

SUMMARY

Disability Data and Evidence Working Group

Date: 13 December 2021

Time: 9.30am-12.30pm

Venue: Teams

Attendees

Government agencies

- Office for Disability Issues: Brian Coffey, Shama Kukkady and Sarah Fuhrer
- Stats NZ: Dr Claire Bretherton (Chair) and Katy Auberson
- Ministry of Social Development: Anne Hawker
- Ministry of Health: Bridget Murphy and Dr Adam Dalgleish
- Ministry of Transport: Olivia Kitson
- Ministry of Social Development: Anne Hawker
- New Zealand Transport Agency: Samantha Eastman
- Health Quality and Safety Commission: Richard Hamblin
- Education Review Office: Mei Lin Harley and Juvena Jalal

Independent agencies

- Human Rights Commission: Frances Anderson
- Office of the Ombudsman: Andrew McCaw

Disabled People's Organisations Coalition

- Jonathan Godfrey

New Zealand Disability Support Network

- Monica Munro

Universities

- Associate Professor Brigit Mirfin-Veitch

Apologies

- ACC: Tina Cronshaw
- DPO Coalition: Tristram Ingham

1. Welcome, introducing new members and approve September 2021 meeting summary & papers for uploading to Office for Disability Issues website

2. Chair vacancies on workstreams

- Resources workstream was led previously by Sam Murray who has now left so there is a need for a new person to facilitate this piece of work. In particular ongoing work with the contractor.
- The research workstream was led previously by Catherine Brennan who is currently on secondment and so this needs a replacement as well.
- The Access to government and IDI workstream needs more people in this group.

Action points:

- Anne Hawker to circulate the workstream descriptions.
- Ring or Email Anne Hawker for more information about these positions.
- Email Sarah Fuhrer if you are interested in being involved in any group.
- Draw up a formal request for the Social Wellbeing Agency to be involved in the wider group

3. Update on engagement and capability building workstream

Paper 1 Report back from Access to Government/IDI Workstream and Engagement and Communications on the Administrative Data

- This work is broader than just the engagement and capability workstream it is also the access to government and IDI.
- Discussion around the questions proposed. These are just the start; the questions can be expanded on and there will be drop down options for these.
- Further testing will occur to make sure they resonate with people before final sign off from the DPO Coalition.

- Questions and comments around being able to use these in other areas and not to restrict them to just the public services.
- It was noted that it is important that the questions are asked in the current order to capture correct info.
- Concern raised regarding the 'implied promise' wording in the reasonable accommodation questions. Needs to have a clear descriptor about what will happen and a need to manage people's expectations.

4. Te Rito Project (MoE)

Paper 2 – Introducing Te Rito

- System works to connect to school to sync specific data (learning information/support needs) about individual students as they transition between schools.
- Currently a lot of information is missed as students shift between schools.
- Design is still in pilot stage so haven't looked at an accessible design yet.
- Overall positive comments. Questions regarding engagement with disabled people, evaluation of the pilot and if there is an opportunity to monitor and use disaggregated data on a systems level.
- No engagement has been planned at this stage but in consultation with DPO Coalition and wants to engage more broadly and as they evaluate the pilot. Wants to engage with DDEWG going forward as well.
- Broad acceptance that opportunities exist, but significant determination that info doesn't belong to Ministry/schools but to students and whānau, needs to be fully supported by governance mechanism-how used, what obligations of inclusions used.
- Note the importance of involving the special(ist) schools and resource teachers who work across a number of schools.

Action points:

- Te Rito Project to connect with Health offline regarding identifying disabled children.
- The DPUP letter to be shared with the group

- A formal letter for other agencies to point to about this (so this project becomes a blueprint for future agencies work).
- For Te Rito to follow up with DDEWG via email about next steps and how DDEWG can be involved going forward.

5. Update on access to government data and data and IDI workstream

- Have been working with engagement workstream on the admin questions with specific topics on children, neurodiverse and older people.
- Outcome's framework data was published for the first time on all 8 outcome areas in annual report
- Need to reconsider the workstreams and purpose of these.

Action points:

- Wider group to send through ideas on potential workstream topics (large-scale projects like NHI work or COVID-19 work) to Shama
- Working group co-leads to meet and discuss approaches, and bring this back to wider group
- ODI to share annual report to wider group once available

6. Update on the Disability Survey consultation and a summary of the annual Washington Group meeting

- Consultation period for disability survey ended end of Oct. Had 200+ submissions from local councils, DHBs, disabled people and their whaanau/family, DPOs, NGO's.
- Stats NZ is currently reviewing the submissions, while keeping in mind the constraints of a sample survey & respondent burden in terms of not making the survey unreasonably long.
- Washington Group (WG) annual meeting attended by Claire. Info that WG is being used in administrative programmes (in particular South Africa, Costa Rica, Rwanda). Specifically Rwanda is using WG + other questions to be implemented nationally.

Action points:

- Once Stats NZ has identified what can feasibly be collected given the sample size and has done some early prioritisation based on the Disability Survey's objectives, a smaller group of DDEWG members will meet in 2022 to give Stats NZ advice on what should be included in the survey.

7. Break**8. Update on reporting workstream**

Paper 3 - Progress update on the Lead Toolkit, Accessibility Charter and Disability Data work programmes

- Gives an outline of where things are at.
- Wanting to know how we consistently record data seems to be the most common question.
- We report every 6 months, first report done, process of gathering responses from second report.

9. Update on resources workstream

Paper 4- Disability Resources Schema Description

- Project about collating resources around data/evidence regarding disability. These will be published on ODI's website. It will depend on where ODI ends up as to who becomes responsible for ongoing maintenance of this.
- Currently grouped into 3 categories (with tags along the way) with examples/guidance and referrals to other groups. May include international examples as well.
- End product is to be used predominately by government agencies, public service, NGOs and individuals.
- It is not an exhaustive repository but just about setting people on a path.
- Timeline is October – March for completion.

- Wider conversations include a: Need for consensus on weighting on validity/reliability of resources; Need more intersectionality and tāngata whaikaha data; Potentially need to consider which documents/guidelines are approved and have a working group for this.
- Questions around a need to consider level of user knowledge needed to navigate this (at the moment medium level of knowledge on disability), Admin data -differentiate between reasonable accommodations and identity?

Action points:

- The workstream group to consider the approval process for documents/guidelines included in this.

10. COVID-19 vaccination data analysis – disability and ethnicity

Paper 5a - Vaccination data analysis – disability and ethnicity

Paper 5b - Disability additional analysis

- Undertaken to collate data in an attempt to align with the WGSS but it is a picture of the best and most up to date data using a number of sources including the 2018 census.
- Approximately 1.2million people with disabilities and simplified the disability categories from 6 down to 3.
- The general population line (the broken line) is made up of approximately 4.3million (eligible population 12 years and over).
- Can see that non-vaccination rate is lower for those with high disability needs and higher for those with less disability needs. Disabled Maaori and Pacifica also have higher non-vaccination rates but still lower than general population peers.
- Line graphs suggest not so much hesitancy but more a delay and reinforces the need to keep working with targeted groups.
- Points to disability rates being better overall than non-disabled counterparts.
- Number of questions around: Clarification about methodology e.g. denominator used; Most feedback- sticking to social model and have avoided diagnostic model; would like to see more data of where we started from at the beginning of vaccinating to compare to where we are at now.

- Noted that they are working on disability persona's/ clusters and have done further indicators for groups such as neuro diverse, residential care, intellectual disability (IQ below 70). Examining mental health data too but very complex.

11. PPNHI Project

Paper 6 - Patient Profile and National Health Index Project (PPNHI)

- Working on a robust but concise disability status questions to identify people at touch points in the health system ie GP enrolments, Child & Youth Screening and an accessible digital channel. That disability status data would then be matched with individual NHI numbers to disaggregate the National Collections. Taking a broad approach to capture as many people as possible within a reasonable number of questions.
- Clearly distinguishes disability status data from access data. Disabled people report differing levels of privacy concerns and want their status data kept private, but access data shared. An accessible digital platform to allow disability status/access information to be updated digitally, not just in health settings is a key requirement. Recognized need for these functions to be available via a non-digital channel e.g. call centre.
- Number of questions raised including: Concern whether those not identified as disabled, or those that don't fall under WGES, can be captured; How to apply this framework across organisations – great blueprint; How link in with the My Health Passport? Could info from this be incorporated?
- Agreement of them potentially having different purposes, with different levels of information i.e. Fast-paced services, where reasonable accommodations need to be identified quickly (e.g. primary care), in comparison to settings where more detailed health profiles are required (e.g. ward).

12. Additional member updates

- Wider group to email through any additional updates.