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**SUMMARY**

**Disability Data and Evidence Working Group**

**Date:** 27 June 2018

**Time:** 9.30am-3.00pm

**Venue:** 1.8 Kahu, Aurora Centre, 56 The Terrace, Wellington

**Attendees:** *Government agencies*

* Statistics New Zealand: Calli Seedall (Chair), Digby Carter, Katy Auberson and Maddie Davison
* Office for Disability Issues: Brian Coffey, Dr Catherine Brennan and Jacinda Keith
* Ministry of Social Development: Anne Hawker
* Ministry of Education: Sally Jackson
* Ministry of Health: Chloe Lynch and Christopher Carroll
* Ministry of Justice: Patrick Power
* Ministry of Transport: Roselle Thoreau
* Social Investment Agency: Danny Mollan

*Independent agencies*

* Human Rights Commission: Kerri Kruse

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

*Disabled People’s Organisations*

* Dr Jonathan Godfrey

*Universities*

* Dr Brigit Mirfin-Veitch (Univeristy of Otago and Donald Beasley Institute)

**Apologies:** Human Rights Commission: Douglas

Hancock

ACC: Julie Shipton-Pasgaard

1. **Introduction**

Calli Seedall (Chair) welcomed all participants to the meeting of the Disability Data and Evidence Working Group (DDEWG).

1. **Overview of the work currently being undertaken by the Disability Advice Working Group**

Presentation 1 focused on the purpose statement of this project which is to recommend a question or set of questions to include in the upcoming Public Sector Workforce Census to determine respondents’ disability status. Other measures from the Census can then be disaggregated by disability status. Stats NZ will give the recommendations to the State Services Commission (SSC).

The Disability Advice Working Group has been formed to offer guidance and advice to Stats NZ on these recommendations. In addition to SSC and Stats NZ, there are representatives from the Office for Disability Issues, the Ministry of Social Development and the Ministry of Health on the Working Group. The Public Sector Workforce Census will collect information on areas that cannot be collected via administrative data.

Presentation 1 also dealt with the Washington Group Enhanced Short Set of questions on disability, which is a proposed solution being discussed by the Disability Advice Working Group.

The following was discussed:

DDEWG members expressed interest in seeing questions in the Public Sector Workforce Census around accessibility, bullying, barriers and opportunities faced by employers and employees, relationships with colleagues, performance and support offered to underperforming staff.

DDEWG comments about the recommended question set included:

* It is important to note the limitations of both the Washington Group Short Set and the Washington Group Enhanced Short Set. Some learning difficulties and autism are not included in the Short Set or Enhanced Short Set.
* Statistics Canada is using a two-part approach to disability which covers activity limitations and is followed by a participation question. The Canadian survey is based on the social model of disability. Questions used in the Canadian survey could be modified to better suit a workplace context or a New Zealand context.
* Self-identification questions were discussed. It was noted that these questions have varying amounts of success which can be related to the context in which they are asked, and whether people feel comfortable disclosing a disability. It was suggested that if the Public Sector Workforce Census is to be run by an independent agency, employees might feel more comfortable disclosing.
* The question or questions used will influence the number of employees identified as disabled. For example, asking whether an employee has an impairment is likely to have a larger number of positive responses than asking if they consider themselves disabled.
* Respondent burden needs to be considered because a question set that is too long will take up too much of the Census.
* The Washington Group Enhanced Short Set has 12 questions (double the length of the Short Set). This might be considered too long for the Public Sector Workforce Census. However, the questions are short and easy to answer for most people. Hence, in terms of respondent burden, the Enhanced Set would not take much time to answer.
* The Washington Group has recommended an introductory sentence to appear before their question sets that have been extensively tested. However, this introductory sentence contains the phrase, “health problem”, which was raised as a concern. *Problem* creates a negative connotation, while *health* suggests a medical model of disability. Given that this introductory statement was used in the 2018 New Zealand Census and other data collections, changing it would mean comparability with existing national and international disability data would be lost.
* Little is known around the context, that is, about other questions in the Census as yet. The DDEWG requested more information on this issue when it is available.

The view of the DDEWG is that the Washington Group Short Set is the minimum requirement for all data collections.

The Washington Group Enhanced Set is more appropriate than the Short Set for the context of a workplace-based collection, largely because it accounts for some mental health conditions. The view of the DDEWG is that the Washington Group Enhanced Short Set is the minimum recommendation for the Public Sector Workforce Census.

A second possible project for SSC was discussed. This project is to recommend an approach to collecting data on disabled people through administrative collection by government agencies. Stats NZ has not confirmed this project with SSC as yet.

1. **Disability data collected via the Washington Group Short Set of Questions in Census 2018**

*Census content development - Overview of the process to include the Short Set in the Census*

Updating of Census content was considered across the board with consideration given to maintaining longitudinal data.

The process to determine the 2018 content was as follows:

* started with 2013 content as a base
* public engagement and consultation
* assessment of formal submissions
* question development and cognitive test (2015-2016)
* continuing question development and public tests (2016-2017)
* Government statistician makes final decision on content.

The Census team received a formal submission suggesting that the Washington Group Short Set of questions would be a feasible way of determining disability status. The Washington Group Short Set went through the consultation and testing process. The testing process involved:

* March 2016 – field test involving 22,000 households (59% response rate, with 64% taking part online).
* July 2016 – two separate samples (8,000 households given paper form, 23,000 people given online form), with 20% response rate.
* April 2017 – 20,000 households in Whanganui with a 36% response rate (with 76% taking part online). The disability rate (as determined by a respondent answering at least one of the Washington Group questions with *A lot of difficulty* or *Cannot do at all*) in this test was 9.2% - similar to the General Social Survey.

The testing was for both content and design.

Final decision was made to present Washington Group questions one after the other (instead of in a matrix format), after confirming space was available in the Census.

*Products and Services Engagement – Census data releases*

Data release was delayed due to lower than expected response rate (although the online response rate met expectations). Stats NZ is considering the best methodological approach to increase the response rate and fill in these gaps. Dates of release yet to be confirmed but data releases will follow this structure:

* First release: Population and occupied dwelling counts.
* Second release: Prioritised topic content & customised data requests.
* Electorates announced.
* Phased release of products.

Disability is likely to be published alongside age, sex, ethnicity, labour force status and income data.

Because disability is a new topic, there is current online and face-to-face engagement to determine information/data needs.

* Suggestion was made to include Disabled People’s Organisations in this discussion.
* The Enduring Questions, previously formulated by the DDEWG, were discussed, and the possibility that Census data might help to answer some of these.

1. **Development of the New Zealand Disability Strategy Outcomes Framework**

Presentation 3 focused on a draft Outcomes Framework for the New Zealand Disability Strategy 2016-2026. The feedback received about the previous Disability Strategy was that although the Strategy was good, there was no accountability. The Outcomes Framework was created in consultation with the New Zealand Disability Strategy Revision Reference Group. The intention is to integrate accountability into the new Disability Strategy that was missing in the previous Strategy.

* Outcomes Framework contains 28 indicators (each with a description of intent) under the eight outcome areas identified in the Disability Strategy 2016-2026.
* Each of the 28 indicators will have at least one measure linked to it. Measures will be used to monitor progress.
* Due to a lack of funding for a Disability Strategy Specific Survey, a lot of the measures will have to come from existing data collections. It was noted that the research community should be included in the discussion of measurements. Disability research should be encouraged and promoted. The Human Rights Commission is undertaking an attitudinal survey which is likely to be relevant to Outcome Six: Attitudes (and its indicators).
* However, funding is needed for longitudinal data collections.
* It was noted that a lot of data is already being collected that relates to the indicators, but it cannot be disaggregated by disability status. The Washington Group Short Set will be in this year’s (and next year’s) New Zealand Health Survey – which should help with Outcome Three: Health and Wellbeing.
* Some constraints were discussed. For example, regarding Outcome Four: Rights Protection and Justice, only a limited number of people interact with the Justice system so quantitative data could be hard to come by. Also noted was the lack of data around disabled children, and that the Washington Group Short Set is designed for adults.

1. **Interagency project on protecting data run by the Social Investment Agency**

Presentation 4, *Your Voice, Your Data*, was given by the Social Investment Agency (SIA). The following are key points from the presentation:

* SIA is currently working on:
  + Data Protection and Use Policy – SIA is developing a policy to guide the social sector on the use of personal data. The policy will cover considerations for collecting, storing, sharing and using personal data.
  + Data exchange – A way of securely and easily sharing data across organisations to improve effectiveness in the social sector.
  + Measurements and Insights – SIA is developing a wellbeing measurement system to support decision makers across the social sector. SIA is also developing population analysis tools.
  + Commissioning and Partnerships – Co-designing services with providers and facilitating partnerships between agencies and providers.
  + Government’s investing for social wellbeing approach – A clear understanding of what *investing for social wellbeing* means is required. SIA is leading a discussion with New Zealanders about this approach, including opportunities to provide feedback and further develop ideas.
* SIA is consulting with service users (including disabled people), government agencies, NGOs/service providers and Disabled People’s Organisations.

1. **Next steps**

* Before the next DDEWG meeting, the previous government stocktake is to be checked to ensure it is still relevant.
* Gap analysis work will be discussed at the next meeting.