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# Submission on content for the 2023 New Zealand Disability Survey

**FEEDBACK CLOSES ON FRIDAY 29th OCTOBER 2021**

## Submission template

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**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?

**GENERAL POSITION:**

* It is noted that 23000 individuals/households will be selected from the 2023 census from approximately 2 million households in New Zealand. In addition, 800 individuals living in residential facilities will be included in the survey. This sample size of 31000 individuals in a total population of about 5 million, means that only about 0.62% of the total population will be surveyed.
* This raises serious concerns about the adequacy of the sampling, especially in relation to disabled adults with significant intellectual disability. We note that in the 2013 survey, of the 800 individuals from the residential facility survey the median age was 84 years and that 75% were > 75 years. Only 6% were in 15-44 age group, that is 48 individuals. This suggests that this survey disproportionately looks at the disability status of older people who tend to have a significantly higher rate of disability than their younger peers. This is largely a consequence of age-related health problems. In 2013 only about 15% of the total population was aged over 65 years.
* As only residential facilities with five or more residents will be included, the survey will largely ignore those people with disability who live in small group homes with four or fewer residents. This will be a significant number of adults with intellectual disability.
* It is our view that the sample is inadequate to generate useful data about the diverse needs of people with a wide range of disabilities and health conditions across the age range.
* Rare Disorders are defined as conditions with a prevalence of less than 1 in 2000 in the general population. There are >8000 recognised rare conditions and the number is steadily increasing with new diagnostic technologies. While individually rare, Rare Disorders as a group are collectively common with an estimated 6-8% of the general population having such a diagnosis. We consider that the limitations on sample size will underestimate the diverse range of people with disabilities and structurally discriminate against those people living with Rare Disorders.
* As an example, a member of the Rare Disorders collective, the Prader-Willi Syndrome Association (PWSA) estimates that there are about 200 people with PWS in New Zealand. PWSA has 135 people in their database. Of those 39 are adults known to be living in residential care; there are a further 32 adults whose residential status is unknown and 19 who are known to be living at home with whānau. It is likely that the majority of those who are in residential care are in small group homes. The likelihood that they will therefore be selected to participate in the survey is extremely low so the unique needs of this group of people living with a rare disorder will remain unknown.
* An estimated 300,000 New Zealanders are currently living with a rare disorder which affects their long-term quality of life. Many of these conditions are hidden illnesses, and some are still undiagnosed and would not be represented in the current survey framework.
* Many people living with a rare disorder in NZ, remain marginalised and largely invisible within the healthcare system despite being a significant part of the population and this survey will not accurately reflect their needs
* The focused use of the word ‘Disabled’ and the fact the active ‘disabled’ community does not connect with ‘health-related impairments’ means those with invisible health related limitations DO NOT identify as disabled even though meeting the definition. This leads to exclusion and discrimination of those who do not feel they identify as “disabled”
* When it comes to defining and measuring disability the approach of those with a public health orientation often focuses on physical or sensory disability which is not always consistent with the reality for people living with a rare disorder whose prime interest may be in, for example:-
* accessing a medical diagnosis and specialist care,
* access to treatment and medical equipment/devices
* impact of the time needed to complete daily medical treatments,
* care available in the community and access to social services,
* eligibility for benefits and the ongoing need to re-apply despite having a chronic condition,
* overall impact on quality of life
* Findings from the 2019 NZ Voice of Rare Disorders Survey showed almost 65% reported that their disorder impacted “a lot” on their health and everyday life and 49% required more than 2 hours per day for illness-related daily tasks. 60 – 75% of people and their families said that their rare disorder made a number of everyday activities difficult
* The medical needs of people with varied impairments have been excluded from the survey as there are no questions on this important aspect. It impacts severely on people and their carers lives. yet impact the lives of people living with a rare disorder. Medical equipment and devices are vital for people with some rare disorders to reduce impairment and improve functionality. There are 27 rare disorder support groups with respiratory issues that use nebulisers, Cpap machines, oxygen concentrators etc every day which places a significant treatment burden on the individual and the family unit, but this would not be shown in the survey in its current format

**RECOMMENDATIONS:**

* Rename survey to be the “Functioning, Health Functioning /Limitation/impairment & Disability Survey”. Looking at level of disability as a separate entity from health implies an interest in the impact of their disability and excludes other aspects and impacts.
* The active Disability community have campaigned hard and moved away from health links with the focus on accessibility of environment, employment, etc however this leads to exclusion for those who have health related conditions. A more inclusive approach is to offer an umbrella term for Health Function and Disability, so no one is left behind. This would factor in invisible conditions that have multiple, complex and often progressive impairments, activity limitations and participation restrictions.
* Treatment burden (time and resources, carers, etc) to be included as a measure of the impact for optimal health.
* Add a question to measure the level of financial burden of care (impact on loss of productivity, income restriction due to multiple appointments, carer needs, etc) for families.
* Look to measure the utilisation of hospital services to understand the cost of providing services to those within the definition of ‘disability’ including those with invisible impairments.
* Include additional functional categories: Stamina or Breathing or Fatigue
* Include information on accessing disability benefit to detail the barriers and solutions, especially when the criteria are rigid and the conditions are complex (rare disorders).

**Below are the specific questions we asked throughout the consultation document. You do not need to answer all the questions, only those which are important to you.**

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.
* Add Stamina/Breathing/Fatigue
* Neurodiversity
* Mental Health/phobias/anxiety/behavioural aspects (personality disorders) and ADHD
* Change Agility to Dexterity
1. Are there any age groups that are particularly important to your use of the data? What are they and why do you need them?

Demographics of age showing youth, women and over 65 would help detail the specific impact on those populations

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

Yes, as children – most children with a chronic functional impairment have significant input from parents/caregivers/whanau for their whole lives, so whilst they are teenagers living at home and attending school, they should be counted as children.

1. 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?
2. Do you need specific information about assistive equipment? What do you need to know and why?

Information on assistive equipment for learning and workplace use will show the accessibility aspects that enable people with impairments to fully participate in society

Include assistive medical equipment including nebulisers, oxygen concentrators, PEP machine etc to maintain breathing function.

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

Ask how difficult it is to access household help or barriers to receiving help. This question will show any structural discrimination around access for those with more complex rare conditions

1. Do you need specific information about health services? What do you need to know and why?
* Include hospital specialists and specialist hospital nurses.
* Access barriers for those on margins would be useful to understand
* We would like to know the level of treatment burden on families. This often has a direct correlation with the quality of life.
* Information about the cost of hospital admissions and time spent in hospital can give comparisons for specific diseases against the whole which helps to detail comparative data for resourcing and prevention.
* How many hospital admissions have you had in the last 12 months?
* How many days have you spent in hospital over the last 12 months?
* How much time each day do you spend on health-related treatment and activities to maintain your functionality?
* How informed are health professionals about your condition/impairment?
* Do you have any unmet health needs?
1. Do you need specific information about employment? What do you need to know and why?
* What is the effect of having limited employment opportunities – (effect on wellbeing).
* Financial implications of reduction in employment hours and promotion
* How informed are people around the rights to financial help they may be entitled to?
1. Do you need specific information about transport? What do you need to know and why?

Access to travel for those with rare conditions who have vast distances and multiple appointments to manage

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

Access to appropriate housing for those with less understood disorders that have variable symptom and expression relating to impairments

1. Do you need specific information about education? What do you need to know and why?
* Access to required support when disorder with less understanding of the condition, also to equipment
* Being too unwell to be at school on multiple occasions.
1. Do you need specific information about leisure? What do you need to know and why?
* Access to supported activities for those with variable and complex neurological disorders or those impacting on mental health and neurodiversity
* Individual sporting/physical activity
* Musical activity
* Been on holiday away from home
* Been to the theatre, cinema or concert
1. Do you need specific information about wellbeing? What do you need to know and why?

Access to mental health support when diagnosed with rare and often life limiting disorder plus whanau inclusion

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

How are carers affected by having a disabled child? Measure level of impact. Data we have shows 30% of parents/caregivers are often unhappy and depressed and unable to overcome their problems. How difficult is it for them to access support for themselves?