Disability Data and Evidence Working Group

Date: 10 March 2023

Time: 9.00am-12.00pm

Venue: Online via Teams

Attendees

Government agencies:

- Office for Disability Issues: Brian Coffey (Co-Chair), Michelle Gezentsvey, Sarah Fuhrer
- Stats NZ: Robbie Blakelock (Co-Chair), Katy Auberson
- ACC: Ben Lucas
- Cancer Control Agency: Giselle Bareta, Michelle Liu
- Health Quality and Safety Commission: Inga O'Brien, Jonathan Tautari
- Ministry of Education: Annie Chenery
- Ministry of Health: David Barnes, Fred Acheampong, Shari Mason
- Ministry of Justice: Kimberly Turrell, Tadhg Daly
- Ministry of Social Development: Sonja Eriksen
- NZ Police: Christine Aitchison
- NZ Transport Agency: Samantha Eastman
- Oranga Tamariki: Ann Walker, Elodie Green, Dr James McIlraith, Sally Tallentire-Jones
- Waka Kotahi: Samantha Eastman
- Whaikaha: Dr Adam Dalgleish, Alex Dixon

Independent agencies:

- Human Rights Commission: Frances Anderson, Kerri Kruse
- NZDSN: Peter Reynolds
- Office of the Ombudsman: Andrew McCaw

Disabled People's Organisations Coalition:

- Jonathan Godfrey

Apologies:

- Andrew Webber, Social Wellbeing Agency
- Bridget Murphy, Ministry of Health
- Brigit Mirfin-Veitch, Donald Beasley Institute
- Catherine Brennan, Office for Disability Issues
- Craig Wright, Social Wellbeing Agency
- Daniel McAuliffe, Ministry of Health
- David Jagger, Ministry of Education
- Juvena Jalal, Education Review Office
- Kelly Palmer, Ministry of Health
- Laura Cleary, Te Whatu Ora
- Olivia Kitson, Ministry of Transport
- Olivia Soesbergen, Office of the Ombudsman
- Richard Hamblin, Health Quality and Safety Commission
- Tina Cronshaw, ACC
- Tristram Ingham, DPO Coalition
- Wesley Pigg, Waitemata DHB

1. Administration

- Minutes from previous meeting (December 8, 2022) approved by group for online publication.

2. Update on the 'Disability and Cancer' research project – Michelle Liu and Giselle Bareta (Te Aho o te Kahu/the Cancer Control Agency)

An update on the Cancer Control Agency's (CCA) research project. This project was introduced to the group at the last DDEWG meeting.

- CCA are aware there is very limited research available on cancer and cancer outcomes for disabled patients. The Disability and Cancer project will provide insight into disabled people's cancer outcomes as compared to non-disabled people and will include specific interest on disabled Māori and Pasifika.
- CCA considered three possible ways of identifying disabled people in admin data for this project:
  1. Using data on accessing support services (interRAI)
  2. Using the 2013 Disability Survey
  3. Using the indicator developed by the Social Wellbeing Agency ([Te Atatū: Developing an indicator of disability](#)).
- CCA have chosen the third approach, the SWA's disability indicator, because it matches better with cancer data and has better age coverage.
  - The group raised two additional benefits of using the SWA indicator – the SWA indicator (and CCA's research) can be updated when 2023 Census data is made available and the SWA indicator picks up a greater number of disabled people increasing the potential for CCA to investigate intersectionality.
- CCA want to further subset the disabled group (identified using the SWA indicator) by age, sex, ethnicity, deprivation index, urban/rural, health district, income, and education level (noting that income and education subsets are subject to data availability and IDI confidentiality rules).
  - Group suggested this research could also investigate differences among disabled people receiving services (interRAI) vs. not, and
  - that the research should subset by impairment type. A particular interest in mental health impairments was discussed. However, using the SWA indicator, the project can only subset by the 6

impairment types included in the Washington Group Short Set, and mental health is not one.

- Having defined the population of interest for this project, CCA's next steps include:
  - Recruiting two advisors with lived experience of disability and cancer. These advisor roles are open to disabled people who had (or have) cancer themselves and disabled people who haven't had cancer but have relevant knowledge or shared experience of cancer and the health system.
  - A literature review is expected to be completed by the end of April.
- CCA is seeking feedback on the project's draft plan's research questions and methodology, and specifically on the project's proposed health outcomes measures:
  - Cancer incidence (both overall and by specific types of cancers)
  - Cancer mortality rates
  - Late-stage presentation
  - PHO enrolment (primary health organisation)
  - 1-year and 2-year survivorship rates.
- Group members suggested including the following measures:
  - Something to represent self-agency and control (referral pathway/self-referrals was suggested).
  - A measure of 'quality of life'. However, it was noted this would likely be impossible to include in this particular project and would be better suited to qualitative research. CCA previously considered a patient experience measure, but this has the same problem as a 'quality of life' measure – patient experience data is limited and is better suited to qualitative research.
  - Health literacy and availability of accessible information. This wouldn't necessarily be an outcomes measure, but it could be analysed alongside outcome measures (correlational variable).

3. Content of the 2023 Household Disability Survey – Katy Auberson (Stats NZ)

- Notes for this section are limited.
- Stats NZ has deliberately excluded highly sensitive questions from the Disability Survey (e.g., experience of abuse, sexual violence), because those selected for the sample are legally required to answer the survey. Therefore, the questions should not be too intrusive or potentially re-traumatising for those who are being made to complete the survey.
- Most participants will provide responses via a telephone interview. Alternatively there is an option to do the survey in-person if it suits the respondent better (or if Stats NZ cannot reach them via the phone).
- Some wellbeing measures included in the Disability Survey are also used in the General Social Survey. They were selected to be in the Disability Survey because they are well-tested.

4. Feedback on the disability outputs from the 2023 Census – Michelle Gezentsvey (ODI)

Stats NZ approached ODI for feedback on two potential approaches for disseminating results from the 2023 Census; specifically, how to report findings from the Washington Group Short Set questions (WGSS).

- Stats are planning to publish results for each of the 6 individual WGSS. Stats NZ want feedback on whether these results should be published using 4 or 2 categories:
  - Four categories: no difficulty, some difficulty, a lot of difficulty, cannot do at all.
  - Two categories: 'disabled' or 'not disabled'.
- DDEWG did not give a clear opinion on which option they would prefer.

Stats NZ also gave ODI a list of potential disability data tables (60+) that could be published following the 2023 Census and asked ODI/DDEWG to identify the 15 tables which were of the greatest importance.

- DDEWG members agreed that all 60+ tables should be published, and that the group should not be asked to pick only a subset of tables deemed as most important.
  - It was noted that selecting the 15 'most important' data tables is highly subjective. Data users will have different and conflicting

priorities and data needs depending on their organisation's interests.

- o Additionally, by only publishing a subset of disability tables – and 'hiding' the equity gaps that would've been presented in the non-published tables – it creates the impression that the gaps present in the other tables are not of concern.
- If capacity is an issue for Stats, DDEWG can provide feedback on which 15 tables should be published first, with the expectation that all remaining tables will be published when capacity allows.
- Census 2023 should extensively publish disability data especially given how scarce this data is and given that Census is the principal data source from which disability data can be disaggregated (to analyse intersectionality).
- Census 2018 was discussed as an example of how scarce disability data is, and that organisations (including Stats NZ) have a history of underreporting data for disabled people.
- No disability tables were published from Census 2018. DDEWG would also like to see 2018 Census data published.

Action: DDEWG to respond to Stats NZ stating that all tables (60+) should be published, but if capacity an issue for Stats NZ, DDEWG can identify which 15 tables are needed most urgently with the expectation that the remainder be published later.

5. Update on the new mixed methods disability victimisation research project – Tadgh Daly and Kimberly Turrell (MOJ)

- MOJ's [NZ Crime and Victims Survey](#) (NZCVS) confirms disabled people are more likely to be victims of crime than non-disabled people.
- MOJ are planning a mixed-modes (quantitative & qualitative) research piece to investigate the question, 'Who is experiencing crime?'
- The research will also look at:
    - o Life experiences prior to, and after being a victim of crime.
    - o Experiences when reporting crime and interactions with the justice system.
- The research will involve follow-up interviews with respondents from the NZCVS (only respondents who gave permission to be recontacted will be selected). The research will also involve the IDI.

- MOJ have a draft proposal paper for this research and are seeking feedback from DDEWG members. Members who are interested in giving feedback were invited to contact MOJ.

6. Update on DDEWG Terms of Reference – Robbie Blakelock (Stats NZ) and Brian Coffey (ODI)

DDEWG co-chairs ODI (Whaikaha) and Stats NZ are updating the group's Terms of Reference (TOR).

- While the group's core purpose will remain the same, the co-chairs are updating the TOR to strengthen the language and emphasise that the group is focused on implementing change (rather than just informing others).
- Updated TOR expected sometime after Easter.
- The group discussed that DDEWG was previously about developing disability data practices, which was a key reason for the group originally being established.
- It is thought that DDEWG should now/also be about creating a community of practice and influencing the public service and others to collect disability data; while DDEWG can't compel other agencies, it could be more directive.
  - It was discussed that perhaps the group *should* have the ability to compel organisations to collect disability data both in terms of a) whether it is collected at all, and b) how it is collected/what questions to be used.
- It was noted that the group's membership is now broader than when the TOR were first written [2015].
- Also noted that DDEWG should endeavour to hold more of a leadership role when it comes to disability data and practices.

7. Potential 'community of practice' – Michelle Gezentsvey (ODI)

Discussion with DDEWG members on potentially establishing a community of practice (COP) and what might be involved in that.

- The idea of a COP came about because DDEWG membership excludes some agencies (for example, TPK, Ministry for Pacific Peoples, Ministry for Ethnic Communities, IHC) but to include everyone into DDEWG would make the group unmanageable.
- It was anticipated that one of the first things the COP might be asked to comment on is a "standard" for disability data.

- Stats NZ had previously attempted a disability standard, but the work was stopped because it was too difficult to create due to the lack of consensus on how disability should be defined including the competing conceptual understandings (social model, human rights model, bio-psychosocial model, Te Ao Māori view, etc).
- There is also a consequence that if a standard/definition is created, other agencies are then expected to adhere to that standard (and it might not suit the different purposes and objectives held by various agencies).

Action: a plan for this community of practice will be put together and presented to DDEWG before proceeding further.

8. Update on the UNCRPD recommended Disability Framework – Robbie Blakelock (Stats NZ)

Last year, the UNCRPD committee recommended that "the State party, in conjunction with Statistics New Zealand, develop a national disability data framework to ensure appropriate, nationally consistent measures for the collection and public reporting of disaggregated data on the full range of obligations contained in the Convention, especially with regard to whaikaha Māori; Pasifika persons with disabilities; LGBTI+ persons with disabilities; children with disabilities; and women and girls with disabilities."

- Stats NZ's response was to agree that there should be a disability data framework and is investigating this internally with the Government Statistician and Data Steward.
- Stats NZ noted that it will not be able to create and implement a framework independent of input from other agencies.