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Tēnā koe

Disability Survey 2023: Consultation

Tōpūtanga Tapuhi Kaitiaki o Aotearoa, New Zealand Nurses Organisation (NZNO) welcomes the opportunity to provide input into the development of the 2023 Disability Survey.

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand, representing 51,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment matters. NZNO embraces te Tiriti o Waitangi and contributes to the improvements of the health status and outcomes of all people of Aotearoa New Zealand through influencing health, employment, and social policy development.

Furthermore, we share the intent of the Ministry of Health's definition of equity which equally applies to NZNO work across professional, industrial and member activities.

NZNO has consulted with members and staff in the preparation of this response and we will respond directly to each question.

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?

- NZNO has noted that sensory processing disabilities are absent. These we would classify as different to vision / hearing and psychiatric / psychological disabilities
- We raise concerns around the concept of ranking impairments, and recording any as the 'main impairment', especially in the context of disabilities that impact across multiple domains that differ in difficulty depending on multiple internal and external contexts. Ranking one impairment as the main in these contexts would do a significant disservice to representing the reality of the issue.

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- What is the benefit of requesting information on the cause of an impairment? What value is there in gathering this data, and what of the potential stigmatising impact that historically has arisen from creating distinction using this approach? Experience has highlighted a differing value attached to a disability within society based on how it arose. An accidental injury leading to disability is treated as morally superior to those arising from disease, illness or present since birth which are treated as morally inferior. Will this survey replicate the same moralising of the cause of a disability?

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?

- Within a Ministry of Health context this is classified as ages 12-24, and there is good developmental rationale for creating a grouping of these ages. From the context of identify development, and the impact of disability on health and youth development this age grouping would be indispensable
- The grouping of 15-44 years is broad and somewhat illogical from this perspective and would render youth and young person's invisible

Question 3

Should people aged 15 to 17 years be considered as children or as adults? Why?

- We consider the 15 to 17 categorisation adds no value. The categorisation should be 12-24, and 12-15 year olds, and they should be interviewed independently or alongside interviews with their parents / carers, but need to be allowed to contribute independently to this survey
- People in this age range often lack maturity and therefore, cannot be considered adults. They require assistance in the recognition and control of their emotions, and they need a person they trust in their life, while adults do not. In the case of disabled youth or youth with limited abilities all these aspects become more significant
- People aged 16 years should be considered as adults, consistent with their ability to make decisions / consent regarding their care within health and disability services

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?

- NZNO have identified that there is no reference to te Tiriti o Waitangi within this discussion document, and that is both a significant and concerning omission
- Understanding the experiences of Māori who are disabled, and being able to capture the intersection of racism and ableism through the collection of data around the experience of privilege experienced by disabled Pakeha will be incredibly valuable in order to formulate ways to overcome these structures of marginalisation
- Understanding how access to important services are compounded across multiple identities associated with marginalisation is important. This can be used to highlight where our systems are creating ableism and magnifying this ableism through institutional racism
- Furthermore, it is fundamental to collect ethnicity data on all participants using health and disability services, regardless of whether it is ever anticipated that the data needs to be reported by ethnicity. The data can also be used to inform culturally appropriate care

Question 5

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

- NZNO supports the collection of information pertaining to the experiences of young people in navigating the gap between paediatric support services / devices and adult support services / devices
- Furthermore, information about the ability of young people to access these independent of their parents / carers as they move forward towards independence, and what issues arise during this development stage would add value
- Additional questions could include the awareness of disabled people about the services and equipment available for them and whom to approach in order to obtain it
- The experience of discrimination that arises from the public use of assistive equipment / services, especially while accessing other services i.e. public transport / medical care / education etc. should be recorded

Question 6

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

- Youth and adults should be asked these questions directly, from the age of 12 years old onwards at the very least, not just parents / carers
- Information about access to and the availability of funding should be required

Question 7

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

- This question highlights the requirement to separate children from youth and adults for the purpose of this survey, especially as we have increasing school-based health services in schools which offer confidential health care services. If you are to combine children with 14-year olds you may miss the data capturing their attempts to access school-based health services for issues that they do not disclose to their parents. You will also miss obvious barriers to access of health care that arise, for example, sexual health and or contraception. We also recommend adding school nurse, Nurse Practitioner or General Practitioner to this list
- There is also a complete lack of reference to accessing mental health in this question. This is an essential area to review, to ensure that primary and secondary mental health services are not creating barriers to access for disabled people. Specifically, information about access to counsellors, psychologists, mental health nurses, allied mental health professionals and psychiatrists is essential

Question 8

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

- This is an important area of inquiry, including the experience of seeking support from employers to accommodate disabilities, and the experience of requesting this support
- There are very significant barriers to employment for individuals with disabilities across all sector. We need to identify how disabled people experience and navigate barriers within employment
- What is required to be added, please: after the question "was it difficult to look for work because of their impairment" - please add "was it difficult to become a successful candidate if you applied for a job"

Question 9

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

- This is another question that really requires a youth specific categorisation, especially as transport is already a major barrier/issue for young people in general, but especially so for young-disabled people
- The experience of being a passenger as a disabled person can also mean experiencing dangerous driving that makes individuals uncomfortable. There is a value in asking a question around the experience or perception of safety in this area, as a driver, passenger, and on public transport

Question 10

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

- From a youth health and youth development perspective asking young people if they have their own room is an important question. Young and disabled people can sometimes have to share a room with siblings, parents / carers in part because of the need for support during the night. This can impact on youth identity development
- There is a significant lack of accessible, affordable housing in Aotearoa NZ. Asking a question around whether people had to turn down housing offers because the house was not accessible would help to highlight how serious this problem is. This is especially relevant with the proliferation of multi-level town houses being touted as the solution to the housing problem, with toilets and or bedrooms on upper levels inaccessible for many

Question 11

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

- It is imperative that young people, at least from the age of 12, are allowed to answer questions about school themselves. Parental input may also be valuable, but the input of young people from the age of 12 will provide a much richer perspective on many of these questions
- Some of the wording around the 'impairment making it difficult for them' around making friends, participating in sports etc is potentially placing the barriers in the wrong place? It is not the impairment's fault if a school fails to address bullying issues, or fails to accommodate accessible sports, events, or outings etc.
- For adult studying, it is valuable to measure the attitudes from educators / lecturers who often assume that a disability disqualifies individuals from pursuing certain professions, especially health care professions
- Being able to capture educator or lecturer attitudes will help better understand the barriers around increasing disability representation within professions that really would benefit from disabled perspectives

Question 12

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

- NZO supports any initiative to expand a youth specific section for these questions, given the very different development needs young people experience around leisure that differs substantially from that of children and adults. This should include talking directly with young people from the age of 12
- Additional questions for disabled adults on whether their impairment makes it difficult for them to "engage in hobbies" Many physically disabled people love reading books, watching movies and most importantly - spend time on playstations, X-Box etc It allows individuals the illusion of being able again. In a game they are able to run, fly, jump etc. In addition, many deaf / mute people succeed in blogging. It gives them the illusion that they are normal people like anybody else.

Section 10 currently only allows people to eat, to have a holiday and to observe sports. Life offers much more other options for "normal" people than just coffee and sport! So too for the disabled

Question 13

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

- Young people face drastically different issues around mental health and wellbeing than children or adults, and given we are seeing increasing rates of mental health issues among youth, and an increasing youth suicide rate, having a specific focus within this survey on youth wellbeing is essential
- Similarly, excluding adults in residential facilities feels like a significant example of ableism and exclusion based on disability. The wellbeing experiences of disabled people in residential facilities is incredibly important to capture

Question 14

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

- We would suggest ensuring that young people from the age of 12 can answer questions around the experience of receiving or requiring care support from a parent or carer. Given the developmental stage being marked by identity development this is an important perspective to capture as well when considering this domain

Additional comments about the proposed Disability Survey

The survey needs to explore how important the social interaction in real space and time is for the disabled person who has being interviewed? Some people do not experience physical human contact, because they involved in online activities: from work on the phone to keeping an active blog, from being a Gamer to being an active reviewer for popular sites etc. Others networking across the globe with emails, "Whatsup" recordings, "Messenger" conversations etc. Many of the questions in the proposed survey focus on real physical interactions, which is a little obsolete for many people, especially in our current COVID and isolated world.

Often people with limited abilities, especially with mild impairment seen as "normal" by public and their issues/suffer/struggle is not recognised or understood. This makes them feel even more isolated within the society and their surroundings than on their own. As a result, they start to withdraw from contacts and interactions to avoid innocent questions or suggestions from others that negatively impact on the disabled.

Next stage, disabled people are those who blamed for being ignorant by their former friends while it's actually not their fault but attempt to protect their own wellbeing. Unfortunately, the result is still total isolation and depression. Hence, many disabled find a solution in escaping online sometimes completely replacing reality with the internet life.

It will be very important to analyse how many people had to withdraw from "real" life due to others' misunderstanding of the important aspects of disabled/limited abilities life. In addition to

understanding how many of those who “escaped” online found this life more engaging, rewarding, useful and accepting.

Warren Forster, Tom Barraclough and Curtis Barnes. *Making New Zealand Accessible: A Design for Effective Accessibility Legislation*. An Independent Research Report. (29 September 2021) may be a useful resource to source additional information.

Thank you for the opportunity to participate in the consultation process.

Nāku noa nā

A handwritten signature in blue ink that reads "Lucia Bercinkas".

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