# 2023 New Zealand Disability Survey - Consultation



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Contact Name:	Nikki Hurst Sonia Scott
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Organisation Name:	New Zealand Council of Christian Social Services (NZCCSS)
Organisation description:	The New Zealand Council of Christian Social Services (NZCCSS) welcomes the opportunity to provide feedback on the consultation towards the 2023 New Zealand Disability Survey.  NZCCSS has six foundation members; the Anglican Care Network, Baptist Churches of New Zealand, Catholic Social Services, Presbyterian Support and the Methodist and Salvation Army Churches.  Through this membership, NZCCSS represents over 250 organisations providing a range of social support services across Aotearoa. We believe in working to achieve a just and compassionate society for all, through our commitment to our faith and Te Tiriti o Waitangi. Further details on NZCCSS can be found on our website <a href="https://www.nzccss.org.nz">www.nzccss.org.nz</a> .

# Tirohanga Whānui | Overview

New Zealand Council of Christian Social Services (NZCCSS) welcomes consultation on 2023 Disability Survey. The data collected is critical to good decision-making and service delivery.

NZCCSS' comments on the 2023 Disability Survey focusses on the following key points:

- 1. 10 years between surveys is too long
- 2. The US-designed Washington Group Short Set of Questions sets the disability threshold in the survey too high
- 3. Proxies are inappropriate and breach human rights conventions
- 4. Age-stages should align to Government standards
- 5. Wellbeing should be included and expanded, particularly across the following areas:
  - a. Tamariki
  - b. Spirituality
  - c. Te Ao Māori
  - d. Inclusion of Whole Person

## Taunakitanga | Recommendations

#### 1. Timing

NZCCSS supports concerns regarding the ten-year gap since Statistics NZ undertook the New Zealand Disability Survey (NZDS). The reasons behind such a lengthy gap are not clear. Given the primary objective of the survey is "to understand the size of the disabled population" this would seem a significant oversight which may well have impacted on funding allocations and service provision to the disability sector over the past 10 years.

#### 2. Washington Group Questions

NZCCSS supports a review of the US designed Washington Group Short Set of Questions, which will be incorporated into the 2023 NZDS. Specifically, we support concerns raised by the advocates in the disability sector that the Washington Group questions set the disability threshold too high and in so doing excludes a broader group of adults, youth and children who are not counted in the survey but who require government funded supports. The discrepancy between the actual number of people with a disability and requiring government funded support and the number of people captured in the survey questions the integrity of the disability data collected.

#### 3. Tamariki & Rangatahi Voice

NZCCSS notes 'all interviews of children are done by proxy'. Under the <u>United Nations Rights of the Child (1989)</u>, alongside the <u>United Nation Convention on the Rights of Persons with Disabilities (2007)</u>, children and young people have the right to be heard to express their views and to participate in their lives regardless of their disability (Article 21).

The blanket proxy approach for children is concerning and makes assumptions about the participants' ability to communicate and understand the questions. There will be a diverse range of abilities and communicate needs. A range of engagement tools is needed to support children and young people's voices to be heard to the greatest extent possible.

The Office of the Children's Commissioner (OCC) has recently undertaken specific <u>research with children and young people with disabilities</u> about what makes a good life, drawing on a range of engagement strategies tailored for children and young from diverse backgrounds. This work would provide a useful starting point for Statistics NZ to re-think how it engages children and young people with disabilities so that the use of proxies could be reduced to a minimum.

NZCCSS also recommends a resource produced by CCS Disability which provides a good discussion on the value of shared decision-making: *Shared-decision making with disabled children and young people* (Pheobe Eden-Man, 2019).

### 4. Age-spans

NZCCSS does not support the inclusion of 15 year olds as adults. We believe a person aged 15-17 represents a significantly different developmental stage and the information gathered should not be aggregated with information on adults. The experience of 44-year-old adult with a disability (page 10) is not comparable to a young person forming their identity, in the education system, or staring out at work, with hopes and aspirations for the future.

The Government's child and youth strategy identifies youth as 15 years to 24 years. We support the inclusion of a new age category which has a specific focus on youth with disabilities across all the domains set in the survey (15 years to 24 years). This category should be incorporated into the general survey so that comparisons between young people (15-24 years) with a disability and those without a disability can be tracked.

#### 5. Wellbeing

#### a. Tamariki

NZCCSS supports the inclusion of new wellbeing content in the 2023 Disability Survey. However, more consideration is needed on the wellbeing question for children which currently only covers the following proxy questions:

- Health status (assessed by parents, guardians, or carer)
- Income adequacy (how well does the household's total income cover everyday needs like accommodation, food clothing).

The OCC report mentioned above engaged directly with children and young people on what factors they thought made for a good life and what barriers got in the way. From this, 6 areas were identified (page 2-4): <a href="https://www.occ.org.nz/assets/Uploads/Disabled-Children-and-Young-People-Report.pdf">https://www.occ.org.nz/assets/Uploads/Disabled-Children-and-Young-People-Report.pdf</a>

- 1. Acceptance: Discrimination is widely experienced by disabled children and young people
- 2. Accessibly: Lack of accessibility gets in the way of a good life
- 3. Education: to work better for us, to be flexible and supportive
- 4. Employment: to have job opportunities, being supportive is important to us.
- 5. Whānau: we want support from and for friends, family and whānau and communities.
- 6. Safety: unique for all of us.

NZCCSS supports the translation of these wellbeing areas into survey questions.

#### b. Spiritual Wellbeing

NZCCSS would like to see the inclusion of a question relating to how people felt able to express their spiritual or religious beliefs and participate in some way in their chosen spiritual or religious community. The role of spirituality plays across all age groups needs to be recognised. The belief in something beyond the individual links to the desire for community connectedness, and the need for good relationships. NZCCSS welcomes traditional forms of spirituality expressed through the establish faith traditions, alongside Māori concepts of spirituality, those of other cultures and the modern trend for more unstructured ways of seeking spiritual connection.

### c. Te Ao Māori

In order to honour and enact Te Tiriti o Waitangi, NZCCSS strongly supports the inclusion of te ao Māori perspectives on disability in the survey.

In order to do so we strongly recommend the need to engage with iwi leaders in the Māori disability sector on the inclusion of additional wellbeing questions. The 2013 Disability Census identified one in five Māori are living with a disability. It is therefore important accurate information is collated to support policy and service providers respond to the needs of Māori in a culturally appropriate way.

#### d. Inclusion of Whole Person

NZCCSS strongly supports the inclusion of a range of diverse perspectives on disability in the survey. Care needs to be taken to ensure voices from the rainbow community, Pacifica, refugee and migrant communities are well represented. No one with a disability is simply their disability, they also bring a range of intersectional perspectives to bear. It is therefore important accurate information is collated to support policy and service providers to respond to the needs of all disabled peoples in way that is honoring of and appropriate to all aspects of a persons culture. The whole person should be surveyed, not simply parts of them.