



**Submission to Stats NZ - consultation on content for  
the 2023 New Zealand Disability Survey**

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## **1. About IHC**

IHC advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in workplaces and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide specialist services such as behaviour support and training.

IHC advocates for the rights of all people in New Zealand with an intellectual disability (estimated population 89,000, NZ Census Disability Survey 2013).

## **2. Questions asked in the consultation document**

- 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.**

It would be useful if social or communication impairments were included to ensure that individuals with autism spectrum disorder and foetal alcohol spectrum disorder are included. This is a growing group of disabled people and it would be helpful to have data about them.

- 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 average life expectancy of an intellectually disabled person in New Zealand is 59 years<sup>1</sup> so if information is unable to be disaggregated into impairment type, we can only focus on data about disabled people who are under 65 years.

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

People aged 15 – 17 should be considered children (or young adults) as they are unlikely to have left school and be working. IHC also submits that children 12 years and over who can answer the survey themselves should be able to without a proxy. This is compliant with article 12 of the UN Convention on the Rights of the Child.

**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?**

N/A

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

N/A

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

IHC would be keenly interested in knowing whether disabled individuals were able to know in advance or be able to choose who provides support in their home. IHC is interested in the quality of life for intellectually disabled people and having choice and control in who enters your home and assists you with very personal matters, such as personal care, is an important part of having choice and control.

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

We need to have information about intellectually disabled people in residential services as well as private residences. It would also be helpful to ask whether people who received respite care or independent living hours were unable to use these hours due to a lack of services.

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

We need to have information about opportunities and supports provided for the employment of intellectually disabled people in residential services as well as private residences. The language used in the questions about

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<sup>1</sup> Health Indicators for New Zealanders with Intellectual Disability, Ministry of Health, 2011.

modifications for employed disabled people are focused on modifications made for physically disabled people, it would also be interesting to know if reasonable accommodations have been made for disabled people in other disability groups when they are in employment.

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

It is important that questions about transport are asked of people in residential care. It would also be useful to ask disabled people if a lack of transportation stops them participating in the community. The question appears of be set up to capture information about how the disability directly interacts with transport, rather than how the characteristics of disability (such as poverty) interact with transport, although the latter would be of greater interest to IHC.

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

We would like to know whether people have a pet or are able to keep a pet. We would like to know whether people are able to choose where they live and who they live with.

We would like to know whether people in residential care have warm houses. Our understanding is that those in residential care who are on benefits do not receive the Winter Energy Payment as it is assumed that the state is responsible for their warmth, however there appears to be minimal oversight about whether residential care facilities are suitably warm.

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

It is important that questions about education are asked of people in residential care. We would also like to know about disabled students' experiences of restraint and seclusion at school. IHC holds strong evidence that disabled students experience astonishingly high rates of restraint, and in the past also of seclusion, in educational settings.

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

It is important that questions about leisure are asked of people in residential care or community settings. We would also like to know whether disabled people were able to choose the activities they have undertaken. The ability to make your own choices is crucial to living a good life.

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

It is critical that questions about wellbeing are asked of people in residential care. We would also like to know about bullying and abuse that disabled people have experienced in the last 12 months. We understand that there is a question on discrimination and on experiencing a crime, but we think that bullying and abuse that does not meet a level of criminality is likely common and an important signifier of wellbeing.

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

We would be interested in knowing if the carer has suffered economic disadvantage due to caring responsibilities – have they had to end their employment, for example. We would particularly be interested in knowing whether they had to end their paid employment due to their child being unable to attend school full-time.

**3. Conclusion**

Thank you for the opportunity to submit on the questions in the 2023 Disability Survey. The Disability Survey is critical to the work we do at IHC and we wish you well with this important work.