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| To: | Disability Data and Evidence Working Group |
| From: | Andrew Webber (SWA) and Jonathan Godfrey (Massey University) |
| Date: | 29 September 2022 |
| Subject: | **Disability indicator report** |
| Action: | For decision |

## Recommendation

It is recommended that the Disability Data and Evidence Working Group:

* Endorse the attached draft paper to describe the disability indicator.
* Discuss what future improvements could be made to the indicator (noting that it is an evolving concept).

## Context/background

The Disability Data and Evidence Working Group (DDEWG) has a long-standing interest in encouraging analysts and researchers (inside and outside of government) to report on the experiences and outcomes of disabled people. DDEWG has previously agreed that a practical way to identify disabled people in administrative data is through the Washington Group Short-Set (WGSS), a series of six questions on functionality. While most government agencies do not currently collect WGSS data, Stats NZ’s Integrated Data Infrastructure (IDI) is a secure database that links administrative data collected by many government agencies, which provides the ability for IDI researchers to identify disabled people in many sectors that do not collect disability data (eg the education, justice, or care and protection systems).

However, the WGSS data is chiefly available through the Census, which does not provide data for everyone in the population. Through work undertaken in collaboration with Ministry of Health, the Social Wellbeing Agency (SWA) created an indicator of disability that was conceptually based on the WGSS, but integrated data from a variety of sources (including data from NASC assessments, InterRAI assessments, and other Stats NZ surveys) in order to provide the most comprehensive and up to date picture of disability. A draft report summarising this indicator was brought to the previous DDEWG group, where it was agreed additional work was needed, both in terms of how the indicator was derived and the language the report used to describe the indicator.

## Proposed report

SWA has since worked with Dr Jonathan Godfrey to revise the report (latest draft attached). The major changes to the report compared to the previous version seen by DDEWG are:

* Using more precise language that is tied to what the indicator actually measures.
* Clarifying the conceptual basis for the indicator, being only one side of the intersection that creates disability.
* Being clearer that the indicator has limitations and is only a rough proxy for disability, but that it can still provide an indication of the extent of social inclusion.
* Changing the indicators so there are six 3-way indicators (showing no limitation, low limitation, and high limitation, where ‘high’ is defined as ‘a lot of difficulty’ or ‘cannot do at all’ on the WGSS), one for each activity type.
* Creation of one new binary (2-way) indicator, which indicates whether the person has at least one activity with high functional limitation (ie consistent with the Washington Group’s recommendation for an overall ‘disability status’ indicator).
* The addition of a section with recommendations about how researchers should use the indicator, including that they should include disabled people in the design and interpretation of research, and that it should not be used to estimate prevalence.

It is important to be clear that we consider both the indicator and the report describing the indicators to be living documents. All authors of the report acknowledge the limitations of the current indicator, and we have identified several opportunities to refine the indicator over time. However, we also recognise the urgent need for researchers to be able to identify the disabled community in a ‘good enough’ way, given the lack of visibility disabled people have had (and continue to have, per recent UN Committee on the Rights of Persons with Disability recommendations) in official data in New Zealand. Therefore, our proposed approach is to publish and disseminate the indicator and report in their current state, and promote them along with the understanding that they will be improved over time.

## Proposed indicator module

We propose to make a SQL code module that will produce the indicator (as described in the attached report) available both inside and outside the IDI (on SWA’s Github page). The beginning of this code module will contain a relatively short description of the intent and conceptual basis of the indicator, as well as some recommendations from use (taken from the report). The module will direct researchers to the published report (on SWA’s website) for more information.

## Potential future improvements

We see there being potential to further incorporate other administrative data, either to address the limitations of the current indicator, or to supplement the current indicator with other indicators of related populations. This could include:

* Better identification of disabled children and young people, drawing on insights from a recent project relating to the Ministry of Education’s Highest Needs Review.
* Incorporation of ACC claims data.
* Incorporation of mental health/illness/wellbeing data, either as part of the existing indicator or as a separate related indicator.
* Synthesis of service receipt of various sorts (eg learning support, health services, DSS, Child Disability Allowance, ACC support) to be used alongside the disability indicator to examine degree of support and unmet need in the disabled population.

We would be guided be DDEWG as to which – if any – of these improvements are worthwhile investigating, as well as their relative priority.