

Meeting Minutes

Disability Data and Evidence Working Group

Meeting number two of four for the 2022 year

Date: 27 June 2022

Time: 10am-1pm

Venue: Online via Teams

Attendees

Brian Coffey (meeting co -chair), Office for Disability Issues
Michelle Gezentsvey, Office for Disability Issues
Sarah Fuhrer, Office for Disability Issues
Catherine Brennan, Office for Disability Issues

Dr Claire Bretherton, Stats NZ
Robbie Blakelock (co-chair), Stats NZ
Katy Auberson, Stats NZ
Laura Jacks, Stats NZ

Anne Hawker, Ministry of Social Development

Andrew Webber, Social Wellbeing Agency

Wesley Pigg, Waitemata DHB

Samantha Eastman, New Zealand Transport Agency

Elodie Green, Oranga Tamariki
Dr James McIlraith, Oranga Tamariki

Tadhg Daly, Ministry of Justice

Dr Adam Dalglish, Ministry of Health

Frances Anderson, Human Rights Commission

Kerri Kruse, Human Rights Commission

Ben Lucas, ACC

Tina Cronshaw, ACC

Christine Aitchison, NZ Police

Tristram Ingham, DPO Coalition

Jonathan Godfrey, DPO Coalition

Monica Munro, New Zealand Disability Support Network

Brigit Mirfin-Veitch, Donald Beasley Institute

Olivia Soesbergen, Ombudsman

Juvena Jalal, Education Review Office

Karen Schwoerer, Health, Quality and Safety Commission

Apologies:

Shari Mason, Ministry of Health

Bridget Murphy, Ministry of Health

Craig Wright, Social Wellbeing Agency

Mei Ling, Education Review Office

1. Welcome, introducing new members and approve March meeting summary & papers for uploading to Office for Disability Issues website

- Opening karakia
- New members introduced
- **Meeting minutes from the meeting held on 21 March were approved for publication by group.**

Actions:

1. Meeting minutes from the 21 March 2022 meeting to be uploaded onto the Office for Disability Issues website.

2. Update on the new Ministry of Disabled People

Oral item

- Health reforms were an opportunity to also reform the disability aspects – this is a recognition of a long-term concern about the medicalised approach to disability rather than approaching disability as a specific population group. Alongside this was the development of Enabling Good Lives approach pilots. There has been a government commitment to take this work to scale nationally, as well as a change in Accessibility legislation.
- DDEWG will continue under the new Ministry which will start on 1 July 2022. The new Ministry will be similar to other population ministry's but also has a large service delivery component. There is also a new Minister (Minister Williams) for the Disability Issues portfolios.
- The difference in the new Ministry is the commitment to service design and system transformation, designed with the voice of disabled people as partners in everything that they do. The challenge is to ensure service delivery is smooth in the transition from MoH's Disability Directorate.
- Another challenge is to give recognition of cross-government agency work in the disability space and for this to continue. Note the Disability Action Plan's actions and activities will still be managed by those lead agencies.

3. Update on the revision of workstreams

Paper 1 – DDEWG workstreams draft outline

- In the review we took on board feedback from this group about acknowledging our obligations in Te Tiriti upfront. This has been updated in the revised version.

- While there is no separate workstream for Māori – we have acknowledged this and have instead ensured data collection is embedded throughout the workstreams for Māori.
- We have streamlined the workstreams and are looking at four areas instead of the original six workstreams.
- There will be an annual review of the workstreams going forward.
- We would like to get endorsement for this to help identify who has responsibility for what going forward.
- Questions and comments:
 - With the new Ministry kicking off, could DDEWG receive some additional resource for this?
 - This has not been explored at this stage.
 - Disability Data Training Project is significant – will need someone to lead this going forward?
 - This is likely to be led from within the specific workstream.
 - Will the Terms of Reference be updated alongside this?
 - Yes.
 - Can this document be updated to add HQSC into the list of agencies?
 - Yes
- **Majority agreement from the group in support of this document and the re-arrangement of the workstreams.**

Actions:

2. ODI to re-look at the Terms of Reference for the group
3. ODI to update the document to include HQSC as a listed agency.

4. Update on engagement and capability building workstream

Oral Item

- Key government agencies have signed the Accessibility Charter and made a commitment to change over time.
- We have developed a training course on the Accessibility Charter that is administered by Ministry of Social Development, that is delivered on a monthly basis by a joint group including DPO representation.
- It is really important for key people to develop the content for the training course on data. Delivery must be in accessible formats.
- It is important that we have made a commitment to the collection of data.
- Ministry of Health may have some earlier work around why disability

- **There was majority agreement from the group endorsing the development of a training programme on data.**

5. Update on access to government data and IDI workstream

Oral Item – Social Wellbeing Agency’s development of the disability indicator. Additional reading (Te Atatu– note, an old version was circulated for this meeting by mistake)

- When people undertake statistical recording or research, particularly in the IDI, it is routine to report outcomes based on certain population groups ie gender, region etc. However, most government agencies don’t tend to collect administrative data on disability.
- Working with experts on disability data and disabled people to come up with a baseline disability indicator so that researchers are able to cut by disability.
- The indicator is based on the Washington Group Short Set (WGSS) from the census and functional assessments collected by Ministry of Health.
- The indicator classifies people into three categories: high, moderate, or no functional limitation, across six functional areas.
- Rates of functional limitation greatly differ by age, so breakdowns of outcomes by disability should adjust for age to provide the most meaningful comparison. Have developed some handbooks around this and how to use this disability indicator.
- It has some limitations to it, and will continue to evolve.
- It is hoped this indicator will help to increase in the amount of research done in the IDI that contains with a focus on the disability community. Have circulated the Te Atatu draft paper that references this work.
- Questions and Comments:
 - The Ministry of Health is in the midst of a data collection programme using the NHI, this has been ongoing and there is the potential for this work to align.
 - DPO representatives held reservations that the Te Atatu paper is not fit for public dissemination as it currently stands. Need to reconsider language used regarding disability particularly relating to ‘functionality.’ This language used is driven by the medical model of disability. ‘Moderate difficulty’ and ‘moderate disability’ are two different things. The existence of a social model of disability is not seen in this paper. [Note, an updated version of the paper had already addressed many of these issues and was sent to DDEWG afterwards].
 - There is a tendency to get stuck in the debate/risk of not capturing people accurately without using a functional basis (WGSS)

questions), but we are currently not in a position to have a better alternative to this. Disability is either an identity or an inequity resulting from the impairment. There is a really poor correlation between impairment and disability identity.

- It could be useful to signal a graded aspect of impairment so as to explore where 'disablement' occurs.
- May be useful to identify what is the purpose of this indicator. There is no perfect measure as the concept of disability is continuously evolving. To look for the best we can do today is perfectly acceptable. But this needs to be acknowledged that this is the state that we are in.
- Overall, this indicator is a mechanism to analyse at a population level outcomes by disability status. It is a statistician's approach and is not intended to take away from a disabled person's self-identification.

Actions:

4. SWA to circulate the latest version of the Te Atatu paper. SWA and Health colleagues get together to discuss the reporting of the measure and re-engage with the disability sector before publication. SWA to work on accessible formats for publication.

6. Break

7. Update on resources workstream

Paper 2 – Disability Data and Evidence Website Framework and Resources List

- What we would like to do today is to get an agreement from the group regarding the outline and direction we have included in Paper 2.
- By way of background, this project started out as key documents for data and evidence but now have more resource to expand on this.
- We have seen significant growth in the amount of disability data that is available.
- It's a really good place in terms of a starting point and can update it as needed. It will be an evolving website that is reviewed regularly.
- Once this information is up on the website we need to look at how we can get this out to the community as a place for people to go.
- Majority agreement from the group endorsing this work to progress.

Actions:

5. ODI and MSD to continue leading the website framework and resources list and make the framework available online

8. Update on reporting workstream

Paper: Progress update on the Lead Toolkit Accessibility Charter and Disability Data work programme.

- Reports to the Minister on the Disability Toolkit and the Accessibility Charter.
- One of the themes coming through is that people are coming forward saying they want to do more but don't know how.
- The reporting template has been sent to agencies and agency feedback is expected on this soon.

9. Additional member updates

- DPO Coalition member: an assessment of data and evidence going to the UN Committee through the IMM determined that a lot of data that already exists is not being fully utilised by agencies. We have plenty of data and it is not being used to its full advantage, this is a massive difference compared to two years ago. Often in the IMM forum attention was drawn that agencies didn't know of data available from their own sources.
- Ministry of Health: As of 1 July the Disability Directorate is no longer in Ministry of Health – so there is an interim agreement that Health NZ will hold this disability data kaupapa. It is still unclear who within MoH or Health NZ that will lead this future work.
- Stats NZ: The 2021 General Social Survey will be released soon This includes the enhanced Washington Group questions. The Household Survey will also be released in August this year for the June 2022 quarter.
- Oranga Tamariki and Donald Beasley Institute: They have just released a good practice report of the review of models of care with disabled children and rangatahi in care. Feedback is welcome.

Actions:

6. ODI will share the report on rangitahi in care with the wider group.

10. Close of meeting

- Closing karakia