

Improving New Zealand disability data





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Purpose and summary

Purpose

Improving New Zealand disability data outlines Stats NZ's plans to publish new data about disabled people. The paper provides information about the way in which the new data has been produced and why it is needed. Understanding this will help to ensure that the data is interpreted correctly and used effectively.

An increasing need for information about **disabled people is driven by the Government's** commitment to the [New Zealand Disability Strategy 2016–2026](#) and to international conventions. These commitments require the monitoring of change across a range of socio-economic measures, to ensure that any disadvantage faced by disabled people is being reduced or eliminated.

Data is also needed to inform planning and funding for programmes that facilitate this goal. These include services, equipment, and environmental change required to ensure that disabled people can achieve at the same level as the rest of the population.

Summary

The 2016/17 New Zealand General Social Survey (NZGSS) and the June 2017 quarter of the Household Labour Force Survey (HLFS) have new questions that allow us to produce findings for disabled and non-disabled people separately. We aim to publish findings from the new questions with the first release of data from both surveys.

The specific measure we are using to identify disabled people in these surveys is known as the [Washington Group Short Set \(WGSS\)](#). The same questions have been tested for inclusion in the 2018 Census, and a decision on this will be made in June or July 2017.

We expect the inclusion of the relevant questions to be a long-term change to the core content of the NZGSS (run every two years) and the June quarter of the HLFS. Census content decisions are made independently each time the census is run.

The decision to use the WGSS is based on a number of factors, including:

- the considerable expertise that has been involved in the development of the questions
- the intended use of the WGSS matches our needs
- the results will be internationally comparable
- the question set is short enough to include in our existing surveys.

The WGSS will be used to produce estimates of key socio-economic measures by disability status. It will not be used to produce estimates of disability prevalence or to investigate levels of need for services or environmental change. To meet these and other data needs, a disability-specific survey, with a more extensive question set, will be required.

Agreed funding for post-censal surveys means that the next disability-specific survey is expected to take place in 2023. This will result in a 10-year gap between disability-specific surveys in New Zealand. We looked into whether a short question set could be added to existing surveys, to

generate regular and timely information about disabled people. The inclusion of the WGSS will also help to maximize the value of data that we are already collecting.

We expect that the population identified as disabled using the WGSS will be considerably smaller than the population identified by past and future disability-specific surveys. We also anticipate some differences in the size of the disabled populations identified in the surveys to which the WGSS has been added.

New disability data from Stats NZ's household surveys

In order to produce information about a population group, such as disabled people, we must be able to identify who is in the group of interest. A disability status measure is based on a set of questions that allows disabled people to be identified in data collections and surveys. We can then analyse the data for disabled people and compare them with other groups.

How to best construct disability status measures continues to be the subject of debate internationally, and there is currently little consistency in the way developed nations identify disabled people in national surveys. There has, however, been some movement towards a shared understanding of concepts and methods in this area.

Deriving disability status in surveys that are not disability-specific requires survey designers to find a short set of suitable questions. One such set is the Washington Group Short Set (WGSS) and this has been chosen as the most suitable available for our purposes. See [The Washington Group on Disability Statistics](#) for more information about this question set.

Both the NZGSS and the HLFS (and potentially the 2018 Census) will include the WGSS questions. Disability status will be derived from answers to the questions in this set.

Including disability status in these surveys addresses, in part, a strongly expressed need for more comprehensive and more frequent data about disabled people in New Zealand. We can obtain greater value from the investment in the NZGSS and HLFS by enabling information already collected to be broken down by disability status. This will help to support decision makers in government and across the disability sector by providing timely and comparable data about this vulnerable population group.

New Zealand General Social Survey

[The NZGSS](#) provides information about the well-being of New Zealanders aged 15 years and over. It covers a wide range of social and economic outcomes and shows how people are faring in these aspects of their lives. In particular, the survey provides a view of how well-being outcomes are distributed across different groups of the population.

The NZGSS is collected over a 12-month period and is carried out every two years. Interviews for the 2016/17 survey year have, for the first time, included questions from which disability status can be derived. This will allow analysts and researchers to examine how well disabled people are faring compared with other groups across the range of well-being outcomes covered by the survey.

Disability status will be available on NZGSS datasets, and tables will be published on the Stats NZ website. The new questions will be included in the NZGSS every time it is run so that results can be compared over time.

Household Labour Force Survey

The HLFS is collected continuously and published every quarter. [The purpose of the HLFS](#) is to produce a timely, relevant, and comprehensive range of statistics relating to the employed, unemployed, and those not in the labour force, using international standards and guidelines.

Disability status will be derived from questions in the HLFS for the June 2017 quarter and in every June quarter from then on. Results by disability status will be published as part of the June quarter Labour Market release on the Stats NZ website and variables will be included in HLFS datasets.

Census of Population and Dwellings

The next Census of Population and Dwellings will be run in 2018. Testing has been carried out on the inclusion of the same questions to derive disability status in this census as we have included in the two households surveys. Decisions about the content of the 2018 Census are due to be released in June or July 2017.

The Washington Group on Disability Statistics

We have chosen to use the Washington Group Short Set of questions to identify disabled people in Stats NZ's existing surveys.

[The Washington Group on Disability Statistics](#) is a [UN city group](#), established to create robust measures of disability status and promote international comparability in disability data.

The Washington Group question sets for identifying disabled people are gaining acceptance and seeing increased use around the world. Considerable work has been carried out on the design and testing of the question sets, and extensive documentation of the processes used can be found on the [Washington Group website](#).

The Washington Group question sets have been developed to enable member states to fulfil the monitoring obligations established by ratification of the United Nations (UN) [Convention on the Rights of Persons with Disabilities \(CRPD\)](#). They are also recommended by the [UN Economic and Social Commission for Asia and the Pacific \(ESCAP\)](#) for use in monitoring progress against the [Incheon Strategy](#). In a joint statement in November 2016, the inter-agency expert group on SDG indicators (IAEG-SDG) endorsed the use of Washington Group question sets by national statistical offices for the disaggregation of data on adults and children. The Washington Group provides information on [international monitoring](#) recommendations on its website.

The Washington Group question sets are based on the [International Classification of Functioning, Disability and Health \(ICF\)](#).

The Washington Group Short Set

The Washington Group Short Set (WGSS) is a set of six questions on functioning difficulties and activity limitations. It was developed for inclusion in population censuses and in surveys where only a small number of questions can be used. It is based on the ICF and was designed with a specific purpose in mind.

[Read the statement of rationale for the Washington Group general measure on disability.](#)

Two important paragraphs from that document are:

Equalization of opportunities was agreed upon and selected as the purpose for the development of an internationally comparable general disability measure. This purpose was chosen because:

- 1) It was relevant (of high importance across countries with respect to policy), and;
- 2) It was feasible (it is possible to collect the proposed information using a comparable general disability measure that includes a small set of 6 census-like questions).

...The [WGSS] questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of this data would compare levels of participation in employment, education, or family life for those with disability versus those without disability to see if persons with disability have achieved social inclusion. In addition the data could be used to monitor prevalence trends for persons with limitations in the particular basic activity domains. It would not represent the total population with limitations nor would it necessarily represent the 'true' population

with disability which would require measuring limitation in all domains and which would require a much more extensive set of questions.

The rationale makes it very clear that the WGSS is not designed for estimating prevalence of disability, nor for use in understanding need for services or interventions that can improve the lives of disabled people. These information needs must be met using a disability-specific survey that allows for the use of more extended question sets.

We have made slight wording adjustments to the questions to accommodate differences in the delivery mode of our household surveys and to be consistent with the rest of the survey. The NZGSS uses face-to-face interviews, while the HLFS is carried out largely by telephone. We have also dropped the optional words shown in brackets.

Washington Group Short Set of questions on disability

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response options

- a) No — no difficulty
- b) Yes — some difficulty
- c) Yes — a lot of difficulty
- d) Cannot do at all

Different thresholds can be set for deriving disability status from these questions. The Washington Group **recommends a threshold that requires people to have at least ‘a lot of difficulty’ with at least one of the activities to be counted as disabled.**

Expectations about the disabled population

The population identified as disabled by the WGSS will be smaller than the one derived from a more extensive question set, such as that used in the [New Zealand Disability Survey](#) (NZDS). Examples from five countries (across several years) give overall disability prevalence rates between 6 and 10 percent (Loeb, 2016) when the WGSS questions are used as intended.

In 2016, the Australian Bureau of Statistics (ABS) ran a [Supplementary Disability Survey](#) using the WGSS and released an estimated disability rate of 6.7 percent for their national population. Note that the ABS uses their [Survey of Disability, Ageing and Carers](#) to generate the official Australian national disability prevalence rate, which was 18.3 percent in 2015.

In New Zealand, the disability prevalence rate from the 2013 NZDS was 24 percent for all people and 23 percent for people living in private dwellings. We are anticipating that the disabled

population identified by WGSS will be about 10 percent. We also expect that the disabled populations identified by different surveys using the WGSS will not be identical. Differences in method and purpose of the surveys will affect the results.

Important reasons for a finding a smaller population using the WGSS compared with the NZDS are:

- the population coverage is smaller
- the threshold for **'disabled' is higher**
- fewer domains are included.

Population coverage

HLFS and the NZGSS are household surveys. Only people who live in private dwellings are in the sample. The NZDS included a sample of residential care facilities, as well as some group homes. The smaller coverage of dwelling types will result in a smaller disabled population, as the dwelling types that are not in these surveys can have large proportions of disabled people.

Threshold for disability

A survey respondent **is required to indicate 'a lot of difficulty' or 'cannot do at all' for at least one** of the six WGSS questions in order to be counted as disabled. This is a higher threshold than used **in the NZDS where the response option 'with difficulty'** did not allow for the separation of people with some difficulty from those with a lot of difficulty. People with low levels of difficulty are counted in the NZDS disabled population but not in the WGSS population.

Disability domains

When designing measures to identify disabled people in surveys, a decision must be made about **how many 'domains' to include**. A domain is usually associated with a particular impairment type or regular activity.

The NZDS identified disabled people across 10 domains:

- hearing
- vision
- mobility
- agility
- intellectual
- psychological/psychiatric
- speaking
- learning
- memory (for adults)
- developmental delay (for children).

The NZDS also had more than one question for some of these domains. The result was 23 questions for identifying disabled adults and 14 for identifying disabled children. A question set of this length is not suitable for use in surveys that are not disability-specific, however, it will identify

a disabled population that is larger than one identified by only six questions. The six domains included in the WGSS were chosen because they were found to be the ones that identified a majority of people at risk of being restricted in their independent participation in society.

Stats NZ will not use the WGSS to estimate official disability prevalence rates, as this is not the intended purpose of the questions. We also advise against comparing findings from surveys using the WGSS with those from the NZDS. Only a disability-specific survey can produce good estimates of the size of the disabled population, by including a more extensive question set covering more domains, and possibly more dwelling types. A disability-specific survey will allow investigation of the use of assistive devices, services, and environmental changes, and will look more closely at reasons for disparities found in other data sources.

Background to New Zealand disability data

The New Zealand Disability Survey

[The NZDS](#) has been carried out by Stats NZ in the same year as the census since 1996, however, it will not be conducted in 2018. To date, this disability-specific sample survey has been the main source of official statistics about disabled people in New Zealand.

The primary purpose of the NZDS is the estimation of disability prevalence rates for key demographic groups. The survey provides information on socio-demographic characteristics of disabled people. It also collects data on met and unmet need for support and assistive equipment, and on outcomes and barriers to participation across a range of social and economic activities.

In 2012, funding for future provision of social statistics was approved by Cabinet. The funding allows for one post-censal survey in the same year as each population census. Te Kupenga (a **survey of Māori well-being**) will be the 2018 post-censal survey. We expect to conduct the next disability-specific survey in 2023.

The growing need for disability data

Since the first NZDS was run in 1996, the field of disability rights, both nationally and internationally, has advanced considerably.

The [New Zealand Disability Strategy 2001](#) was heralded as internationally significant in its approach to identifying and addressing inequities faced by disabled people across the full range of rights and entitlements. The recent launch of the [New Zealand Disability Strategy 2016–2026](#) sets out a course for the next 10 years. Monitoring how well we are progressing against the goals of the Strategy requires regular and high quality data.

Ratification of the CRPD by the New Zealand Government in 2008 meant a new set of obligations for New Zealand to demonstrate that opportunities for disabled people do not differ from the rest **of society, that people's rights under the CRPD are upheld, and their dignity respected in all** aspects of life. Regular reports to the [UN Committee on the Rights of Persons with Disabilities](#) are required in which New Zealand must show that we are meeting our obligations under the CRPD or, if not, what we are doing about it.

Other important international initiatives include the UN [Sustainable Development Goals](#) (SDGs), which came out of the [Rio+20 Conference](#) held in 2012. New Zealand is working out how to prioritise and progress domestic action relating to the SDGs, and timely data will be needed to report progress for vulnerable population groups, including disabled people.

International agreement is growing on the need for more data, and specifically more internationally comparable data, about disabled people, in order for countries to demonstrate their commitment to specified goals.

Conceptualising disability

In recent years, considerable work has been carried out in national statistical offices and by international agencies to develop and standardise methods for identifying disabled people in population surveys.

Since its publication in 2001, the ICF has seen growing acceptance as a common language and framework for use in disability measurement. In this framework, disability is seen as a dynamic **process that involves the interaction of a person's functional status with their physical, cultural, and policy environments. The focus is on a person's ability to function within an environment, not on the presence of disease or on self-identity. The ICF approach is described as being a 'bio-psycho-social' model. It takes into account impairments in body function and structure, difficulties in daily activities, and restrictions in participation in a range of life domains.**

The ICF is the underlying model of disability adopted by the UN in the CRPD. It was used in the first World Report on Disability published by WHO in 2011. The ABS and Statistics Canada both use the ICF as the basis for their national disability surveys, and Stats NZ has endorsed this idea of disability. The changes made to the disability status indicator for children in our 2013 survey were specifically aimed at bringing the measure into line with ICF concepts that were reflected in the adult indicator.

A shared conceptual basis for understanding disability, while a good start, is only part of the picture. In the detailed specification of a disability status measure, a number of other issues must be resolved. These include:

- For what purpose are disabled people being identified?
- Which aspects of body function or structure, activity limitations, or participation restrictions should be made explicit?
- What question wording, order, format, and collection method will elicit the best answers?
- How should thresholds for assigning disability status be set?

Even when there is agreement on the concept under investigation, any variation in addressing these issues will result in different measures and different, albeit overlapping, groups of people being identified as disabled.

There is increased international consensus on the idea of disability and its place in social data. However, differences remain in the specific methods used to identify disabled people in surveys.

From an operational perspective, there have been long-standing reservations in New Zealand about publishing statistics from surveys that use different disability status measures, due to concerns about confusing users.

Survey designers have been unwilling to add extensive question sets to existing surveys when response rates are generally declining and respondent burden is of concern. This has certainly been the case in New Zealand, where the NZDS module for identifying disabled people includes 23 questions for adults and 14 for children.

Resistance to adding large question sets to existing surveys, combined with a desire to have one standard approach to identifying disabled people in official statistics, has meant that Stats NZ has shied away from mainstreaming disability measurement. The development of the WGSS and its growing endorsement internationally have been important drivers of change in this area. A greater

strategic focus within Stats NZ on maximising the value of our data collections to meet customer needs has also underpinned the changes.

Conclusion

There are considerable advantages to mainstreaming disability data by including a measure of disability status as a standard demographic characteristic in relevant official data collections. The ability to disaggregate existing, high-quality data collections by disability status can add substantially to available information about disabled people.

The inclusion of the WGSS in household surveys does not remove the need for a comprehensive disability-specific population survey. It does mean that a range of new information about disabled people will be available, and the continuous inclusion of the measure in these surveys will allow trends over time to be monitored in a way that has not been possible before.

Providing robust disability statistics is both complex and controversial, and having more than one disability status measure is new territory for data users in New Zealand. We are sure, however, that adopting the WGSS to provide more information about this vulnerable population group will be of great value in the ongoing quest to improve the lives of disabled people.

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