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Minutes - Disability Data and Evidence Advisory Group

Date: 29 July 2024

Time: 10.00-12.00pm

Venue: Teams

Invited members – Attended in bold

Whaikaha	Claire Bretherton & Ronelle Baker
Stats	Chris Pooch & Simon Brown
SWA	Andrew Webber
MSD	Sonja Eriksen
Health	Shari Mason
Manatu Hauora	Laura Cleary
Justice	Sara Bishop
Oranga Tamariki	Roy de Groot
Education	Katrina Young
ACC	Ben Lucas
Human Rights Commission	Frances Anderson
Te Ao Marama	Tristram Ingham
DPO Coalition	Jonathan Godfrey
Donald Beasley Institute	Brigit Mirfin-Veitch
NZ Disability Support Network	Peter Reynolds

Welcome and approve previous minutes

Minutes approved from 29 April and 6 June 2024.

Confirm additional Stats NZ member – Simon Brown, Principal Statistician

Update on Wai 2575

Whaikaha Policy, Strategy and Partnership DCE Ben O'Meara is the Crown witness speaking to the Data Brief of Evidence at the Waitangi Tribunal Inquiry on Monday 5 August.

The Brief of Evidence has been shared with DDEAG. Whaikaha colleagues are busy providing support.

Acknowledge a member of DDEAG is also a claimant in the Inquiry.

Update on PPNHI

DDEAG members who attended recent workshops run by Te Whatu Ora on PPNHI noted that the current direction focuses more on accommodations for accessing health services rather than disability measurement, which limits its potential as a cross-agency disability indicator.

Tristram noted he was involved previously and was surprised he was not included. Although the project team includes a tāngata whaikaha Māori representative, it was noted that Crown officials do not adequately represent the wider community. Whaikaha to follow up on membership of the governance group.

Disabled People's Organisation (DPO) Coalition monitoring procurement process

Expressions of interest were sought through an RFP process.

Applications have been received and will be reviewed by Whaikaha with DPO representatives.

Context for today's discussion on the need to develop administrative measure(s) of disability

There are known challenges with collecting disability data, with systemic issues because of data gaps. Data is needed at the person-level and at the system-level, collected in a way that upholds the mana of disabled people.

DDEWG played a key role in the introduction of the Washington Group Short Set (WGSS) of questions into a wide range of surveys across NZ. DDEAG has a strong voice in administrative data also, it is not just a Stats NZ responsibility (context of Future Census submissions and the role of administrative data from both DDEAG and Whaikaha).

Current chairs of DDEAG consider that current advice on the ODI website on administrative measures of disability is not adequate to meet current and emerging data needs. It only has two points – one to determine if the individual identifies as disabled and the other to ask what support they need to access services.

[Note: previous DDEWG decisions/guidance on agencies using an administrative measure was discussed in the DDEWG March 2021 meeting: www.odj.govt.nz/guidance-and-resources/improving-information-about-disabled-people/disability-data-and-evidence-working-group-meeting-march-2021/. Also see DDEWG March 2022 paper on Administrative data report back].

Prior to the current meeting, a short Rationale document (2 pages) was sent out with excerpts from Haumaru Covid-19 Priority Report (2021) and the Wai 2575 Data Brief of Evidence (2023). These note **the importance of government agencies growing administrative data on disability.**

Note that an administrative data measure(s) may or may not result in a data standard.

Discussion on the needs, concepts, and complexity of administrative data

There was discussion on how to progress development of administrative data. Key points from this discussion included:

- Disability data in the Census is used as a sampling frame for the Disability Survey. **Reassurance was given by Stats NZ that administrative data is not intended to replace a specialised disability survey.** Administrative data is not meant to meet all data needs. For all its limitations, the inclusion of the WGSS in the Census has been critical in obtaining intersectional data and enabling comparisons in the IDI.
- A polished method to identify the disabled population is not sought. What are the features of the system that make it more likely to work for some vs others (who have impairments)? WG questions are agnostic in terms of identity.
- The goal of administrative measures(s) could be for **agencies to understand who they are serving, what their needs are and what are their outcomes.**
- Disability is context dependent and is not carried with an individual like gender – so it cannot be a standard demographic variable. It is a paradigm flip.
- Both paradigms are valid – **there is currently a desire to identify disability like a demographic variable vs temporal nature of disability & context-dependency.**
- **It was suggested that impairment can be viewed as the denominator like ethnicity while Disability is the equivalent of Racism.**
- Are we interested in a population measure (which is useful for informing levels of funding) and/or in capturing the process of disablement where people with impairments/disabled people are measured as a comparator?
- Inequity is measured through the WGSS but it is a narrow set of questions and has a high cut-off point. WHODAS questions have a **broader scope of functional limitations.**

- Note the importance of capturing origin of disability as that is related to support received and outcomes e.g., birth, accident, health condition, ageing. Also nuance based on individual impairment.
- Identity questions could potentially be presented with the UNCRPD definition of disability as preamble? Other questions relating to how often they experience impairment etc. Note that participants may not read that level of information.
- This conversation is highlighting various data needs to meet and a number of uses of disability administrative data. How do we measure disability above and beyond impairment?
- Even if all conditions were listed, what would the response convey?
- **Māori tend not to identify as disabled; they identify as Māori and they perceive the system which is non-accommodating as a manifestation of racism.**
- What are we measuring? System responsiveness (equity and service provision) vs living an ordinary life e.g., impact of breathlessness.
- What is the responsibility of DDEAG as government-centred and service providers aiming to achieve equitable outcomes vs academic study of disability as a process?
- **Agree for DDEAG to establish a shared position first before coordinating wider hui.** Go back to the 5 whys – what is the purpose we want to achieve? Is it to make disabled people visible in administrative data (to identify victims of a system that is unaccommodating) and reduce the impact of prejudice/disablement? To identify policy-amenable changes to make the system more responsive.
- Root cause analysis. Each system has its own mechanisms that generate inequity. Would it be possible to have a question set that captures all of this? Also quality of service received can be very subjective. Would it be possible to develop a suite of options with an interoperable set of questions? Risk of building a house of cards.
- If measuring inequity is the aim (comparisons are an important part of the social model), work back to the WG questions and intersection with different population groups.
- Importance of touchpoints/funnel spaces that can lead to inequity e.g., school.
- Possible commissioning approach with content experts e.g. current TAMA research of Te Ao Māori view of disability, sociocultural needs?
- Could be looking at WG questions + other questions to meet individual accommodation needs, understand social support, intersectionality, context.
- Note that measures have been acknowledged as important before systems were put in place for measurement e.g. for smoking cessation.

Actions

- **to prepare a piece of analytical work/data needs statement** on what is missing in current measurement guidance and measurement goals/needs of government vs disability community, risks entailed in using a bigger set of questions, and whether administrative measures would provide a solution. Examples include need to track progress for Child Youth Wellbeing Strategy and Te Aorerekura FVSV, so measuring in order to compare outcomes with non-disabled people is not sufficient.
- **Actions for DDEAG members – to go back to their own agency and see how/whether effectiveness is measured?** Note PSC and Office of Auditor General measure agency effectiveness.
- Question on feedback from Stats NZ on Future Census submissions? **Action for Stats NZ to come back with information.**

Closing