Submission on Content for the 2023 New Zealand Disability Survey

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We have some concerns regarding the sampling of our population living with disabilities. In the previous survey, the median age of adults living in a residential facility was 84 years, which provides a disproportionate view of adults in residential care, focusing more on age-related health and disability issues. Why does the survey only include adults living in residential facilities of 5 people or more? This is not inclusive of those who live in small group homes, which is the norm today in New Zealand, except in aged care. Our adult members living in residential care tend to live in homes of 2, 3 or 4.

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 would like to ensure this survey covers a wide range of neurodiversity, where those diversities may impact on everyday life. It is also important to include those managing behavioural disorders / differences which are not always linked to psychological / psychiatric disorders. In Prader-Willi syndrome, a complex spectrum neurological disorder, our members are likely to fall into several subgroups.

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 15 – 44 group is very wide ranging. It might be more useful to look at what is happening at transition age, i.e. 16-25. Many school leavers struggle with lack of opportunity for filling their days (particularly in rural areas), social isolation, finding employment, and finding suitable accommodation and support when trying to leave home. It would also be interesting to see how issues get resolved or what might go wrong by including up until around 30yrs, when we hope our young adults with PWS will have become more settled.

Life expectancy is also an issue for many of our adults with PWS as many do not live into the older age groups, especially the older generation of our current community, who were often diagnosed later in childhood and didn’t receive the therapies available today. Therefore, life goals differ – there is no retirement plan!

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

As children, because the parent role is often like that of looking after a much younger child. That being said, it is important to consider this age group carefully. We have noticed many of our adolescent members are leaving school earlier today – mainly because ORS funding was available for nearly all with a PWS diagnosis historically, but due to a limited fund increase, around 1/3 do not receive this today, so a) they cannot stay at school until 21yrs, b) they often end up having to leave via suspension or expulsion if they are not supported well enough and able to cope in mainstream high school. So, our children are being forced into an ‘adult’ life earlier on, but the parents are still primary caregivers of a child who is no longer at school.

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?

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

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

Obtaining appropriate help and support as a family can be very difficult. The NASCs seem to be overly stretched with long wait times for assessments, respite opportunities are extremely limited, and agencies don't seem able to maintain enough support worker staff. Families should be asked about the barriers they might face in applying for and obtaining appropriate help.

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

The question asks families to select which services they have seen in the last 12 months and does ask about unmet need if unable to get an appointment, however, there is no mention of therapists (essential in the early years) and unmet medicinal needs. Lack of access to medicines is an essential question to ask because many families either self-fund medications if they can or the patients miss out on life changing treatments.

There should be a question about access to specialists with relevant expertise. In a rare condition like PWS (I in 16,000) and other rare disorders, access to appropriate knowledge is limited and often somewhat dependent upon where you live.

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

There are no questions asked of those who are unemployed about why that might be. Without directly asking that, it would be good to find out about what employment opportunities are or are not available to them where they live. This question as it is, is not really considering those with intellectual disabilities who still want to have meaningful work like everyone and feel like they are contributing to society. In some areas there are more employment opportunities, especially with more social enterprise companies taking off, but options are still very limited in some areas. What support is available to them in finding work (supported employment opportunities)?

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

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

Those in residential care are excluded from this question, but it should not be assumed that all people with intellectual disabilities want to spend their life living in a residential care group home. They have dreams of finding a partner, or living by themselves, or finding a flatmate in the same way that others do. However, because of their inability to earn sufficient wages, financial limitations of their subsidies / benefits and of their need for some degree of support, they are often directed towards the more economical group home option. Some people end up living in several group homes with different providers before they find one that works better for them. We hope this might change as Enabling Good Lives becomes nationwide in that people will have a little more choice in how they live, within financial means. Please ask about what housing options are preferred and whether there is unmet need.

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

Asking about whether they receive extra help with their schoolwork is very vague. This could include someone who has ORS funding, and who may also attend a special school / unit, and group them with someone who receives a little support with minimal teacher aide time. This is a good opportunity to ask what funding streams are available to them – ORS, SHHNF etc. Are their learning support needs met?

It would also be very worthwhile asking if their support needs at school are understood. With rare disorders such as PWS, there is limited knowledge and the PWSA are often asked to help with school issues or training. When things go wrong behaviourally, it is often because the behaviours are not understood. This situation is not helped when the application process for obtaining support does not make allowances for children who may have global, complex health and learning issues, yet they do not meet a particular prescriptive and restrictive ORS criterion. Ask whether the assessment system for obtaining school support appropriately evaluated their child's needs.

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

Why are adults in residential facilities not included in this question? If employment is either not possible or not available, there needs to be vocational activities or leisure / hobbies available to fill time and help provide a full life. These also need to be available for those who do work.

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

There isn't a question about accessing mental health services – were they successful? How easy has this been? What was the wait time?

Also, it should be asked how well they are understood in terms of their wellbeing. (In mental health services, patients with a combination of intellectual disability, complex behavioural problems and potential mental health issues are often not well understood, particularly when due to a rare disorder)

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

This question does not measure the level of impact very well. For example, amongst other things, more information is needed on financial impact due to parent inability to work. A condition such as PWS can impact on many aspects of life – more detail needs to be collected. Studies have shown level of caregiver burden can be very high, particularly during teenage years.

The question also does not ask whether the family have enough support. What support is available to them?

It also does not consider the impact on siblings. (A study in PWS found many were showing symptoms of PTSD.)