Identifying Disabled People in the 2023 New Zealand Disability Survey

A discussion document for the DDEWG meeting, March 2021

[Purpose 2](#_Toc66540651)

[Introduction 2](#_Toc66540652)

[A brief history of Stats NZ disability data collections 2](#_Toc66540653)

[Cultural considerations 3](#_Toc66540654)

[Why run a national disability survey? 4](#_Toc66540655)

[Conceptualising Disability 4](#_Toc66540656)

[Screening Method 4](#_Toc66540657)

[Why change the screening method now? 5](#_Toc66540658)

[Other ways to identify disabled people in surveys 7](#_Toc66540659)

[UN Washington Group on Disability Statistics 8](#_Toc66540660)

[WHODAS 2 9](#_Toc66540661)

[The Model Disability Survey 9](#_Toc66540662)

[Canada 9](#_Toc66540663)

[Australia 10](#_Toc66540664)

[UK 10](#_Toc66540665)

[Final comment 11](#_Toc66540666)

[References 12](#_Toc66540667)

[Appendix One: Disability screening method from 2013 NZDS 14](#_Toc66540668)

[Appendix Two: Links for other ways to identify disabled people 17](#_Toc66540669)

## Purpose

The next national disability survey will be carried out by Stats NZ in 2023. This paper aims to inform discussion about ways in which disabled people might be identified in that and future occurrences of the survey.

The way in which disabled people are identified in a survey is based on a combination of one or more survey questions and a threshold. The questions are referred to as screening questions and the threshold defines the response options that are required for a person to be counted as disabled. Together they are called the screening method.

As well as providing background information this paper sets out some of the desired features of a screening method. Stats NZ is seeking views on:

1. screening method characteristics and their relative importance
2. the screening method itself.

## Introduction

Stats NZ has run a national disability survey four times. Recent developments with regard to the identification of disabled people in national surveys need to be considered prior to running the survey again. Any changes that result from this consultation should help to ensure that the survey produces data of the greatest possible value.

Deciding how disabled and non-disabled people are to be separated in survey data is challenging. However, it remains an essential task if we are to achieve the survey objectives.

The following section provides a brief history of the collection of data about disabled people by Stats NZ. This is followed by some background information on survey concepts and screening methods. A number of ways in which disabled people can be identified in surveys are outlined. The approaches described here are not exhaustive; the aim is to set out some options for discussion.

## A brief history of Stats NZ disability data collections

Each of the four national disability surveys carried out by Stats NZ so far have been made up of two components, the Household Disability Survey (HDS) and the Disability Survey of Residential Facilities (DSRF). Together they are referred to as the New Zealand Disability Survey (NZDS).

The HDS is a post-censal survey. A sampling frame is constructed using records from the national population census. The HDS covers people of all ages living in private households (or in group homes[[1]](#footnote-1) ). Survey participants are selected randomly from the frame. People who were identified as disabled in the census are given a higher chance of being selected for the survey. This helps to ensure that sufficient disabled people are included in the survey to provide robust estimates. Without this ‘boosted’ approach the sample would need to be larger to include a good representation across different groups of disabled people.

Once selected for the survey all participants are screened for disability using the survey screening method. This means that people who are classified as disabled in the census may not be classified as disabled in the survey and vice versa.

Having the HDS and census linked has the additional advantage that data from the census can be included in the survey dataset. This frees up survey space for disability-specific content.

The DSRF does not use the census for a sampling frame, it uses a list of residential care facilities from the Ministry of Health. Sample selection is a two-stage process with participants chosen from residents in selected care facilities.

The first NZDS was run in the mid-1990s (HDS in 1996 and DSRF in 1997). Further occurrences of the survey were in the census years 2001, 2006 and 2013. To support the use of the census as a frame for the HDS, disability-related questions have been included in the census individual questionnaire since 1996. Prior to 2018 these questions were included only to aid in the selection of respondents for the HDS and no findings from them were published.

In 2012 a decision by Cabinet on the funding of post-censal surveys led to a 10-year gap between disability surveys with the next one scheduled for 2023.

To provide information about disabled people from alternative data sources, Stats NZ introduced the [Washington Group Short Set](https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/) of questions on functioning (WGSS) into two national household surveys - the general social survey (GSS) from 2016, and June quarters of the household labour force survey (HLFS) from 2017. WGSS questions were also included in the 2018 Census.

This question set is designed for use in large scale surveys and censuses that are primarily about topics other than disability. It allows comparisons to be made between disabled and non-disabled people in the high-level findings from these surveys. The purpose is to see if there is evidence of a gap between disabled and non-disabled people in key survey outcomes. It does not provide a comprehensive count of disabled people. For that purpose, Stats NZ uses a more inclusive screening method in a disability-specific survey.

From 2019/20 Washington Group (WG) questions have also been included in the Household Economic Survey (HES). The HES uses longer WG question sets in order to achieve the survey objectives. WG questions are now part of the core content of these Stats NZ surveys and the WGSS is also included in both the NZ [Health Survey](https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/surveys/new-zealand-health-survey) and the NZ [Crime and Victims Survey](https://www.justice.govt.nz/justice-sector-policy/research-data/nzcvs/).

## Cultural considerations

Data about Māori and Pacific people living with disability in New Zealand show that these groups experience relative disadvantage across many aspects of their lives.[[2]](#footnote-2)

Research currently funded by the Health Research Council aims to investigate disability from a Māori perspective. This has the potential to add much needed knowledge in this area.[[3]](#footnote-3)

Cultural variation within the population must be considered when selecting the disability screening method. The aim is to achieve consistency across cultural boundaries in the group being identified. Without this consistency, ethnic group differences in the size, needs of, and outcomes for disabled people cannot be meaningfully compared.

Boosted ethnic group samples have been used in the NZDS to help ensure that robust estimates can be produced for Māori and also for Pacific peoples combined (i.e. not enough for individual Pacific ethnic group estimates). Decisions about doing this in 2021 have yet to be made.

## Why run a national disability survey?

The main reasons for running a national disability survey are:

* to understand the size and characteristics of the disabled population,
* to understand the support needs faced by disabled people and the extent to which they are being met, and
* to compare social and economic outcomes between disabled and non-disabled people.

Use of a short set of questions (like the WGSS) in household surveys that are not disability specific serves to provide a broad indication of whether there are outcome gaps between disabled people and others in society. It allows data to be made available from a range of sources and with greater frequency than could be obtained from a large-scale disability survey. However, it is recognised that the WGSS is not ideal for use with children and also misses some groups of disabled adults. A national disability survey allows for a more comprehensive determination and analysis of the relevant group than can be achieved using the WGSS. It also enables the production of a wider range of estimates about that population, to greater levels of accuracy.

## Conceptualising Disability

A functional understanding of disability has been used by Stats NZ since their first disability survey in 1996[[4]](#footnote-4). Human functioning is understood as a continuum of health states, and everyone exhibits some degree of functioning at the level of the body, the person, and society.

The survey has always been based on concepts embodied in international classifications. Originally this was the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and then, in 2013, the [International Classification of Functioning, Disability and Health](https://www.who.int/classifications/international-classification-of-functioning-disability-and-health) (ICF).

“ICF is the WHO framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001(resolution [WHA 54.21](http://apps.who.int/gb/archive/pdf_files/WHA54/ea54r21.pdf)) as the international standard to describe and measure health and disability.” [[5]](#footnote-5)

For the 2013 NZDS Stats NZ made the conceptual basis explicit and amended the child screening questions to better align with the ICF.[[6]](#footnote-6) Stats NZ endorses ICF concepts for understanding disability and the use of the common language that the ICF promotes.[[7]](#footnote-7)

There are some approaches to identifying disabled people that are not consistent with the ICF. An approach that uses the presence of specified medical conditions to indicate disability status is not consistent, nor is disability self-identity where the respondent is asked if they regard themselves as disabled. These approaches are not being considered as screening methods for the NZDS.

## Screening Method

There are many ways of operationalising ICF concepts in a screening method. The group of people identified as disabled in a survey will depend on the questions used and the threshold chosen. Both are important. The questions must include the range of functions (called functional domains) that are considered relevant to disability status for the survey’s purposes. The threshold specifies the degree of difficulty a person must have to count as disabled in the survey.

In countries where funding has been available to carry out dedicated disability surveys, National Statistical Offices (NSOs) and other government agencies have developed their own screening methods. These were driven in part by factors specific to their country as well as the way in which disability was understood at the time the work was done. This has led to a variety of methods being used around the world even when the ICF is the conceptual basis for measurement.

Developing a unique screening method from scratch for 2023 and beyond is not being considered by Stats NZ. The resources and expertise to do this are not available and so much work in this area has already been done by others. International best practice combined with local consultation is seen as the most appropriate and cost-effective way to find a suitable screening method.

Stats NZ regards the following as important features of a disability screening method for the NZDS.

1. That it is robust, well tested and trusted by stakeholders.
2. That it can be expected to remain appropriate and produce consistent data over time.
3. That it is cross-culturally consistent both domestically and internationally.
4. That it is based on a functional approach using ICF concepts.
5. That it includes the assessment of function across a wide range of domains.
6. That graded response options are used (so levels of difficulty can be identified and a threshold for being disabled can be defined).
7. That functional domains are specified (so that subgroups of the disabled population such as people who are vision impaired or hearing impaired can be identified).
8. That it makes explicit the treatment of assistive devices.
9. That it makes explicit the time period for functional difficulties to count as disability.
10. That it allows for flexibility in data analysis and comparison with other sources.
11. That it has suitable questions for all age-groups that are in scope.

**Comments are sought on this list of features and their relative importance.**

While considerable effort has gone into the development of screening methods around the world, there remains no standard definition, question set, or threshold for identifying the disabled population. The word ‘disabled’ continues to be used in different ways and measured using a range of screening methods.

In measuring disability prevalence, the lack of international comparability has been a source of concern for many[[8]](#footnote-8). This lead to the creation of the [UN Washington Group on Disability Statistics](https://www.washingtongroup-disability.com/about/about-the-wg/) in 2001 as well as efforts by the World Health Organisation (WHO) to develop and promote consistent approaches to determining who is and is not disabled.

## Why change the screening method now?

As we look towards the first NZDS in 10 years it is timely to explore recent developments to see if the NZDS can be improved.

The screening questions and thresholds used in the 2013 NZDS are shown in Appendix One. It remains an option to use them again. However, some issues with that screening method should be noted.

Firstly, while the 2013 NZDS was based on a functional approach, and the ICF provided the conceptual framework, not all of the screening questions were framed around current functioning. For example, ‘Does the selected child have a recognised intellectual disability?’ and ‘Did the selected adult go to a special school or receive special education because of an intellectual disability?’. These questions are not consistent with a functional understanding of disability.

The 2013 questions mapped to specific impairment types for which findings were output. The relationship is shown in Appendix One.

The impairment types for which findings were output are not all functional domains. Vision impairment maps directly to vision as a functional domain however there isn’t an equivalent mapping for intellectual impairment.

If a desired output from the survey is separate information about people who are intellectually disabled, then criteria for being so will need to be specified. Being intellectually disabled will include one or many functional domains to varying levels of difficulty and some of these domains would not be suitable for measuring in a survey.

A second issue with the 2013 screening questions is that response options allow for only limited derivation of the amount of functional difficulty being experienced. A detailed and consistent graded response system across all questions would be an improvement.

For adults the response options were yes/no on 7 questions and easily/with difficulty/not at all on the other 16. This arrangement limits the derivation of different levels of functional difficulty. More detailed graded response options would provide greater flexibility in defining a threshold for the disabled population or in specifying levels of difficulty. This in turn allows for more sophisticated analysis by researchers. It has also been shown that graded/scaled responses improve respondents’ ability to report.[[9]](#footnote-9) The wording in some of the 2013 screening questions means that graded response options can’t be used.

A final point about the screening method used previously is the extent to which it can produce a robust time series. It is the important that differences over time found in the data can, within the usual limits of a sample survey, be treated as showing real change. From 2023 the NZDS needs a screening method that can provide a sound basis from which to measure change over time.

In-depth investigations carried out after the surveys in 2006 and 2013 were unable to explain the size of some of the changes that were observed from previous occurrences of the survey. Observed differences over time were regarded as implausible in both years.

The screening method may not be the only, or even the main, culprit. Investigations concluded that a number of issues may underpin the variations over time. However, data from the NZDS is used as if it does provide valid comparisons over time and all factors that may contribute to unwanted variation should be reviewed. If an alternative screening method would allow for more sophisticated analysis and understanding of the change over time observed in the data, this would be an advantage.

An example of differences over time in disability rates by age is shown below.

**Disability prevalence rates from four occurrences of the NZDS**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Year | Children | Adults | | | Total |
|  | 0 to 14 | 15 to 44 | 45 to 64 | 65 plus | All ages |
| 1996/97 | 11% | 12% | 25% | 52% | 20% |
| 2001 | 11% | 13% | 25% | 54% | 20% |
| 2006 | 10% | 9% | 20% | 45% | 17% |
| 2013 | 11% | 16% | 28% | 59% | 24% |

The child rates appear to be consistent over time however they were expected to differ between 2006 and 2013 due to changes made to align the child questions with the ICF. Older age groups show changes over time that were considered implausible. Investigations into weighting and survey practices found no single reason for these differences. It was agreed that a number of changes in survey practice may have been influential. One of the goals of adopting a new screening method is to reduce unwanted variation in the underlying population so that only real-world charge is shown.

Another example of change over time is for the number of people with vision impairment.

**Prevalence of vision impairment from two occurrences of the NZDS**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Children | Adults | | | |
|  | 0 to 14 | 15 to 44 | 45 to 64 | 65 plus | All adults |
| 2001 | 13,312 | 15,189 | 23,558 | 44,893 | 83,640 |
| 2013 | 5,911 | 31,823 | 60,788 | 69,739 | 162,350 |
| % change in 12 years | -56% | +110% | +158% | +55% | +94% |

Investigations after the 2013 NZDS found no reasonable explanation for these differences. With no alternative sources available, it could not be known which of these figures is closer to the actual number of people with a vision impairment. Variation in the subjective assessment of one’s functional difficulty may exceed that observed in an objective measure, however the variation seen here makes it impossible to draw accurate conclusions over time about the vision impaired population.

The work of the Washington Group on Disability Statistics and the adoption of the WGSS by Stats NZ have implications for the screening method in the NZDS. It is not possible or appropriate to use WG methods in every data collection. Where it is valid to do so, the use of consistent methods to identify disabled people is an advantage.

## Other ways to identify disabled people in surveys

In considering a change to the way disabled people are identified in the NZDS, Stats NZ is looking for screening questions that are based on functional difficulties and operationalised as limitations in basic activities. This is consistent with current international practice.

Limitations in basic activities are used to assess functional difficulty because the inclusion of limitations in complex activities (such as driving a car), or restrictions in participation (such as having a job ) becomes problematic when these are the aspects of life to be measured as outcomes.

Other disability related matters could be considered for inclusion as part of the wider survey content. This may include whether participants have specified medical conditions or whether they identify as disabled. Both of these topics are of interest to data users. Final content decisions will be driven by the consultation and survey objectives.

When choosing screening questions, some issues are routinely debated. They include: the range of functional domains to be covered, the treatment of assistive devices, and the use of a minimum duration of difficulty (usually 6 or 12 months). In addition, the question wording must allow survey participants to provide high quality responses to questions that are both subjective and self-assessed, and practical matters, like survey mode, are also important in question design. Cross-cultural comparability in interpretation of the questions and their relevance to different cultural groups are also important. Some of these considerations are features of a suitable screening method as listed earlier and some are wider issues of survey design.

Addressing New Zealand specific matters could be done by adjusting questions used by other organisations, although loss of international comparability should be balanced against this.

The countries with which Stats NZ traditionally collaborates and compares social outcomes are Australia, Canada, and the UK. UN methods for identifying disabled people which have an emphasis on international comparability and human development goals are outlined below, this is followed by some information on the methods used by each of these three countries.

### UN Washington Group on Disability Statistics

Stats NZ currently regards WG methods as the most suitable for use as a screening method in the NZDS for 2023 and beyond. WG methods are the closest available to an international standard.

Since it was set up in 2001 The WG has developed several question-sets for identifying disabled people in surveys. The ongoing efforts of NSOs that belong to the group and the WG Secretariate, based at the [US Centers for Disease Control and Prevention](https://www.cdc.gov/nchs/washington_group/) (CDC), have resulted in work that is intellectually rigorous as well as extensively reviewed and tested.

WG methods have been endorsed by the UN for use in the assessment of outcomes for both the [Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) (CRPD) and the [Sustainable Development Goals](https://www.un.org/sustainabledevelopment/). The [WG website](https://www.washingtongroup-disability.com/) provides comprehensive documentation on the methods; they are transparent and well supported by the secretariate. Seminars and workshops to facilitate the use of WG methods provide much needed guidance on implementation, analysis, and intellectual justification for the methods. They have been tested in a range of cultural settings around the world, and international comparability and human development were key drivers.

Having adopted WG question sets for some purposes there would be advantages to the use of consistent questions in the New Zealand Disability Survey. Suitable question sets for the NZDS would be the [extended set on functioning](https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/) for people aged 18 or over and the [child functional modules](https://www.washingtongroup-disability.com/question-sets/wgunicef-child-functioning-module-cfm/) for people aged 2 to 17 years.

The WG questions allow different levels of functional difficulty to be derived which also enables more than one disability threshold to be set.

Disabled children under 2 years of age are not included in WG methods. This age-group has been in the NZDS to date and work is needed on how best to estimate disability prevalence for children of this age for future occurrences of the survey.

### WHODAS 2

Interest has been expressed in using the WHO Disability Assessment Schedule ([WHODAS 2](https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule).0) in New Zealand, and specifically in the NZDS. WHODAS 2.0 is based on the ICF and is described as an assessment instrument for use in both clinical and population measurement settings.

The instrument produces a score for each person and does not provide a threshold for determining if a person is disabled or not. This, along with the inclusion of life activities and participation as domains in the derivation of the score, makes it unsuitable for use as screening questions in the NZDS.

### The Model Disability Survey

The Model Disability Survey (MDS) was developed by the World Health Organisation and World Bank to help member states collect a range of information related to disability. It provides a complete package, as outlined in the [Survey Manual](https://apps.who.int/iris/bitstream/handle/10665/258513/9789241512862-eng.pdf?sequence=1), that can be used to collect data about multiple dimensions of disability.

Several ways to identify disabled people are embedded in the MDS, including the WGSS. Stats NZ would prefer to have one agreed method for determining the disabled population. The MDS approach presents a range of interesting options to consider for survey content and analysis.

### Canada

New Zealand’s first HDS in 1996 was based on Statistics Canada’s approach, with some adaptations for the local context. It was not used again by its originating agency and significant changes have been made to the Canadian survey several times since.

In a 2018 note entitled [The evolution of disability data in Canada: Keeping in step with a more inclusive Canada](https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018003-eng.htm) Stats Canada said:

“Since 1983, Statistics Canada, with the support of Employment and Social Development Canada (ESDC), has conducted seven surveys focussed on persons with disabilities: the 1983/84 Canadian Health and Disability Survey (a supplement of the monthly Labour Force Survey), the 1986 and 1991 Health and Activity Limitation Surveys (HALS), the 2001 and 2006 Participation and Activity Limitation Surveys (PALS), and the 2012 and 2017 Canadian Surveys on Disability (CSD).”[[10]](#footnote-10)

In Canada, census questions are used to identify people ‘most likely to have a disability’. From this group (called census Yes), a sample is selected for the disability survey. A narrower set of questions in the disability survey, and the predetermined threshold, are then used to determine whether the person is to be included in the disabled population from which estimates are produced.

Cases in the survey sample who are deemed not to be disabled using the survey screening method are combined with a sample selected directly from census NO respondents to form the non-disabled sample population for estimates of prevalence. These cases do not go through the CSD questionnaire.

Using the latest available census filter questions and survey screening questions meant that for 2017 the reported disability prevalence was higher than previously. While acknowledging that there are problems with analysis of the survey over time, Stats Canada aims to use the 2017 findings as a benchmark for monitoring future change. The survey does not include children under 15 years.

### Australia

In 2020 a report called [People with Disability in Australia](https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary) was released and included data based on 21 different ways of identifying disabled people. The report notes:

“the Australian Bureau of Statistics’ (ABS) Survey of Disability, Ageing and Carers (SDAC) uses a comprehensive set of questions to determine disability and is considered the gold standard of disability identification in Australia”[[11]](#footnote-11)

The ABS SDAC is used to estimate disability prevalence statistics for Australia, on comparability over time the ABS reports:

“Most of the content of the nine disability surveys conducted by the ABS is comparable. There are differences, however, as more recent surveys have tried to get better coverage of disability and of specific tasks and activities previously thought to be too sensitive for a population survey.”[[12]](#footnote-12)

While explicitly based on the ICF, the questions asked in the SDAC to establish disability status and severity (about 120 questions) are different from those used by other countries. In 2018, the ABS released a report on [Sources of Disability Information](https://www.abs.gov.au/ausstats/abs@.nsf/mf/4431.0.55.002) 2012 – 2016. This report outlines three approaches used in other surveys run by the ABS and explains the different disabled populations identified, it also shows the value of having both long and short question sets.

The SDAC is not a post-censal survey. A total of 65,805 people across all age groups participated in the 2018 SDAC: 54,142 from households and 11,663 from care-accommodation.[[13]](#footnote-13) The SDAC covers private dwellings and self-care retirement villages; as well as health establishments that provide long-term care accommodation (for at least three months).

### UK

In the UK, a number of different government agencies collect survey information about disabled people. Driven by the Equality Act 2010 a [harmonised system](https://gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/) for measuring disability has been developed and guidance on its use is provided. The questions are referred to as the Equalities Act Disability Definition (EADD). The [long-lasting health conditions and illness (LLHCI) standard](https://gss.civilservice.gov.uk/policy-store/long-lasting-health-conditions-and-illness/) and the [activity restriction standard](https://gss.civilservice.gov.uk/policy-store/activity-restriction/) are combined to determine if a person is identified as disabled in a survey.

The UK does not run a post-censal disability survey. Their questions provide an alternative to specifying separate domains of functioning to determine the disabled population. They use a wide, simple distinction that is based on the presence of a least one activity-limiting health condition. In 2021 the questions that will be used in the UK Census are set as: *Do you have any physical or mental health conditions or illnesses lasting or expecting to last 12 months or more?* If yes: *Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities? (*Yes, a lot/Yes, a little/Not at all)[[14]](#footnote-14)

The UK uses Equality Act criteria to monitor compliance with the [public sector equality duty](https://www.gov.uk/government/publications/public-sector-equality-duty) that came into force in 2011. While this creates a preference for using questions in the harmonised system it is acknowledged that other question sets identify different disabled populations. A comparison published in August 2019 concluded that while the EADD and Washington Group questions are based on similar concepts of disability, their different approaches identify substantially different disabled populations. [[15]](#footnote-15)

# Final comment

Stats NZ currently regards the WG question sets as most suitable for use in the NZDS 2023 and beyond. They have many of the features wanted in a screening method and are consistent with the adoption of the WGSS in other Stats NZ surveys.

The identification of disabled children under 2 years of age would need further work as this group is not covered by WG questions.

Stakeholders, including disabled people and users of disability data, as represented by the DDEWG are asked to express their views on possible screening methods and also on the features that are important to them in a screening method.

The support of stakeholders in any decisions made is essential to the success of this project.

# References

Australian Institute of Health and Welfare (2020). People with Disability in Australia. Retrieved from

<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary>

Australian Bureau of Statistics (2018) Disability, Ageing and Carers, Australia: Summary of Findings methodology. <https://www.abs.gov.au/methodologies/disability-ageing-and-carers-australia-summary-findings/2018>

Groce, Nora E and Mont, D. (2017) Counting disability: emerging consensus on the Washington Group questionnaire PDF [36 KB]. <https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30207-3/fulltext>

Madans, JH, Loeb, ME, Altman BM (2011). Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. In BMC Public Health 2011, 11 (Suppl 4): S4. <http://www.biomedcentral.com/1471-2458/11/S4/S4>

Mont, D (2007) Measuring Disability Prevalence. The World Bank social protection discussion paper no. 0706 <http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf>

Palmer M. and Harley D. 2011. Models and measurement in disability: an international review. Health Policy and Planning 2011; 1–8

Statistics Canada (2018) Canadian Survey on Disability, 2017: Concepts and Methods Guide

<https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018001-eng.htm>

Statistics Canada (2018). The evolution of disability data in Canada: Keeping in step with a more inclusive Canada. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018003-eng.htm>

Statistics New Zealand (2015). He hauā Māori: Findings from the 2013 Disability Survey. Wellington: Statistics New Zealand. Retrieved from <https://www.stats.govt.nz/assets/Uploads/Retirement-of-archive-website-project-files/Reports/He-haua-Maori-Findings-from-the-2013-Disability-Survey/he-haua-maori-disability-survey.pdf>

Statistics New Zealand (2015). Measuring disability in New Zealand: Current status and issues. A discussion document for the Working Group on Disability Data and Evidence. Retrieved from

<http://www.odi.govt.nz/assets/Uploads/2015-08-28-paper-1-measuring-disability-in-nz-current-status-and-issues.docx>

Statistics New Zealand (2017). Improving New Zealand disability data. Retrieved from

<https://www.stats.govt.nz/methods/improving-new-zealand-disability-data>

Statistics New Zealand (2000). Key Statistics. 2001 Post-Census Surveys: Māori Language Survey & Disability Survey. November 2000. Retrieved from <https://statsnz.contentdm.oclc.org/digital/collection/p20045coll19/id/0/rec/1>

NZ Ministry of Health. 2008. Pacific Peoples’ Experience of Disability: A paper for the Pacific Health and Disability Action Plan review. Wellington: Ministry of Health. Retrieved from

<https://www.health.govt.nz/system/files/documents/publications/pacific-peoples-experience-of-disability-may08.pdf>

UK Office for National Statistics (2019) Measuring Disability: comparing approaches. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/measuringdisabilitycomparingapproaches/2019-08-06>

UN Convention of the Rights of Persons with Disabilities (2006) <http://www.un.org/disabilities/default.asp?navid=15&pid=150>

United Nations Department of Economic and Social Affairs Statistics Division Series M No. 67/Rev.2. (2008) Principles and Recommendations for Population and Housing Censuses <http://unstats.un.org/unsd/demographic/sources/census/census3.htm>

Weeks, Julie D. (2017) National Center for Health Statistics, USA, and Washington Group on Disability Statistics; International Training Workshop on Disability for NGOs; Lincoln’s Inn Fields, London, UK March 16, 2017

World Health Organisation (2002) Towards a common language for functioning, disability, and health. <http://www.who.int/classifications/icf/icfbeginnersguide.pdf>

World Health Organisation. International Classification of Functioning, Disability and Health (ICF)

<https://www.who.int/classifications/international-classification-of-functioning-disability-and-health>

World Health Organisation and World Bank (2001) World Disability Report <http://www.who.int/disabilities/world_report/2011/en/>

World Health Organisation and World Bank (2017) Model Disability Survey Manual

<https://apps.who.int/iris/bitstream/handle/10665/258513/9789241512862-eng.pdf?sequence=1>

# Appendix One: Disability screening method from 2013 NZDS

Response options:

|  |  |
| --- | --- |
| Type A | Type B |
| * easily * with difficulty * not at all * don’t know * refused | * yes * no * don’t know * refused |

|  | **Screening Questions for Adults (15 years and over)** | **Impairment type** | **Response option** |
| --- | --- | --- | --- |
| 1 | Can the selected adult hear what is said in a conversation with one other person? | Hearing | Type A |
| 2 | Not counting noisy places such as a café, can the selected adult hear what is said in a group conversation with three other people? | Hearing | Type A |
| 3 | Because of a long-term condition or health problem does the selected adult have any difficulty speaking and being understood? If other people have difficulty understanding the person, select 'yes' | Speaking | Type B |
| 4 | Can the selected adult see ordinary newspaper print (using their glasses or contact lenses if they wear them)? | Seeing | Type A |
| 5 | Can the selected adult clearly see the face of someone across a room, that is, from four metres away (using their glasses or contact lenses if they wear them)? | Seeing | Type A |
| 6 | Can the selected adult walk the distance around a rugby field, without resting, that is about 350 metres? If they can walk 350 metres easily using a walking stick or some other aid, select 'easily' | Mobility | Type A |
| 7 | Can the selected adult walk up and down a flight of stairs, that is, about 12 steps? | Mobility | Type A |
| 8 | Can the selected adult carry something as heavy as a 5-kilogram bag of potatoes, while walking for 10 metres? That is about the length of three cars parked alongside the footpath? | Mobility | Type A |
| 9 | Can the selected adult move from one room to another? If they can move from room to room easily in a wheelchair or using some other aid, select 'easily' | Mobility | Type A |
| 10 | Can the selected adult stand for 20 minutes? If they can stand easily using crutches or another aid, select 'easily' | Mobility | Type A |
| 11 | Can the selected adult bend down and pick something up off the floor? | Mobility | Type A |
| 12 | Can the selected adult get in and out of bed by themselves? | Mobility | Type A |
| 13 | Can the selected adult reach in any direction, for example above their head? | Agility | Type A |
| 14 | Can the selected adult dress and undress themselves? | Agility | Type A |
| 15 | Can the selected adult cut their own fingernails or toenails? If they have difficulty ONLY because nails are very tough, select 'easily'. If they can cut their fingernails but cannot reach their toenails, select 'easily'. | Agility | Type A |
| 16 | Can the selected adult use their fingers to grasp or handle things like scissors or pliers? | Agility | Type A |
| 17 | Can the selected adult cut their own food, for example meat or fruit? | Agility | Type A |
| 18 | Does the selected adult have a long-term condition that makes it hard in general for them to learn? This question is about the capacity to learn new things. If they have difficulty ONLY because of physical barriers or physical limitations, select 'no' | Learning | Type B |
| 19 | Does the selected adult have a long-term condition or health problem that causes them on-going difficulty with their ability to remember? Excluding occasional memory lapses. | Memory | Type B |
| 20 | Does the selected adult need support or help from other people or organisations because of an intellectual disability? If they get support from an individual, or an organisation/group such as IHC or People First, select 'yes'. | Intellectual | Type B |
| 21 | Did the selected adult go to a special school or receive special education because of an intellectual disability? | Intellectual | Type B |
| 22 | Does a long-term emotional, psychological, or psychiatric condition cause the selected adult difficulty with everyday activities that people their age can usually do? Common conditions include depression, anxiety, or bipolar disorder. | Psychiatric/  psychological | Type B |
| 23 | Does a long-term emotional, psychological, or psychiatric condition cause the selected adult difficulty communicating, mixing with others, or socialising? | Psychiatric/  psychological | Type B |

|  | **Screening Questions for Children (under 15 years)** | **Impairment type** | **Response**  **option** |
| --- | --- | --- | --- |
| 1 | Can the selected child hear? | Hearing | Type A |
| 2 | Because of a long-term condition or health problem, does the selected child have any difficulty speaking and being understood? | Speaking | Type A |
| 3 | Can the selected child see (with glasses if wears them)? | Seeing | Type A |
| 4 | Can the selected child stand? (If they can stand easily with braces or crutches then select 'easily'). | Mobility | Type A |
| 5 | Compared with other children their age, can the selected child bend down? | Mobility | Type A |
| 6 | Can the selected child move from one room to another at home? | Mobility | Type A |
| 7 | Compared with other children their age, can the selected child walk on a flat footpath? | Mobility | Type A |
| 8 | Can the selected child use their hands to grasp an object such as a spoon or a crayon/pencil? | Agility | Type A |
| 9a | Compared with other children their age, can the selected child take off their T-shirt? | Agility | Type A |
| 9b | [If 9a response is with difficulty or not at all]  Is that because they have difficulty raising their arms? | Agility | Type B |
| 10 | Does a condition or health problem make it difficult for the selected child in general to learn? | Learning | Type B |
| 11 | Does the selected child have a recognised intellectual disability? | Intellectual | Type B |
| 12 | Most children have occasional emotional, nervous, or behavioural problems. Does the selected child have any of these problems long-term that limits the type or amount of activity that they can do? | Psychiatric/  psychological | Type B |
| 13 | Does a long-term psychological or mental health condition make it difficult for the selected child to do everyday activities? | Psychiatric/  psychological | Type B |
| 14 | Has the selected child been diagnosed with a disorder or impairment that significantly delays their development? | Developmental delay | Type B |

**Disability Threshold**

To be counted as disabled a respondent must answer:

‘with difficulty’ or ‘not at all’ to at least one question with Type A response options or

‘yes’ to at least one question with Type B response options.

# Appendix Two: Links for other ways to identify disabled people

Washington Group [extended set on functioning](https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/) for people aged 18 or over and the [child functional modules](https://www.washingtongroup-disability.com/question-sets/wgunicef-child-functioning-module-cfm/) for people aged 2 to 17 years.

The Canadian Disability Survey [disability screening questions](https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item_Id=348023#qb353069)

The ABS SDAC questionnaire is attached as a PDF on [this page](https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#survey-material)

[Census UK 2021 paper questionnaires](https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/census2021paperquestionnaires)

1. The term group home is used to mean a community/independent-living residence. In 2013, the HDS included group homes with fewer than five occupants. [↑](#footnote-ref-1)
2. Statistics New Zealand. (2015). *He hauā Māori: Findings from the 2013 Disability Survey.* Ministry of Health. 2008. Pacific Peoples’ Experience of Disability: A paper for the Pacific Health and Disability Action Plan review. [↑](#footnote-ref-2)
3. <https://www.hrc.govt.nz/resources/research-repository/te-ao-marama-disability-perspectives-tangata-whaikaha-maori> [↑](#footnote-ref-3)
4. <https://statsnz.contentdm.oclc.org/digital/collection/p20045coll1/id/2662> [↑](#footnote-ref-4)
5. <https://www.who.int/classifications/international-classification-of-functioning-disability-and-health> [↑](#footnote-ref-5)
6. <https://www.stats.govt.nz/methods/improving-new-zealand-disability-data> [↑](#footnote-ref-6)
7. <https://www.who.int/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4> [↑](#footnote-ref-7)
8. <http://www.who.int/disabilities/world_report/2011/en/> [↑](#footnote-ref-8)
9. Julie D. Weeks National Center for Health Statistics, USA, and Washington Group on Disability Statistics; International Training Workshop on Disability for NGOs; Lincoln’s Inn Fields, London, UK March 16, 2017 [↑](#footnote-ref-9)
10. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018003-eng.htm> [↑](#footnote-ref-10)
11. <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/about-this-report/defining-disability> [↑](#footnote-ref-11)
12. <https://www.abs.gov.au/methodologies/disability-ageing-and-carers-australia-summary-findings/2018> [↑](#footnote-ref-12)
13. <https://www.abs.gov.au/methodologies/disability-ageing-and-carers-australia-summary-findings/2018> [↑](#footnote-ref-13)
14. [Census UK 2021 paper questionnaires](https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/census2021paperquestionnaires) [↑](#footnote-ref-14)
15. [Measuring disability: comparing approaches](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/measuringdisabilitycomparingapproaches/2019-08-06) [↑](#footnote-ref-15)