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S21.26

Submission to Statistics NZ on content for the 2023 New Zealand Disability Survey

Introduction

1. The National Council of Women of New Zealand, Te Kaunihera Wahine o Aotearoa (NCWNZ) is an umbrella group representing over 200 organisations affiliated at either national level or to one of our 14 branches. In addition, about 450 people are individual members. Collectively our reach is over 450,000 with many of our membership organisations representing all genders. NCWNZ's vision is a gender equal New Zealand and research shows we will be better off socially and economically if we are gender equal. Through research, discussion and action, NCWNZ in partnership with others, seeks to realise its vision of gender equality because it is a basic human right.
2. This submission has been prepared by the NCWNZ Parliamentary Watch Committee.

General position

3. An estimated 1 in 4 women and girls in Aotearoa New Zealand live with a disability. Disability can be anything from physical, sensory or intellectual impairment, neurodiversity of learning or thought processing, chronic mental or physical illness and more. Some people experience multiple disabilities they are by no means a homogenous group. Girls and women of all ages with any form of disability are generally among the more vulnerable and marginalized of society¹. NCWNZ therefore welcomes the reinstatement of the Disability Survey as a means to gather data on the impact of disability on the lives of New Zealanders, and cautions that the needs of women and girls need to be specifically reflected in the survey design if they are not to remain marginalised.

¹ United Nations General Assembly. Resolution adopted by the General Assembly. S-23/3. Further actions and initiatives to implement the Beijing Declaration and Platform for Action. A/RES/S-23/3. Para 63.
<https://www.un.org/womenwatch/daw/followup/ress233e.pdf>

4. In New Zealand, research shows that 40% of disabled women experience family violence², men with disabilities are almost twice as likely to have jobs than women with disabilities,³ the gender pay gap for disabled people is 10.6% in favour of men⁴, and women with disabilities face significant barriers in accessing adequate housing and services⁵. These are all significant issues for disabled women, and therefore the Disability survey must be designed to produce data that can be used to design policy that will improve this situation. This ultimate purpose of the survey should be in the forefront of design thinking.
5. "Disabled" is a contested term. Paula Tesoriero, the Disability Rights Commissioner, is clear that the term "disabled" refers to environmental factors disabling people, rather than any inherent impairment. This is confirmed by the Convention on the Rights of Persons with Disabilities (CRPD)⁶ which says that disability results from the interaction between a non-inclusive society and individuals with impairments. However, this terminology is not in general usage in our society, and many people have different views on how to talk about "people with disabilities" or "disabled people". More work will need to be done to establish a consistent terminology that is widely understood.

Recommendations

6. Ensure equitable participation of disabled women and girls in the disability survey⁷.
7. The consultation process should specifically include consultation with interested sector groups, such as the disability sector and women's organisations.
8. Good quality data is needed to inform decision-making in mainstream disability issues in New Zealand. This is in line with the CEDAW Committee recommendation⁸:

The Committee recommends that the State party set up a centralized system for the collection, analysis and dissemination of comprehensive data, disaggregated by sex, age, disability, ethnicity, location, gender identity and sexual orientation and socioeconomic status, while maintaining the confidentiality thereof, and that it uses measurable indicators to assess trends in the situation of women and progress

² 2019 New Zealand Family Violence Survey. <https://nzfdc.org.nz/family-violence-statistics>

³ O'Reilly A. 2007. *Employment Barriers for Women with Disabilities*. In: The Right to Decent Work of Persons with Disabilities. Rev. International Labour Organization: p. 49-50.

⁴ Ministry for Women. Disability. <https://women.govt.nz/gpg/disability>

⁵ Kothari M. 2003. Women and adequate housing: study by the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination ... E/CN.4/2003/55: para 32, 64. file:///C:/Users/Beryl/AppData/Local/Temp/E_CN-4_2003_55-EN.pdf

⁶ United Nations. 2006. Convention on the Rights of Persons with Disabilities. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

⁷ United Nations. Department of Economic and Social Affairs. Sustainable Development. 2015. *Transforming our world: the 2030 Agenda for Sustainable Development*. <https://sdgs.un.org/2030agenda>

⁸ United Nations. Committee on the Elimination of Discrimination against Women. 2018. *Concluding observations on the eighth periodic report of New Zealand*. CEDAW/C/NZL/CO/8. https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CEDAW%2fC%2fNZL%2fCO%2f8&Lang=en

towards the realization of substantive equality in all areas covered by the Convention.

9. NCWNZ would like to see questions in each section focused on structural features that discriminate against disabled people, and women and girls in particular. We would like to know what the barriers and enablers are to be able to access support and live their lives to the fullest potential.
10. The impacts on disabled people's support team – whānau, carers, friends – should be assessed.
11. Discrimination is intersectional, so it should be a general principle to design the survey to enable data to be disaggregated by gender, age, ethnicity and disability, at a minimum.

Questions

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.

12. Add:
 - a. Stamina/Breathing/Fatigue
 - b. Neurodiversity
 - c. Mental Health/phobias/anxiety/behavioural aspects (personality disorders) and ADHD
13. Change Agility to Dexterity

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?

14. Youth (under 25 years) and seniors (over 65 years), disaggregated by gender, would be useful for us as these groups of women have particular needs that are sometimes overlooked. They are also groups who do not always have the means to advocate for themselves.

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

15. It would be useful for them to be counted as children. Most children with a chronic functional impairment have significant input from parents/caregivers/whānau for their whole lives, so it is useful for these family members to have legal status in terms of caring for their children.

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?

16. NCWNZ takes an intersectional approach to feminism, and believes that multiple forms of discrimination need to be considered for any one person, so data that is disaggregated by ethnicity is useful. We would need information about Pacific (disabled women) as well as women from our major migrant groupings.

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

17. Information on assistive equipment for learning and workplace use will show the accessibility aspects that enable people with impairments to fully participate in society. Our particular interest is in how easy or difficult it is for people (women in particular) to access assistive equipment.

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

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

19. Again, our interest is in the structural barriers to accessing household or general help.

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

20. Our interest is in the barriers and enablers of access to health services, particularly for women.

21. We are interested in the level of treatment burden on families who support disabled people, especially in relation to health services. This has a direct correlation with the quality of life for the whole whānau.

22. Information about disabled women's, and their families', interactions with the different levels of healthcare would be useful in order to know where the greatest difficulties lie. NCWNZ advocates for the rights of women and girls, so data that focuses this advocacy is particularly helpful.

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

23. NCWNZ would like to know how employment conditions for disabled women contributes or detracts from their wellbeing and quality of life, including financial implications.

24. We would also like to know how informed disabled women are about their rights to support, such as financial assistance and support within employment.

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

25. We would like to know the specific difficulties related to transport encountered by disabled women living rurally.
26. Those people with rare conditions generally have to travel long distances for treatment. We would like to know more about the implications of this, in terms of ease of access to such transport, and the financial and other burdens it places on them.

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

27. Given the difficulties disabled people, especially women, have with finding employment and maintaining financial security, we would want to know the relationship between disabled women and social housing. What is the scale of the problem with appropriate social housing for disabled women?

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

28. Despite the Education legislation⁹ enshrining the right to education for all New Zealanders, we know that many disabled people have difficulty accessing education appropriate for their needs. We would like the survey to monitor the scale of this issue and what the barriers are.

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

29. Leisure activities are as important for disabled people as for anyone else, especially as leisure activities are often where friendships are formed – essential for wellbeing. NCWNZ would like to know what support is required by disabled women to access leisure activities of their choice, and what the barriers and frustrations are.

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

30. Many of the previous questions contribute to assessing wellbeing. However, specific questions about people's mental health would be useful, including that of the whānau who support those disabled people, and information about the successful and not-so-successful support from mental health services.

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

31. Information about carers should be asked throughout the survey, as women are disproportionately the gender who does the caring work – whether it be as parents/

⁹ Education and Training Act 2020.

https://www.legislation.govt.nz/all/results.aspx?search=ta_act%40act_E_ac%40ainf%40anif_an%40bn%40rn_25_a&p=1

guardians of disabled children, teacher aides at schools, carers in homes, or children of disabled parents. The impacts of caring for others should always be included in this survey.

Conclusion

There have been many recommendations and feedback made to the Government when there is reporting on international conventions and the Universal Periodic Review (UPR)¹⁰. This is an opportunity to redress the failings that have been identified.



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¹⁰ United Nations. Human Rights Council. 2019. *Universal Periodic Review - New Zealand*. <https://www.ohchr.org/EN/HRBodies/UPR/Pages/NZIndex.aspx>