



Scan for
NZSL name



Disability Data and Evidence Advisory Group

Date: 29 April 2024

Time: 10.00am-12.00pm

Venue: Online via Zoom

Invited members

Whaikaha	Claire Bretherton Ronelle Baker Michelle Gezentsvey
Stats	Chris Pooch Sean Broughton Rachael Milicich Meg Jackson
SWA	Andrew Webber
MSD	Sonja Eriksen
Health	Shari Mason
Manatu Hauora	Laura Cleary
Justice	Michael Slyuzberg
Oranga Tamariki	Roy de Groot
Education	Katrina Young
ACC	Ben Lucas
Human Rights Commission	Kerri Kruse
Te Ao Marama	Tristram Ingham
DPO Coalition	Jonathan Godfrey
Donald Beasley Institute	Brigit Mirfin-Veitch
NZ Disability Support Network	Peter Reynolds

Apologies

- Roy de Groot
- Peter Reynolds
- Sonja Eriksen
- Brigit Mirfin-Veitch

Absent

- Kerri Kruse
- Michael Slyuzberg
- Laura Cleary

Meeting opened with karakia at 10:05am.

1. Welcome and DDEAG admin

- Approved minutes from March 2024.

2. Discussion on membership of DDEAG

- Expertise as a criteria
- Membership must be related to the direct purpose of the DDEAG, so more appropriate to consider ToR first.
- Figure NZ (Anton Sammons, with technical and lived experience) have expressed an interest in participating
- Insights Alliance may also be appropriate?

3. Confirming Terms of Reference

- Terms of reference in the current state are broad by design.
- Discussion on the value on the breadth, the value of working on data capability and maturity cross agencies and cross government.
- Risk that the scope is too far narrowed and therefore the group's value is limited.

- Terms of reference were approved with the inclusion of the following statement:

The advisory group is not a substitute for representation of lived experience when considering insights and data.

4. Updates from Stats NZ and Whaikaha

Stats NZ update on three pieces of work highly relevant to the disability data space in 2024:

- Household Disability Survey is on track, with a tentative release date of late November. Intention is to have the IDI data available at the same time, using an ad hoc link to the IDI, instead of going through the refresh process.
- Census 2023 is on track for the published deliverable dates.
- Future Census work, along with work on the Disability Data Framework will be the topics of further discussions with DDEAG
- Comment on intersectionality and the importance of ensuring data will meet the needs of different population groups, particularly Māori.

Whaikaha is currently working on the following areas:

- Data & Insights workplan
- Updating NZDS Outcome Area dashboards
- Measureable outcomes for Whaikaha Strategic Intent
- Relevant analysis possible in IDI

5. Discussion on future workplan for DDEAG, including date and topic for discussion in May

- Suggested focus on developing capability and working across the disability landscape rather than in a 1-1 relationship with agencies.
- Administrative data should be the focus, with a view to develop consistency.
- Standardisation about how data is collected and then used c.f. IDI code modules.
- Broader thought leadership about the evidence ecosystem and how does that fit in with other data, researchers, etc. (c.f. how does PPNHI link in with everything that already exists, so we can answer the most important/most enduring questions)
- While we ascribe to the social model, we are focused on identifying those “at risk of unaccommodating environments”.
- We have accepted the limitations of WGSS, and by continuing its use as is, means that we are risking skew towards a particular ‘definition’ of disability, such as an ageing population with mobility impairments. This group should then be focused on how we do not perpetuate inequities, for instance, by using fit for purpose measures in the Aotearoa New Zealand context.

6. Te Whatu Ora PPNHI project progress

Guest speakers Rachel Noble, General Manager Disability Strategy, Planning and Performance, and Leo Goldie-Andersen, Chief Advisor, Digital & Data.

- Te Whatu Ora has been through big changes. Progress on this mahi has been slow with a focus on bringing people up to speed, no changes to the plan as it was 18 months ago.
- Purpose of PPNHI is to enable good health outcomes through equitable access to services, by identifying disabled people within the health system and recording their access needs.
- Focus on being useful for disabled people and providers.
- Delivering a 'proof of concept' first.
 - What do we need to ask?
 - How do we need to ask it?
 - How do we support people to answer?
 - How does it get to Health?
 - How does it get used?
- Intopia- doing cognitive testing look at the question set.
- Working at the Porirua Health Hub, with focus groups, individuals, or broad surveys.
- Intention for 30 June 2024 for the first two bullet points to be provided.

Questions

- Tangata whaikaha Māori- engagement within Porirua is good, with specific and relevant capability being embedded in the project.
- Highlighted that the socio-cultural context questions has not been developed. Is there a plan in place to develop these at a national level? Application beyond health?

- What are the governance arrangements for the projects?
New structure to come into place, the current work plan was signed off by the previous group. Project lead is Nicola Bird.
- What would you like from this group to help with this work? Interested to hear the conversations earlier in the discussion- needing to get fully back up to speed on the broader contextual work.

Actions:

- Whaikaha to share a working document with DDEAG members on previous DDEWG decisions.
- Share location of work from Synergia commissioned before Whaikaha was established.
- Updating online presence of DDEAG
- Previous workstreams.
- Next meeting: consider how DDEAG will provide feedback on Future Census and 2024 work plan

6. Close

Meeting closed with karakia at 12pm.