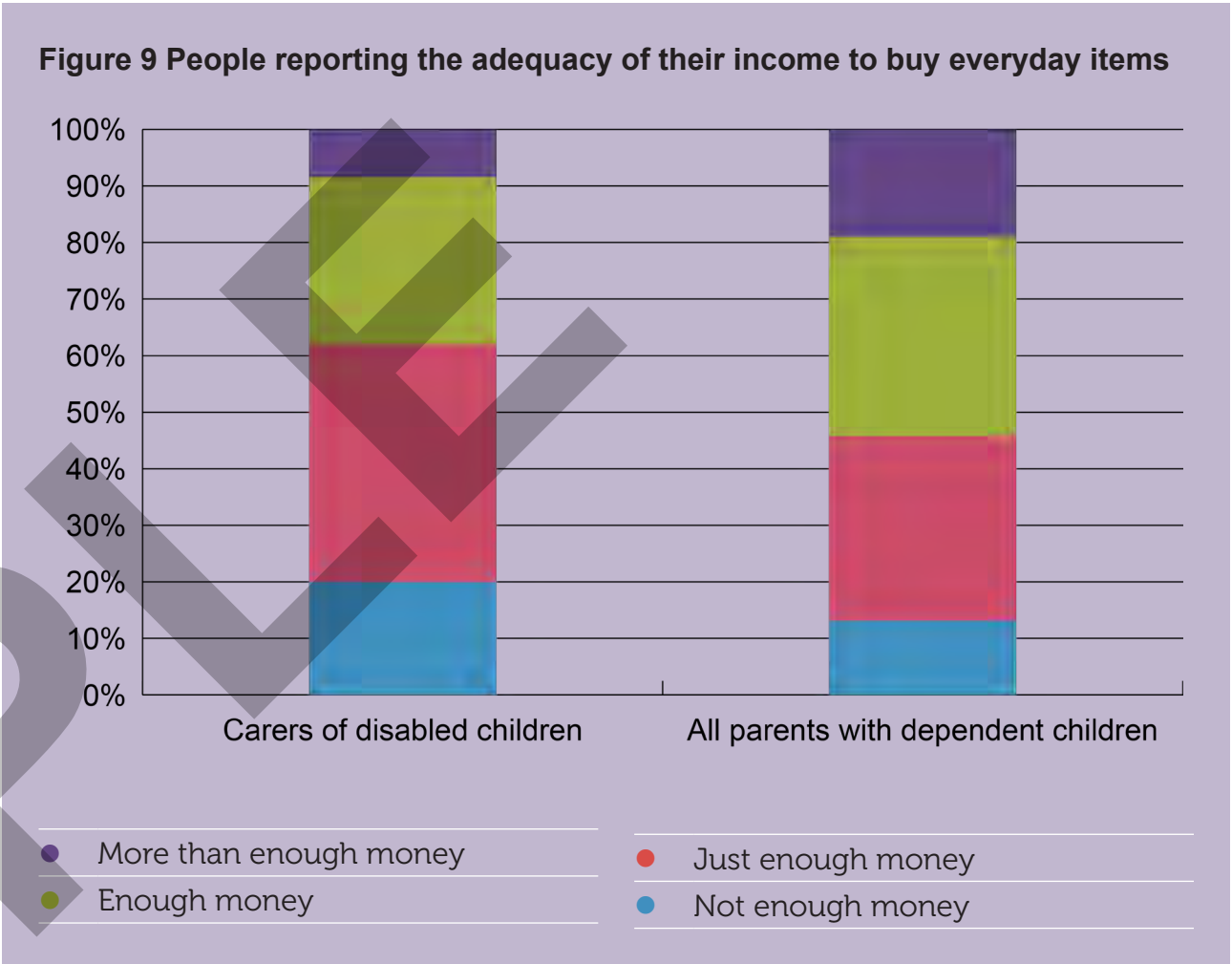


Table 9 People reporting the adequacy of their income to buy everyday items

	Carers of disabled children	All parents with dependent children
Not enough money	20.2%	13.2%
Just enough money	42.6%	32.6%
Enough money	29.8%	35.2%
More than enough money	8.5%	19.1%



Poverty and school decile

Until the Household Economic Survey data starts including disability, we lack any regularly updated poverty figures. We can, however, look at the percentage of students receiving the Ongoing Resourcing Scheme (ORS) at low decile schools. ORS is for school students who have high or very high learning support needs.

School decile measures five socio-economic indicators in neighbourhoods where students of that school live. Decile ratings go from 1 to 10. Decile 1 means a school is in the 10% of all schools that have the highest proportion of students that live in disadvantaged areas, according to the five indicators. Note while each decile has the same rough number of schools, they do not necessarily have the same number of students.

Students receiving ORS are 1.5 times more likely to be at decile 4 and below schools, compared to all students. This is up from 1.4 in 2009.

There is a complex range of reasons for why students receiving ORS might attend a low decile school. Low decile schools may be more welcoming and inclusive because they are more diverse. It does not necessarily mean students receiving ORS live in low decile neighbourhoods.

The decile ratings of special schools, however, are driven by students receiving ORS. This is because nearly all students at special schools receive ORS. In 2018, 92% of all students at special schools received ORS. So, the decile ratings of special schools give us some insight into the neighbourhoods' students receiving ORS live.

Students receiving ORS at special schools are 1.9 times more likely to be at decile 4 and below schools, compared to all students. This is up from 1.7 in 2009.

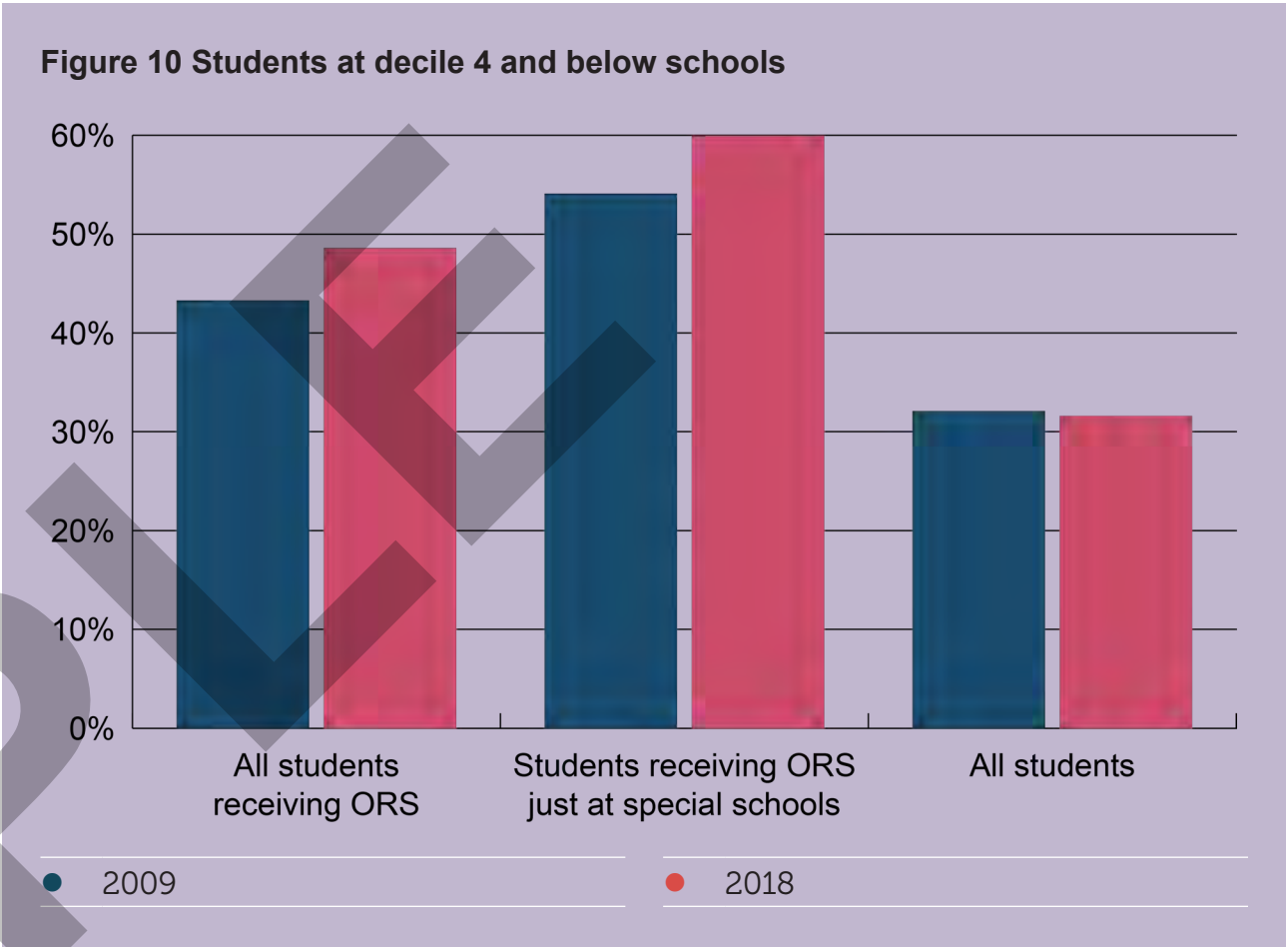


Table 10 Students at decile 4 and below schools

	2009	2018	Change between 2009 and 2018
All students receiving ORS	43.3%	48.6%	4.5%
Students receiving ORS just at special schools	54.1%	60.0%	5.8%
All students	32.1%	31.6%	-0.5%

# The changing demographics of disabled children and young people

We can get some insight into the changing demographics of disabled children through administrative data. This comes with plenty of caveats, especially the issue of groups being under-represented in the data because they are less likely to access support.

For all its flaws, data from the Ongoing Resourcing Scheme (ORS) appears to be the best administrative data source for looking at ethnicity. Data from ORS appears to be more representative than either data from the Child Disability Allowance or the Ministry of Health’s Disability Support Services, especially after the recent expansion of ORS. This is perhaps because schooling is compulsory and ORS applications can be assisted by education professionals.

Only a small number of students receive ORS; 9,377 students in 2018. The ORS data represents a small segment of the population of disabled children and young people. Nevertheless, it provides useful, annually updated data on a small group of children and young people with high and very high learning support needs. It can highlight the changing demographics of students receiving ORS.

We will look at new entrants. New entrants are students aged 5 and 6 years old. They offer a glimpse into the future of students receiving ORS and can help highlight coming trends. The demographics of new entrant students receiving ORS have changed considerably between 2009 and 2018. The percentage of European/Pākehā students has plummeted and the percentage of Māori students has sharply risen.

Based on current trends, Māori students may soon be the largest group of new entrant students receiving ORS. This trend is likely to mean disabled Māori, whānau hauā, will increasingly become a larger part of the disability community and people receiving disability-related support. This means being culturally responsive to disabled Māori, growing whānau hauā leadership, and committing to Te Tiriti o Waitangi will become increasingly important for disability-related support.

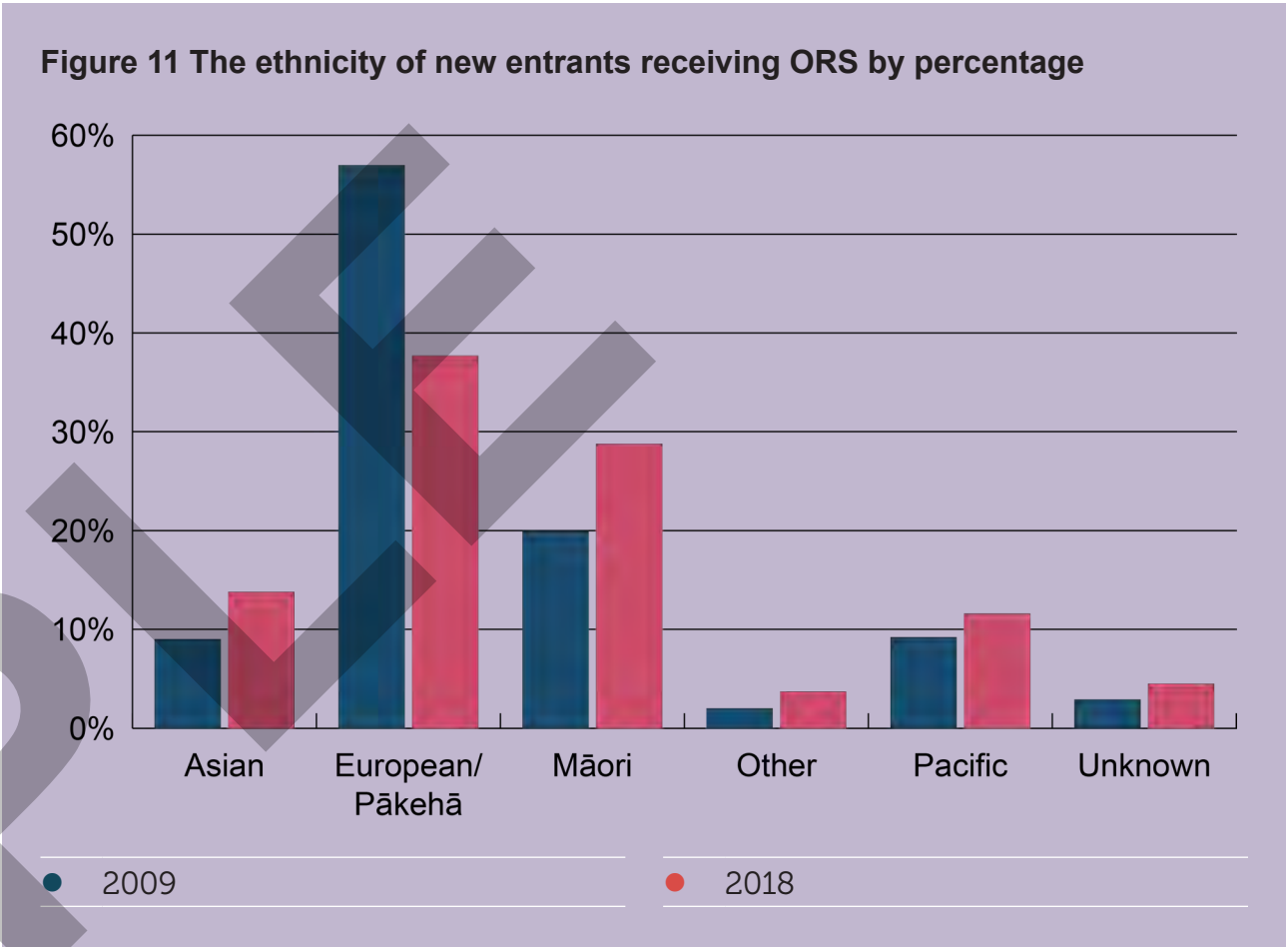


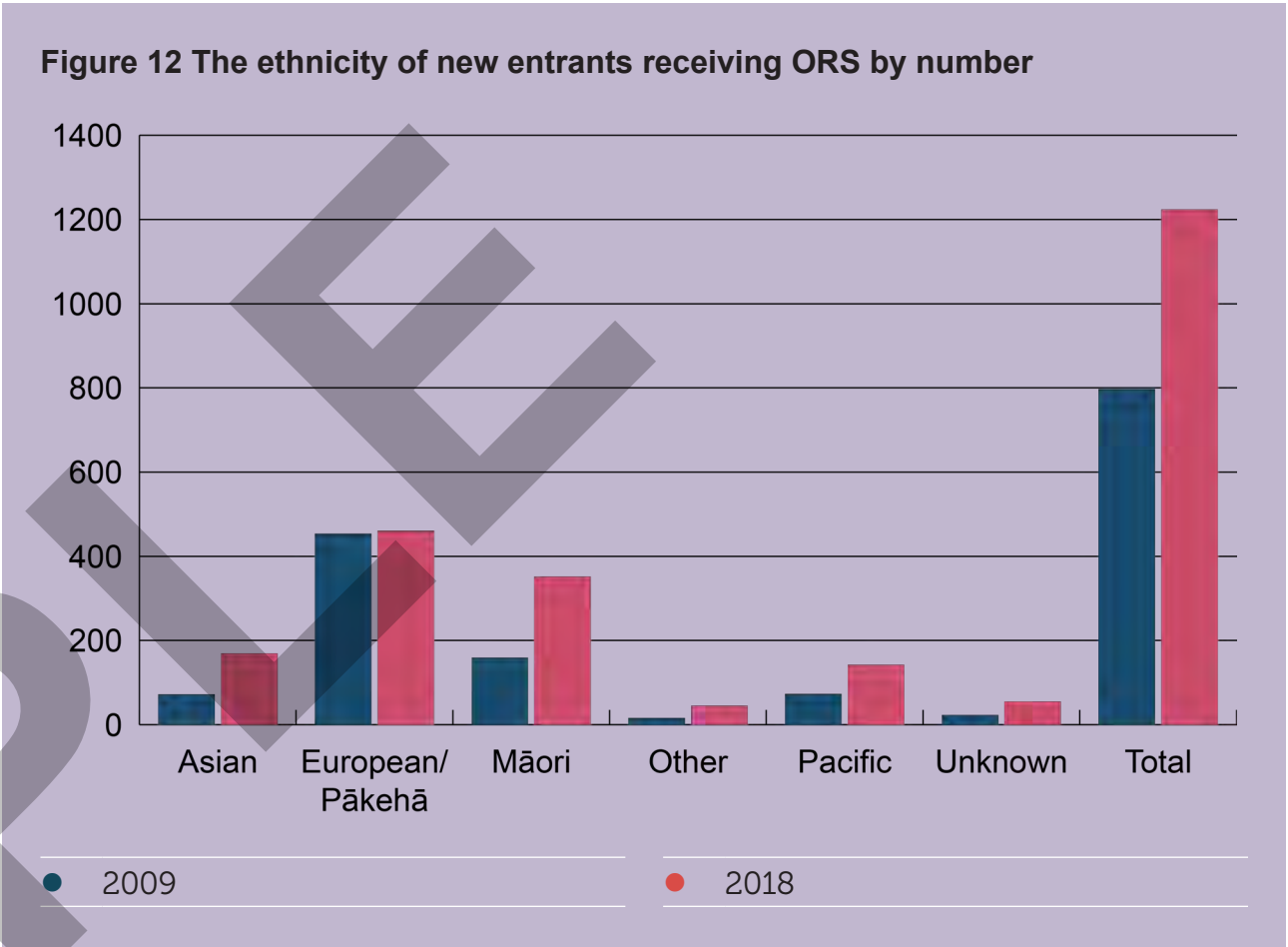
Table 11 The ethnicity of new entrants receiving ORS by percentage

	2009	2018	Change between 2009 and 2018
Asian	9.0%	13.8%	4.8%
European/Pākehā	57.0%	37.7%	-19.3%
Māori	20.0%	28.8%	8.8%
Other	2.0%	3.7%	1.7%
Pacific	9.2%	11.6%	2.4%
Unknown	2.9%	4.5%	1.6%





Here is what it looks like in actual student numbers. The number of new entrant students receiving ORS has increased by 427 students, while the number of European/Pākehā students has remained almost flat and other ethnicities have increased, including an additional 193 Māori students and 97 Asian students.



**Table 12 The ethnicity of new entrants receiving ORS by number**

New entrants	2009	2018	Change between 2009 and 2018
Asian	72	169	97
European/Pākehā	454	461	7
Māori	159	352	193
Other	16	45	29
Pacific	73	142	69
Unknown	23	55	32
Total	797	1224	427

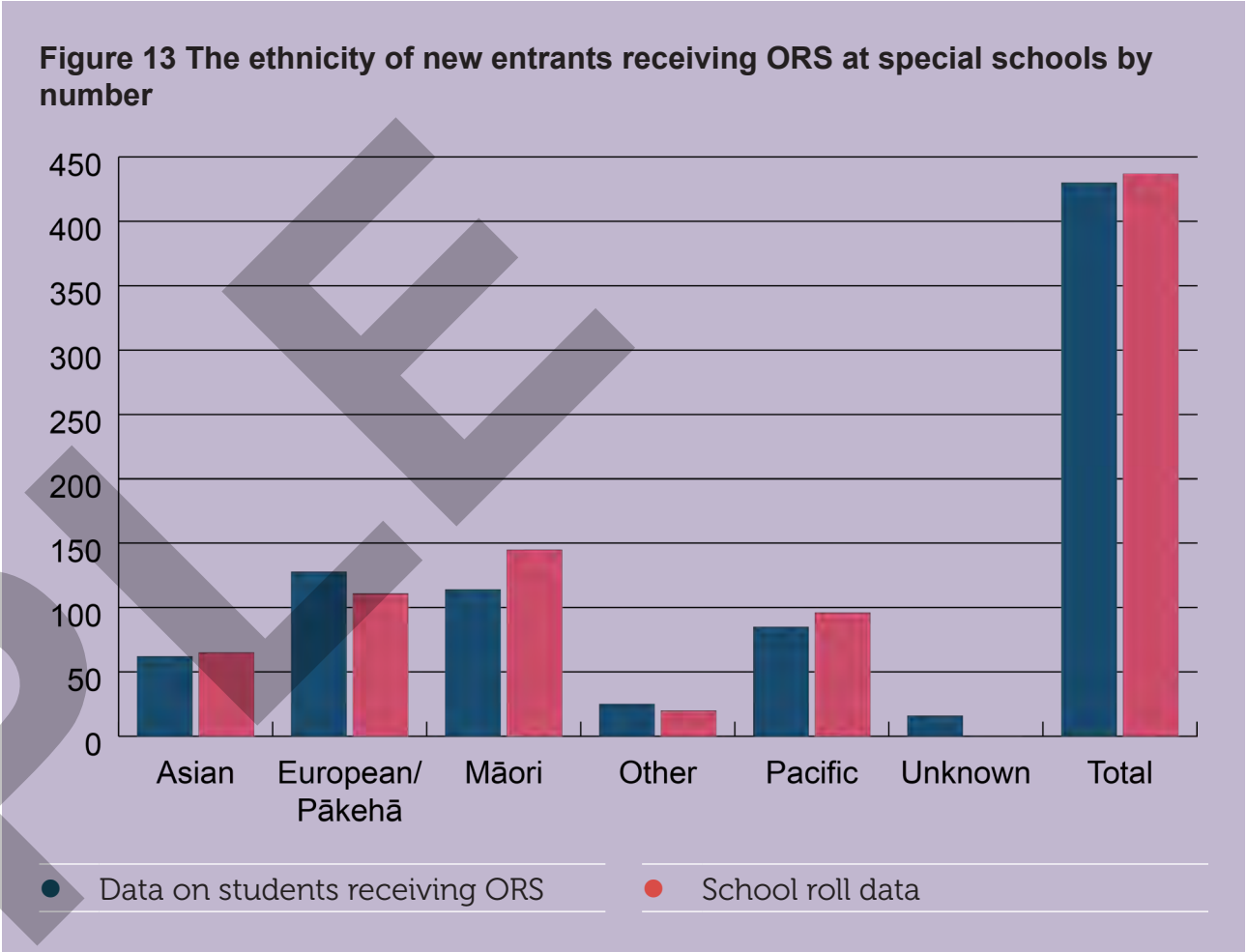
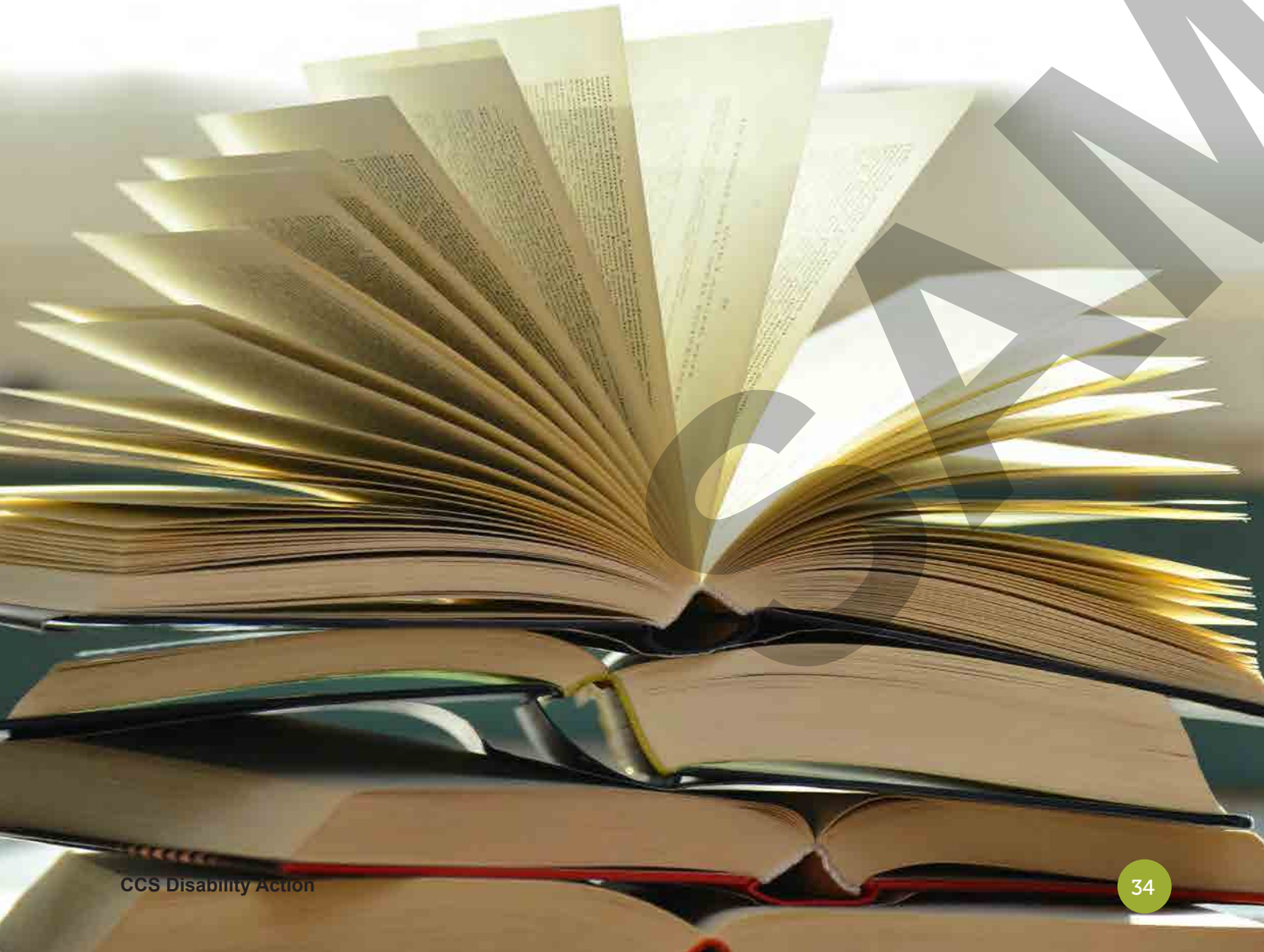




There is more to the story. The ethnicity data for ORS students comes from the ORS application process and unlike the ethnicity data for school rolls is not checked against other data sources. This makes the ORS data less reliable and appears to result in an increase in the students recorded as European/Pākehā and a decrease in students recorded as Māori and Pacific peoples compared to the school roll data.

For example, if we compare the ORS data and school roll data for new entrant students at special schools in 2018. There are only an additional seven students in the school roll data (430 students vs 437 students). This is because there are only seven new entrant students at special schools who do not receive ORS. Yet the ethnicity data is very different. In the ORS data, there are 17 more European/Pākehā students and 42 fewer Māori and Pacific students, compared to the school roll data. The table opposite shows the difference between the data sources.

The School roll data should be more accurate. This means the percentage of Māori students may be even higher than the data currently shows. The Ministry of Education plans to change how ORS ethnicity data is reported next year so we should be able to see then.



**Table 13 The ethnicity of new entrants receiving ORS at special schools by number**

	Data on students receiving ORS	School roll data	Difference between school roll and ORS data
Asian	62	65	3
European/Pākehā	128	111	-17
Māori	114	145	31
Other	25	20	-5
Pacific	85	96	11
Unknown	16	0	-16
Total	430	437	7

## We need change

Data from the 2013 Disability Survey together with data from the Ongoing Resourcing Scheme (ORS) shows that disabled children and young people face a considerably higher risk of poverty and that this does not appear to be improving. Data from ORS shows that disabled children and young people appear to be becoming more diverse. Māori are a rising percentage of disabled children and young people.

We also need a dual focus here on offsetting support, particularly a sharp increase to the Child Disability Allowance, and removing barriers. An issue here is that the Ministries of Education and Health just see their role as providing support to meet learning and disability support needs. They do not see reducing poverty as their role. Yet their policies and practices can create barriers and affect poverty levels amongst disabled children and disabled parents as well as their families and whānau.

For example, if a child requires an education support worker to attend early childhood education, allocating less than 20 hours will leave their parents unable to use the full 20 hours of funded early childhood education. This is likely to have flow-on effects for the parents' ability to find work, especially for one-parent households.

Likewise, because the Ministry of Health's Carer Support subsidy only meets part of the cost of employing a relief carer, it is only usable by people with higher incomes and/or good support networks. This means it is likely to increase inequality and is of little use for lower-income families and one-parent households.

A large gap is the lack of support for disabled parents. This affects not only the parents, but the children too. Disabled parents have told me that Need Assessment and Service Coordination agencies will not provide support to meet parenting needs because their role is just to meet individual disability support needs. This short-sighted thinking needs to end.

Like the Welfare Expert Advisory Group's recommendation about the Ministries of Health and Social Development, we need the Ministries of Education, Health, and Social Development to sit down and work out a comprehensive support system for both disabled children and disabled parents. This needs to include a focus on reducing poverty.

We also need to be accelerating the cultural responsiveness of the disability and learning support sectors. Disabled children are becoming more culturally diverse. We need to be thinking about the diversity of the workforce as well as ways to empower and grow leadership by a diverse range of disabled children, young people, and adults.

## Conclusion

The data shows unacceptably high levels of inequality. Disabled people, especially disabled people under 65 as well as disabled children and young people, face significant barriers. Government support and policy has been inadequate in addressing these barriers or in providing enough offsetting support.

Yet successive governments have been content to tweak supports and look, fruitlessly, for ways to reform that do not require substantial investment. It should be clear that substantial investment is needed. The inequalities are too large to address through slow change and minor increases in spending.

We need new ideas, big ideas, and big changes. We need a new Access Law. We need a doubling or tripling of allowances. We need major reforms to Carer Support and education support worker allocation processes. We need the development of cross-government comprehensive support systems that meet the real costs and barriers disabled people face. With big enough ideas and changes in society, we can eliminate the inequality disabled people face. What we need is a willingness to do what it takes.

## Musings on data

In the following section there are a few comments and a very short history of New Zealand's story with disability statistics.

## What is data good for?

Data is a means to an end. It is not an end. Data is a tool. Data is useful for highlighting inequalities and areas where disabled peoples' rights are not being upheld. Data is also useful for showing the diversity within the disability community and how this might be changing.

Data is no substitute for the lived experience of disabled people and their whānau. It can be a useful supplement though. The kind of data this report focused on, survey and administrative data, can help shed light on the scale of inequality and issues. It can give breadth, but not depth.

There is always a clear need for more in-depth qualitative research and disability leadership that data can never fulfil.



## Statistics have stories behind them, and they are glimpses of people's stories

Statistics and data are often seen as just numbers, but there are often complicated stories and histories behind what is collected and how it is collected. There are politics, drama, arguments, and compromises behind the data we have.

This is very true with disability-related data. Disability-related data can be hard to collect. There is also a significant range of government spending that is related to disability and fierce debates about whether it is enough. For the record, it is not. As a result, there is plenty of stories behind the disability-related data we have and do not have.

Statistics and data are also glimpses of people's lives. They are a way for people to tell a small part of their story. If disabled people are more likely than non-disabled people to say they do not have enough income that tells us there is a serious problem.

## New Zealand's story with disability statistics

Despite the high level of government spending on disability-related support, there has historically been little interest from the government on collecting statistics on disabled people. Between 1916 and 1996 no disability-related questions were included in the Census.

Partly this may be because significant numbers of disabled people were living in institutions. In the mid-1980s, with deinstitutionalisation looming, the government began taking disability statistics more seriously. Between 1986 and 1993, the government commissioned several surveys from the research agency BERL and Statistics New Zealand. These surveys gave wildly inconsistent results, with disability prevalence rates varying from 14 per cent to 40 per cent.

With other methods deemed unreliable, the disability community began to pressure the government to include disability questions in the Census. Statistics New Zealand was reluctant to do this as they thought questions in the Census would be too unreliable without a follow-up survey to interview those that had identified themselves as having a disability in the Census. There was limited funding, however, so Statistics New Zealand got CCS Disability Action and IHC to help fund the first follow-up survey in 1996.

From there, we had a disability survey for four Census so surveys in 1996, 2001, 2006, and 2013. These Surveys were the preeminent source of disability data in New Zealand, although not without their flaws. This is where statistics such as one in four New Zealanders are disabled people come from (that was from the 2013 Disability Survey).

Then in 2012, the government cancelled the 2018 Disability Survey. This was not announced publicly until 2015, however, which was very disappointing. Since then another

strategy has been tried of putting a short disability question set in non-disability specific surveys. A short disability question set has been put in the General Social Survey, the Household Labour Force Survey, and the 2018 Census.

This has led to an expansion of disability data, especially regularly collected data. The downside is the short disability question set collects data from a much smaller and less representative group of disabled people than the disability surveys. Disabled people under 65 and people with learning disability, neurodiversity, and mental health conditions tend to be underrepresented in this data. The small number of people identified with this short disability question set also makes it difficult to break the data apart to look at groups, such as young disabled people and different ethnic groups.

In a nutshell, that's where we are at now. We have a growing amount of regularly collected disability data, but with major gaps. A 2023 Disability Survey is still on the cards and is still needed. We need it to give us reliable data on the actual number of disabled people. We also need it to provide disability data that can be broken apart to look at groups.

## Endnotes

Page 4: See Amartya Sen's book, the Idea of Justice. You can get it from our library.

Page 8: See this great disability estimates for small areas tool here:

[http://archive.stats.govt.nz/browse\\_for\\_stats/health/disabilities/disability-small-areas-2013.aspx](http://archive.stats.govt.nz/browse_for_stats/health/disabilities/disability-small-areas-2013.aspx)

Page 18 The Counting Ourselves report also found low rates of life satisfaction amongst disabled trans and non-binary people. See page 50 of the great report below:

[https://countingourselves.nz/wp-content/uploads/2019/09/Counting-Ourselves\\_FINAL.pdf](https://countingourselves.nz/wp-content/uploads/2019/09/Counting-Ourselves_FINAL.pdf)

Page 23: One recent New Zealand study was turned into a comic and is useful for highlighting some of the attitudinal barriers disabled people face:

<http://theconversation.com/comic-explainer-young-disabled-new-zealanders-on-the-barriers-to-a-better-life-122226>

Page 36 I have covered the Child Disability Allowance and child poverty data in more depth in this article:

[https://www.victoria.ac.nz/\\_data/assets/pdf\\_file/0003/1713621/Murray.pdf](https://www.victoria.ac.nz/_data/assets/pdf_file/0003/1713621/Murray.pdf)

Page 38 The first part of the story is based on Peter Beatson's great book the Disability Revolution in New Zealand. You can borrow a copy for free from our Library, providing our librarian can get it back off me!

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