Te Atatū – Insights

October 2022

Developing an indicator relating to disability

At a glance

The Social Wellbeing Agency has worked with experts in Disabled People's Organisations and in government to create a new proxy indicator based on government administrative data that can be used to explore outcomes of disabled people. This report summarises the new indicator, the sources from which it is derived, and some guidance on how the indicator should be used.

Key features

- The indicator measures one half of the intersection that creates disability: the functional limitations people experience in day-to-day life.

- The indicator is based on the Washington Group Short Set questions on functioning, but also supplemented with other data.

- The code produces 3-way indicators of limitation across six functional activities, as well as one overall 2-way 'disability status' indicator.

- The indicator should be used by researchers (in collaboration with disabled people) to understand the experiences and outcomes of disabled people.

Why this matters

Disabled people are a priority group for government. Community and research evidence tells us that disabled people are often underserved by government services, and face disadvantage across a range of social and economic domains (Office for Disability Issues, 2016). This means it is important for the evidence that guides policy and practice to highlight the experiences and outcomes of disabled people. However, most administrative data collections tend not to capture adequate measures of disability, making it a challenge for researchers to routinely identify and focus on disabled people.

Measuring disability is a complex and still evolving issue. This report summarises the results of the Social Wellbeing Agency's work to create an indicator that identifies people who are likely to be disabled. This can be used to undertake research with and about disabled people, in order to describe outcomes and experiences, evaluate supports or improve system-level policies. This indicator cannot be used to provide or deny services to any individual, whether or not they are disabled.

There is no perfect way to classify people into categories and no full agreement amongst the disabled community on the language to be used. Any categories we create, and the language we use to describe them, will not be the way some disabled people would want to describe themselves. However, it is important for the disabled community, researchers, and policy makers to have a common language to describe varying levels of participation as citizens, clients, or consumers of services. We hope that this enables a broader understanding of the experiences of disabled people, and how the government can better support them to achieve their aspirations.

Researchers interested in using this indicator can use this code on GitHub.

This indicator can be used to undertake research with and about disabled people to describe outcomes and experiences, evaluate supports or improve system-level policies.

How we have made the indicator

Disability is a social construct that arises through the combination of two things:

1. The limitations some people have in completing some activities.
2. The barriers that exist in a person's environment (or society in general) that limit participation.

This means to comprehensively identify the disabled population requires collecting a lot of information from people about their lives and the barriers or accommodations they experience. This type of information is currently not available in administrative data collected by government agencies.

However, there are some sources of government data that tell us about the first of these factors: the functional limitations that some people have. Given the importance of including and focusing on disabled people in research to improve government services, one alternative for researchers is to use information on limitations to identify groups who are *more likely to be* disabled, and then compare outcomes for those people to outcomes for other people who are less likely to be disabled. Where there are differences in outcomes between these groups, this tells us about the extent to which society is disabling.

The indicator is constructed using Stats NZ's Integrated Data Infrastructure (IDI). The IDI is a secure database that brings together data collected by different government agencies for research use. It allows researchers to explore the experiences and outcomes for groups in the population, in order to help improve government policies or services.

The indicator is based mainly on the Washington Group Short Set (WGSS) questions on functioning, which are included in the 2018 Census (of the entire population), and the General Social Survey and Household Labour Force Survey (of samples of the adult population) conducted by Stats NZ. The WGSS is a series of six questions about difficulties people might encounter doing everyday things:

- Walking
- Seeing
- Hearing
- Remembering
- Washing
- Communication.

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However, not everyone has answered these questions (some people were not in the country at the time of the Census, for example), and some people might have acquired impairments after the questions were asked. We have supplemented these questions with data from some Ministry of Health collections: SOCRATES, which captures functional assessments for disability clients (based on information collected from Needs Assessment and Service Coordination services); and InterRAI, which captures similar information for older people.

In collaboration with experts in the disabled community, the Ministry of Health and Office for Disability Issues, we have aligned each of these data sources[1], resulting in a three-level indicator for each of the six functional activities:

- **No limitation:** This group does not report any limitations in undertaking everyday tasks. They are *unlikely* to be disabled. However, because the WGSS does not ask about some factors, a small number of these people may identify as disabled, or be indicated as disabled, if we had more accurate data.
- **Low functional limitation:** This group reports some difficulty with everyday tasks. They are *somewhat likely* to be disabled. Some of this group may be disabled, while others have some impairment but face relatively few barriers in society, and/or have impairments that are temporary in nature.
- **High functional limitation:** This group reports a lot of difficulty with everyday tasks or cannot do them at all. They are *very likely* to be disabled. Almost all people with high functional limitation are likely to face high barriers to participation in society. However, not all people with high functional limitation may identify as disabled themselves, and people with high limitation might be a relatively small part of the overall disabled population.

While a three-level indicator across each of six functional activities provides a lot of detail about the potential for someone to be disabled, it might not be feasible to report this level of detail in all situations. Following guidance from the

We have supplemented the Washington Group Short-Set questions with data from some Ministry of Health collections.

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[1] The mapping of data sources to level of limitation for each of the six functional areas is summarised in the appendix. Where multiple data sources indicate different levels for the same person within the same functional area, the indicator shows the most recent level of limitation.

Washington Group (2020), we have also used the six functional indicators to produce one overall proxy indicator for disability status for each person. This takes the value of 'disabled' if the person had high functional limitation in at least one activity, and 'not disabled' otherwise. (This overall indicator is consistent with how many agencies, such as Stats NZ, are already using the WGSS to report on outcomes for disabled people.) Researchers have also explored other ways to combine across activities to arrive at a single indicator – see Washington Group (2021) for some examples.

How we recommend others use this indicator

Involve disabled people in your research, including when designing your approach and interpreting your results

Researchers inside and outside of government already know that to make sure research is most relevant, insightful, and beneficial, it needs to have input from experts in the relevant area. Disabled people are experts in their own lives and should know about and be involved in research that affects them. We recognise that finding relevant experts can be difficult, particularly when analysis is done in short timeframes. The Social Wellbeing Agency can help to connect you with relevant experts on disability data and lived experience that will improve the quality of your insights: info@swa.govt.nz.

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Use it to compare outcomes, not to estimate the size of groups

Since this indicator provides an indication of the *likelihood* that a given individual is disabled, it cannot be used to accurately count the disabled population. The official measure of the disabled population in New Zealand is derived from the Disability Survey undertaken by Stats NZ. Use of this indicator of functional impairment should be constrained to comparing outcomes or experiences between groups, rather than discussing the size of those groups.

Adjust for age in your analysis

There is a very strong relationship between age and functional impairment. Almost half (47%) of the people in the high

functional limitation group are over 65, compared with only 13% of those in the no limitation group. The group of older people with functional impairments will also be a mix of people who have acquired impairment due to age, and people who have experienced disability throughout their lives (who are likely to have quite different experiences and outcomes). To account for this, we recommend adjusting for age when comparing between functional groups, either through use of a statistical model, or by reporting outcomes by both functional limitation and age (at minimum, reporting separately those below and above the age of 65).

There are other differences between the disabled and non-disabled populations, including socio-economic status and where they live. Depending on your research question, these factors might also be important to adjust for.

Where possible, explore differences within the groups we have identified

The disabled population is highly diverse, and experiences are likely to differ a lot within the three broad functional limitation groups. While it may not always be possible (due to time, resource, or data limitations) to further break up these groups, we recommend exploring differences where possible. In our overall disability indicator, we have grouped people with low functional limitation in the 'non-disabled' group, but these people might have quite different experiences from those reporting no functional limitations. Comparing outcomes between the three functional limitation groups (no, low and high limitation) can provide an idea of how many barriers there are in the area you are focused on.

Other breakdowns in outcomes you could consider reporting are by type of functional limitation – for example, reporting results for people with vision impairments separately to people with limitations relating to remembering. Where your sample allows it, consider also include exploration of people with functional impairment and specific ethnicities, genders, or regions.

We recommend exploring differences within the functional limitation groups where possible.

Limitations of this indicator

This indicator was designed to provide us a way to describe experiences of the disabled population with the data currently collected by the government and available in the IDI. However, it has some limitations that researchers should keep in mind when using it:

- The indicator is not as accurate and comprehensive as the measure of disability in the Disability Survey. The Disability Survey is a collection run every ten years by Stats NZ and is the official source of disability prevalence statistics. Our indicator is a credible alternative estimate to use only in situations where Disability Survey data is not feasible – it is not a replacement for the official measure.
- The Washington Group Short Set (WGSS) is not a fully comprehensive measure of functional limitations. The Washington Group (2022) notes that their questions 'represent the majority of, but not all, persons with limitation in basic actions'. The functional areas covered by the indicator might be more likely to pick up disability relating to sensory or mobility impairment than people for whom society is disabling relating to social, behavioural, learning, or cognitive functions.
- For children under 12, the WGSS is less sensitive at moderate levels of functional limitation: it is harder to distinguish children with 'some difficulty' from those with 'no difficulty'. The WGSS is also not collected for children under the age of five.
- The indicator may capture people who are disabled only temporarily. These people may have very different experiences to people who have permanent or ongoing impairments.

Ultimately, the comprehensiveness of this indicator is dependent on the source data about functional impairment collected by agencies and made available in the IDI. We will continue to explore improvements to this indicator to reduce these limitations as new data becomes available.

This indicator opens up many different uses of evidence that will be helpful to support the disabled community.

How researchers and policy makers can use this indicator

We believe the creation of this indicator opens up the possibility for many different uses of evidence helpful to support the disabled community. This includes:

- Research undertaken by government, non-government, and academic organisations, to better understand the experiences and pathways of disabled people, and how they can be better supported by government services.
- Evaluations undertaken by government agencies, to identify any differential effects of programmes on disabled people.
- Regular monitoring on how government is currently supporting disabled people to achieve their aspirations. This includes monitoring activities and outcomes relating to the New Zealand Disability Strategy. Regularly monitoring the outcomes of disabled people is also a requirement under the United Nations Conventions on the Rights of People with Disabilities (United Nations, 2006).
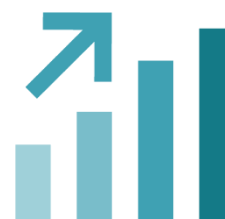
IDI researchers interested in incorporating this indicator into their work can use this code published on GitHub: https://github.com/nz-social-wellbeing-agency/definitions_library/blob/main/health/multi-source%20indicator%20of%20functional%20disability.sql.

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Appendix: Mapping of data sources

Hearing

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI
	Do you have difficulty hearing, even if using a hearing aid?	NASC assessment: Hearing impaired; deaf or nearly deaf	Hearing
No functional limitation	1: No – no difficulty	No	0: Adequate
Moderate functional limitation	2: Yes – some difficulty		1: Minimal difficulty
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	2: Moderate difficulty 3: Severe difficulty 4: No hearing

Seeing

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI
	Do you have difficulty seeing, even if wearing glasses?	NASC assessment: Vision impaired; blind or nearly blind	Vision in adequate light
No functional limitation	1: No – no difficulty	No	0: Adequate
Moderate functional limitation	2: Yes – some difficulty		1: Minimal difficulty
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	2: Moderate difficulty 3: Severe difficulty 4: No vision

Walking

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI	
	Do you have difficulty walking or climbing steps?	NASC assessment: Wheelchair user; moving around inside home; moving around outside home; moving around in the community	ADL self performance	iADL capacity and performance
No functional limitation	1: No – no difficulty	No	0: Independent	0: Independent
Moderate functional limitation	2: Yes – some difficulty		1: Setup help only	1: Setup help only
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	2: Supervision 3: Limited assistance 4: Extensive assistance 5: Maximal assistance 6: Total dependence	2: Supervision 3: Limited assistance 4: Extensive assistance 5: Maximal assistance 6: Total dependence

Remembering

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI	
	Do you have difficulty remembering or concentrating?	NASC assessment: Memory; attention e.g. concentration; intellectual disability; learning ability; other difficulties with above	Short term memory; procedural memory; situational memory; long-term memory; residential history over last 5 years – person with intellectual disability	Easily distracted
No functional limitation	1: No – no difficulty	No	0: Memory OK	0: Behaviour not present
Moderate functional limitation	2: Yes – some difficulty			1: Behaviour present, consistent with usual functioning
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	1: Memory problem	2: Behaviour present, appears different from usual functioning

Washing

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI
	Do you have difficulty (with self-care such as) washing all over or dressing?	NASC assessment: Dressing or un-dressing; toileting; bathing, showering, washing self; grooming and caring for body parts	ADL self performance – bathing
No functional limitation	1: No – no difficulty	No	0: Independent
Moderate functional limitation	2: Yes – some difficulty		1: Setup help only
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	2: Supervision 3: Limited assistance 4: Extensive assistance 5: Maximal assistance 6: Total dependence

Communication

Recoded indicator	Stats NZ surveys	MoH – SOCRATES	MoH – InterRAI
	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	NASC assessment: Non verbal; ability to express core needs; mute or nearly mute; speech impaired	Scale communication
No functional limitation	1: No – no difficulty	No	0: Intact
Moderate functional limitation	2: Yes – some difficulty		1: Borderline intact 2: Mild impairment
High functional limitation	3: Yes – a lot of difficulty 4: Cannot do at all	Yes	3: Mild/moderate impairment 4: Moderate impairment 5: Moderate/severe impairment 6: Severe impairment 7: Severe/very severe impairment 8: Very severe impairment

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Ka pō, ka ao, ka awatea is a well-known tauparapara (traditional incantation) within te ao Māori, which refers to the separation of Ranginui (the sky-father) and Papatūānuku (the earth-mother) which brought light into this world. It talks about 'coming from darkness to light' or 'transiting from a place of not knowing to knowledge'. Te Atatū, indicates the morning light and acknowledges this series of events, and the importance of light representing knowledge in te ao Māori.

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