**Submission on the Disability Survey 2023**

[**https://www.stats.govt.nz/consultations/disability-survey-2023-consultation**](https://www.stats.govt.nz/consultations/disability-survey-2023-consultation)

Tēnā koutou,

Thank you for the opportunity to participate in the above consultation. Disability Connect offers Disability Information, Advice and Support to over 6,500 members in Auckland, around half of whom are families, the remainder professionals working in the disability sector. Our mission is to lead and influence positive change for people with disabilities and their families. The responses to the questions posed have been collated from members and staff.

Question 1. For what impairment types or functional domains do you need outputs from the survey? Please tell us if you think there are important subgroups or functional domains missing, or if you think any listed are not needed. Note that these are not medical conditions, they are aspects of functioning with which people may have difficulty.

“For people who report difficulties in more than one functional domain, the one that gives them the most difficulty is identified and recorded as their main impairment.”

* Someone with FALS, paraplegia, ADHD and dyslexia has equal difficulty in life across every aspect of life. It is not as simple as choosing the “worst”.
* Communication might be a better term than speaking in this section. It is possible that you can speak but still not be able to communicate well.
* Neurodiversity should be included as a form of disability.
* Proxys- as far as possible disabled people should respond to questions themselves. Parents and guardians should, where respondents have limited agency, be able to participate in the research on behalf of their dependents.

Question 2. Are there any age groups that are particularly important to your use of the data? What are they and why do you need them?

* The last year of school for disabled school children with Very High ORS funding, determined by the Ministry of Education is when they turn 21. This is an important differentiator to understand outcomes of children post school.

* Education is a huge consideration so being able to get data related to the age group engaged in education makes sense.
* Oranga Tamariki has responsibilities for disabled children through to age 24.

Question 3. Would you find it useful for people aged 15 to 17 years to be counted as children or as adults? Why?

* 15 to 44 years makes no sense, the age range is far too wide.  Brain development is not finished by age 15 – a 15 year old is nothing like a 44 year old.

* Per answer to question 2 disabled children with Very High Needs often do not finished school until they are 21. They are not adults. They have not left school.
* Observing changing needs of disability cohort with age would be better with the following;

15-17; 18-21; 22 to 24; 25-34; 35-49; 50-64; 65-79; 80+

Question 4. Do you need information about disabled people who identify with an ethnic group other than Māori or European? What information do you need and why?

* Surely Census Data could be used to provide this information for the sample selected?
* The Health and Disability Survey should use the same ethnicity categories as the Census, including rainbow categories to cover the diversity of our disability sector. Distinct ethnicities should be used rather than Asian or Pacific groupings as this does not indicate the language and cultural needs of families.
* Our organisation is contracted to provide disability services to families from Chinese and Indian backgrounds. Knowing the nature of their disability and their needs with respect to housing, education and disability supports allows us to forecast demand and provide services.

Question 5. Do you need specific information about assistive equipment? What do you need to know and why?

* Would be helpful to include the type of assistive equipment used and the role the technology plays in daily life.
* Assistive equipment includes i-pads for children with dyslexia, fidget spinners and sensory furniture for children with chronic anxiety and ADHD.
* This information is required to inform education provision and to ensure facilities, buildings and staffing needs are appropriate.
* The information will also be required to assess that our building code is responsive and compliant with the New Zealand Disability Strategy in respect of inclusion and equity across employment, education and community participation.
* Assistive equipment is used across education and employment. Knowing what is working, what is and being used and is useful will inform agency and funding decisions for supports.

Question 6. Do you need specific information about household or general help? What do you need to know and why?

* We need to know the type of help people use; household, respite, personal cares, social support to measure changing needs and shortages for training.
* As disabled people are living longer agencies need to forecast demand and government needs to understand and quantify the range of assistance provided by family members in support of whanau.

* We also need to know needs and costs of care:
  + - If people have been asked if they need help
    - how long people wait for assessments
    - how much caregivers/helpers are paid
    - what portion is paid for by DHB/Govt versus private funding

Question 7. Do you need specific information about health services? What do you need to know and why?

* What barriers to accessing health services are experienced by disabled people. To assess the NZ Disability Strategy implementation.
* Long term health conditions as well as disabilities impact on family and whanau wellbeing. Social cohesion is not possible without rigorous data of all health conditions experienced by families and whanau over their lifetimes and the supports needed to implement “enabling good lives” policies.

Question 8. Do you need specific information about employment? What do you need to know and why?

* What barriers to accessing employment are experienced by disabled people. To assess the NZ Disability Strategy implementation.
* Transition of disabled people to a good life after school finishes at 21 is not possible without data highlight barriers that exist and the possibilities available for families. Barriers include transportation, access needs, communication and physical barriers, workplace policies. Possible steps to employment include day programmes and social skills activities, volunteer work such as internships and tertiary education.

Question 9. Do you need specific information about transport? What do you need to know and why?

* What barriers to accessing transportation are experienced by disabled people. To assess the NZ Disability Strategy implementation and inform Transport and Urban Design Planning.
* NZ Disability Strategy 2016-2026, outcome 5 p33. “Decision making on issues regarding housing, transport, public buildings and spaces and information, communication and technology are informed by robust data and evidence”

Question 10. Do you need specific information about housing? What do you need to know and why?

* What barriers to Emergency Housing, Social Housing, Residential Care Housing, Private Rentals and Home Ownership are experienced by not only disabled people but families with disabled people in particular?
* To assess the NZ Disability Strategy implementation and inform Kainga Ora accessibility policy.
* The questions on housing need to be broadened beyond physical disabilities. Neurodiverse needs including fencing, security measures, sensory factors and access to transportation.
* Consider the needs of housing to cater for family carers and employed carers working in the home as well as whether they need to stay in the home too.
* There is no data available to quantify the range of care required for a disabled person to live independently away from their family, particularly their parents. This includes managing finances, social diary, employment supports, education supports, personal hygiene, food preparation and home maintenance.
* The survey should also consider the prevalence and role of assistance service animals. This is required to inform housing and urban design for example grass spaces available for toileting when visiting family and development of accessible workplaces.

Question 11. Do you need specific information about education? What do you need to know and why?

* What barriers are experienced in choice of school?
* What assistive hours do they receive per week?,
* What modifications have been made to the school to meet their needs?
* How many days has their disabled child been sent home early from school over the past year?
* Have they applied for ORS funding? If yes, was it successful.

Question 12. Do you need specific information about leisure? What do you need to know and why?

* What barriers to leisure activities are experienced by disabled people?

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* To assess the NZ Disability Strategy implementation and inform central government, councils and activity providers.

Question 13. Do you need specific information about wellbeing? What do you need to know and why?

* Aspects of wellbeing:
* Physical health, mental health, addiction, offending, employment. This should be measure for family members as well as their disabled whanau.
* Our service is delivering the above outcomes under Ministry of Health and MSD contracts.

Question 14. Do you need specific information on the carers of disabled children? What do you need to know and why?

* Number of hours?
* Do carers require specific training to perform their role?
* Does the carer want to work more hours a week but is unable to because of carer obligations?
* This information shows how well NZ is meeting it obligations under the UNCRPD and how well the New Zealand Disability Strategy has been implemented.

**Additional Comments**

Given the size of the disability sector from the previous survey noted in 2013, the diverse nature of disabilities and the New Zealand Disability Strategy 2016-2026 we believe the methodology selected is simply inadequate to research the information needs of government agencies and providers. Sampling needs to be much larger and stratified so research instruments can be targeted to the needs of specific disabilities. Research tools incorporating easy-read, braille and sign language should be utilised. We appreciate this comes at a cost, but so does living with a disability and providing most services for disabled people.

For the research to be credible in lie with the United Nations Convention on the Rights of People with Disabilities it should be designed by disabled people and incorporate disabled researchers. If disabled researchers are not utilised by Statistics New Zealand, New Zealand is failing to meet its obligations under the UNCRPD.

The Ministry of Health has recognised several prevalent neurodiverse disabilities, including ASD, since the previous survey was scoped. The prevalence of disability is also greater with a population that has aged since the previous survey was undertaken. Given the government has acknowledged significant gaps in disability data across health, housing, education and social services Statistics New Zealand must consider a greater investment in disability research to provide the data needed by government agencies and organisations like Disability Connect, so future and current needs can be met.

I would be happy to discuss this consultation further. Data collected by Statistics New Zealand on disabled people needs to be robust, inclusive of families, whanau and carers is essential if we are to have a society where no one is left behind.

Nga Mihi

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Mike Potter

CEO Disability Connect

**Appendix**

Stats NZ wants to know whether the proposed content for the 2023 Disability Survey will meet priority data needs.

As you provide feedback on each topic area, please consider the following:

* Is there any new content that you would like to see included in the survey, and if so, what information do you require?
* Do you think any of the current content does not need to be collected, and could be removed to make way for more important data?
* Do you have any suggestions for including te ao Māori perspectives on disability in the survey?
* What should be asked of both disabled and non-disabled people (to allow for comparisons between the two groups)?
* Respondents who report a mild impairment will not be considered disabled but may still be impacted by their impairment in some situations. Are there any topics that you think should be asked of respondents that have a mild impairment?

We are interested in hearing about your information needs. Tell us what you want to know from the survey rather than the questions you think we should ask. Once we have finalised the information needs, we will work with our questionnaire designers to determine the best way to ask survey respondents for that information.

Respondent burden caused by long questionnaires is always of concern to us. This means that we will carefully consider the impact of adding new content to the Disability Survey and balance this with removing some of the questions that are currently included. Survey content will need to be prioritised based on the greatest data need and perceived benefits. When making your submission, please provide clear reasons for your information need to help us to prioritise.

We are interested in hearing whether any of this content should no longer be collected, whether it should be modified, or whether there is a need for additional information that we have not already proposed

In early 2022, Stats NZ will publish a summary of the feedback received, followed by our decisions on the survey content. This will be available on our website and will be emailed to everyone who made a submission.

Your submission should be made in writing using the template at the end of this document, or as a video or audio recording. It can be sent by email or post to the addresses below. We need to receive your submission by 5pm on Friday 29th October 2021 to include it in our content review process.

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