



Submission to Stats NZ on Disability Survey 2023 from the Child Development Special Interest Group of the Paediatric Society of New Zealand

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We note that the principal objectives of the survey are:

- to understand the size of the disabled population usually resident in New Zealand and describe characteristics of that population. More specifically to:
 - produce reliable national estimates of the disabled population by demographic characteristics, such as age group, gender, and ethnicity
 - produce reliable national estimates of the disabled population by functional domain
- to understand the extent to which social, wellbeing, and economic outcomes for disabled people differ from those for non-disabled people, and how those outcomes differ between groups within the disabled population
- to understand the level and type of support disabled people need to perform activities of daily living, including identifying unmet need for support
- to understand what creates barriers or enables participation by disabled people in important aspects of life, such as work, education, civic society, and recreation.

General Comments

We have 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
- 75% were > 75 years
- 6% were in 15-44 age group i.e 48 individuals

This suggests that this survey disproportionately looks 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.

We need to know about the wellbeing of younger people living with disability. What level of unmet need do they have? What proportion of people in the 25-64 age group who have a disability (particularly, but not confined to, intellectual disability) live in small group homes (four or fewer people) and are cared for by non-kin caregivers? This group is at risk. Many of the care workers in these homes are compassionate dedicated people who work very hard to provide quality care within limited resources. But not all provide a high standard of care, and the small size of these homes can make abuse difficult to detect.

With 23000 individuals/households selected from the census of about 2 million households plus the 800 individuals from the residential facilities survey in a total population of about 5 million, about 0.62% of the total population will be surveyed. It is our view that this sample is inadequate to generate useful data about the diverse needs of people with a wide range of disabilities across the age range. One way to address this would be sample residential care providers for people with disability. These organisations provide care for people with disability (mainly adults) in small group homes, usually with four or less residents. Some of these

organisations will have a large number of people in their care in total. Sampling these organisations as residential entities will provide data on people who would be missed by the household survey limit. They will include many of the people with the most severe disability, especially intellectual disability. They are cared for by a workforce which is poorly paid and has limited access to training and career progression. A proportion of the workforce will be somewhat transient, for example tertiary students working part-time.

There are several providers. The larger providers include IDEA services, Spectrum Care, NZCare Disability, te Roopu o Manukau, and Creative Abilities. Small providers may run only one or two facilities; these providers are less likely to have the infrastructure to provide comprehensive support of staff and residents.

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

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.

- We note that the impairments list does not include social and communication impairments; these are not the same as impairments in speaking/intellectual/psychiatric or psychosocial. Many people with Autism Spectrum Disorders (ASD) would not be picked up by the current list.

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?

- We need to understand the needs of the following age groups
 - Children and young people under the age of 21 years (also see Q3)
 - Rangatahi aged from 14-29 who are transitioning from parental/whānau care, the compulsory education sector, and child health services in to the adult world
 - Adults with disability up to the age of 64 years. Health and support service for this age group are very limited.

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

- There is logic to including 15-17 year olds in the child age bracket, given that covers the education system to year 13.
- Young people with significant disability who are supported by Ongoing Resourcing Scheme (ORS) funding may currently remain in the secondary education sector until the end of the year in which they turn 21.
- We note that all child surveys are completed by a caregiving adult. We recommend that all child subjects who are able and willing to provide their own answers to some or all of the survey questions are enabled to do so. Most children over the age of 12

years (and some younger) would be able to participate. Participation by the 15 plus age group is essential.

- The 0-2 age group also need consideration. It is important to recognise that many children who have a condition associated with disability will not be diagnosed/recognised in the first months or years of life.

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?

- The Covid19 pandemic has taught us the importance of socio-economic, cultural and ethnicity factors in determining outcomes. It is essential to identify those who identify as Pasifika and those who have refugee status. The latter have high rates of health (physical and mental) issues and disability.
- We need to know whether these groups have poorer access to services including disability support, education and training, employment, health care and leisure activities.
- We need to know whether they are more likely to suffer abuse than their able peers.

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

- We need to know how many people who need assistive equipment and/or housing modifications have been unable to access what they need
- We need to know why their needs have not been met
 - e.g. in temporary housing
 - e.g. live between two residences (e.g. as a result of custody arrangements) and only one residence modified
 - landlord has declined to have modifications made to property
- Note that where modifications have been made or equipment (e.g. hoist) provided, a carer may still be needed to assist
- We need to know what has not been provided and why, for example
 - Assistive equipment to manage challenging behaviours to ensure safety such as buggies and modified wheelchairs (note that Enable NZ are more likely to fund a wheelchair than a buggy for a child aged >5 years), carseats with anti-escape buckles, walking harnesses.
 - Equipment not funded through Ministry of Health because it does not fit Enable NZ criteria as seen as a “medical need” e.g. epilepsy, respiratory issues
 - Equipment not funded because it is for rehabilitation but will have long-term benefits
 - Communication devices
 - Mobility devices.
 - Assistive equipment for children with Sensory Processing issues such as weighted blankets, compression clothing or tracking devices
 - Issues with joint funding e.g. Ministry of Health and Ministry of Education and lack of agreement.

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

- We have recommended that people living in small group homes are included in the sampling of residential facilities. These people may well be engaged in assisting with cooking and preparing meals and housework. This is entirely appropriate and contributes to enabling “an ordinary life”. For this group the questions should be the same as for those living in private homes.
- This group of questions should include a question about support with healthcare. Some people with disability need regular support with procedures such as intermittent catheterisation or manual bowel evacuation e.g. as a result of a spinal injury or spina bifida.

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

- The term “alternative healthcare worker” is not appropriate. It implies someone providing “alternative healthcare” or “alternative medicine” instead of “traditional” medicine. Many alternative healthcare providers are not subject to the HPCA Act which ensures public safety by regulating the activities of health professionals. It is important to obtain data on whether people with disabilities are using alternative or complementary (in addition to traditional healthcare) approaches, but we do not think this question would provide that information.
- It is **essential** to obtain data about access to allied health professionals such as physiotherapists, occupational therapists, speech language therapists, psychologists, behaviour specialists and mental health services. These are the professional groups who are most likely to make a positive difference to people’s lives. Allied health professionals should be close to the top of the list directly after GP and primary health care nurse. Perhaps this is what is meant by other health professional? Medical specialist should read medical and/or surgical specialist.
- We need to know about access to diagnosis, so we recommend the following question: Have you/or your child had any difficulty accessing health diagnostic services?
- Has the person or their whānau experienced stress or difficulty in accessing health services?

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

- Again questions about employment are excluded for people in residential care; at least the question “whether they have a job” should be included.
- Employed people with disability who work limited hours should be asked whether the limitation is through personal choice, limitations imposed by their disability, or limitations imposed by their employer.
- See also Q 14 on employment for carers of children with disability.

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

- It is good to see comprehensive questions about transport.
- We would like to see public transport at the top of the transport questions
 - we note that we are in a climate crisis and use of private cars may/should become increasingly limited in the future. Therefore, public transport must become more accessible to people with disability.

- we would be interested to know how the definitions of short and long distance have been arrived at.
- Specifically for children we need to know about
 - Access to suitable car seats for children with disability, especially those with physical and/or behavioural issues.
 - Access to modified carseat for whānau with modified wheelchair van. Example: funding declined because child could be transported in wheelchair at back of van. Child's aspiration (choking) risk seen as "medical need" therefore not meeting Enable NZ criteria.
 - Exemptions e.g. disabling air bag so child with frequent epileptic seizures can be seated next to the driver for close monitoring.
- Specifically for rangatahi
 - Access to modification of vehicle to enable a young person to learn to drive if they are not funded through ACC.

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

- Insulation
- For those in rental accommodation – number of moves in previous three years
- Time on social housing waitlist where applicable
- Availability and adequacy of housing modifications that meet the needs of the disabled person.
- "out of pocket" expenses for whānau where only limited modification is provided

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

- There are no questions specific to Early Childhood Education (ECE) provision. Considering that we know that ECE has very significant impact on future functioning, we need to know how this is working for young children with disability. This is where the most resource needs to be invested. Data can help to drive resourcing, Questions about access to ECE and the level of support needed and provided should be included in the survey for children aged <5 years.
- Current questions do not reflect current educational provision. For example, the question – "if they attend mainstream school, do they attend special education classes". More appropriate questions are outlined below.
- Type of educational provision (early childhood/primary/secondary/tertiary education)
- Need for additional support in education at early childhood/primary/secondary/tertiary education
- Type of educational support provided e.g.
 - ongoing resourcing scheme funding (ORS) and level/type of ORS support – this may of course have changed by the time of the survey, but questions about what support is provided are likely to yield much more useful information than the vague question currently suggested – define special education class!
 - in class support
 - high health needs funding
 - teacher aide funded from the school budget (including the Special Education Grant)

- teacher aide funded by the parents or whānau
- Specialist teacher input (e.g. vision resource teacher)
- Adequacy of support provided (degree of unmet need)
- When required, does the student receive adequate assistance from Allied Health Professionals (e.g. Physiotherapists) in their educational programme?
- School attendance and exclusion from school
- Has your child been unable to attend school fulltime? If no
 - Is this because of health issues such as illness or fatigue
 - Is this because there is not sufficient support at school
 - Is this because your child has been excluded from school?
 - How much school has your child missed in the last 12 months?

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

- Leisure questions for children should be whānau centred
- The questions smack of white privilege. Questionnaires in any form change behaviour. Are people to be left thinking that they have failed their children because they have not organised art lessons?
- Surely a better approach is an open-ended question with coding of the answers?
- And if there must be a list and an order please start with “gone out with friends or family” and follow with “visited friends” or even more telling “been invited to a friend’s house to play”
- and rather than “whether the child’s impairment makes it difficult for them to play with other children” should be “are there barriers that make it difficult for them to play with other children/play sport/go away on holiday”
- Why are there no leisure questions for adults in residential care?

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

- Wellbeing is important for everyone. Therefore, adults living in residential facilities must be included. Not to do so is to make an assumption that either adults in these facilities are unable to have opinions about their wellbeing or that their wellbeing is unimportant.

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

- The carer’s self-assessed health status must include mental health status – it is not clear from the information provided whether this is the case.
- Has the carer been prescribed medication to assist them with their mental wellbeing in the last 12 months?
- The carer’s self-assessed marital status (rate of marital break-up of children with disability is variable – but important to know how much impact this has)
- Does the carer have support in their caregiving from another adult?
- Are they receiving respite through disability support or ACC?
- Is this support adequate?

- Note that Disability System is currently undergoing a transformation process and may be different by 2023.
- Has carer's ability to find work been limited by reasons related to the child's disability?
- Does the carer worry about what will happen to the child they care for in the event of the carer becoming ill/injured or experiencing age-related disability themselves?
- Availability of support. Often whānau are asked to identify or find their own support workers. Whānau may need flexible support or support at times when support workers are not available. Agencies are not always reliable.