

## SUMMARY

### Disability Data and Evidence Working Group

**Date:** 7 September 2021

**Time:** 9.30am-12.30pm

**Venue:** Zoom

#### Attendees

##### *Government agencies*

- Office for Disability Issues: Brian Coffey (Chair), Shama Kukkady and Sarah Fuhrer
- Stats NZ: Dr Claire Bretherton, Sophie Flynn, Katy Auberson and Chelsea Dickson
- Ministry of Social Development: Anne Hawker
- Ministry of Health: Bridget Murphy and Dr Adam Dalglish
- Ministry of Justice: Tadhg Daly
- Oranga Tamariki: Dr James McIlraith
- New Zealand Transport Agency: Samantha Eastman
- Health Quality and Safety Commission: Richard Hamblin
- ACC: Tina Cronshaw
- Education Review Office: Mei Lin Harley and Juvena Jalal

##### *Independent agencies*

- Human Rights Commission: Frances Anderson and Kerri Kruse
- Office of the Ombudsman: Andrew McCaw and Olivia Soesbergen (in an observatory capacity)

##### *Disabled People's Organisations Coalition*

- Dr Jonathan Godfrey

##### *New Zealand Disability Support Network*

- Monica Munro

## *Universities*

- Associate Professor Brigit Mirfin-Veitch

## **Apologies**

- Oranga Tamariki: Dr Ann Walker and Elodie Green
- Ministry of Health: Shari Mason
- Ministry of Education: Matt Frost
- Disabled People's Organisations Coalition: Dr Tristram Ingham

## **1. Welcome**

## **2. Approve June 2021 meeting summary & papers for uploading to Office for Disability Issues website**

## **3. Results from the Patient Experience Survey (Health Quality and Safety Commission)**

- HQSC was set up in 2010 and are responsible for the improvement of NZ's health system. Their responsibilities include monitoring and reporting on the health system, and they run two surveys for people who access health services. The first survey is for in-patient hospital stays, and the second is primary care services (which is everything other than in-patient hospital stays, including emergency medical services)
- Last year, disability status was included into the primary care services survey, allowing the data to be broken down by disability status.
  - The survey used the Washington Group Short Set (WGSS) along with a self-reporting question.
  - Of the survey respondents, 19 percent were identified as disabled. Roughly a third were identified as being disabled by only the WGSS, a third from the self-reporting question only and the final third were identified as disabled in both the WGSS and the self-report.
  - Stats NZ was interested in seeing the characteristics of people who identified as disabled using either the WGSS or the self-report but not the other. For example, were older people more likely to be captured by the WGSS but answer 'no' to the self-reporting question.
- The 19 percent was questioned by the group, and concerns were raised that it seems low for a survey of people accessing health

services. This could have been caused by low response rates from disabled people, and because the survey omits people who cannot access health services (who are likely to be disabled). Questions were raised on what could be done to improve the response rate and how the 19 percent compares to actual health system users.

- The survey showed that disabled people faced more issues with accessibility and reported worse experiences with primary health care. Survey respondents gave mixed responses for telehealth services.
- There were not large differences between Māori vs non-Māori and Pacific vs non-Pacific disabled people.
- It was suggested that an executive summary of the results should be produced in alternate formats.
- It was suggested that subjective wellbeing measures would be good to include.

#### **4. Upcoming Human Rights Survey (Human Rights Commission)**

##### *Paper 1 A new human rights survey*

- The Human Rights Commission are developing a survey on human rights. It is currently in the planning stage and data collection will be in 2022.
- The key purpose of this survey is to capture data on human rights which is not elsewhere collected, and the HRC are consulting further to ensure the survey aligns with the principles of Te Tiriti o Waitangi. It is intended that this survey will be repeated.
- The survey scope is broad, and will cover topics such as education, employment, housing, and health. Given the wide scope, the HRC is seeking advice on which disability data gaps currently exist and are appropriate to be included in this survey.
- Group members suggested the following gaps:
  - Intersectional data. That is, data on disabled people who also belong to another vulnerable group e.g. the Rainbow community.
  - Disabled children and young people. The 'Youth19' and 'What About Me' surveys were pointed out as existing data sources for children.
  - Disabled women are a group particularly mentioned in the UNCRPD.
  - Collecting data on accessibility and reasonable accommodations (which are known as a barrier for disabled people getting into employment), and how these could be captured from a te ao Māori perspective.

- The issue of duplication was mentioned. The survey should not duplicate the efforts of other surveys and agencies. If data collected by other agencies was able to be broken down by disability status, this survey could focus on human rights questions that are not being answered elsewhere, e.g. are people able to access tools or services if their rights are being breached, are those services working?
- Stats NZ is currently developing the 2023 Disability Survey and they suggested it would be useful to work together to prevent duplication of content. However, it was pointed out that the Disability Survey only runs every 10 years. It was felt that more frequent data collection (such as the Human Rights Survey) was needed to measure things like reasonable accommodations and accessibility, as these are constantly evolving.

## **5. Evaluation of education provision for disabled learners (Education Review Office)**

- ERO are partnering with Office for Disability Issues and the Human Rights Commission on this project to evaluate education systems and inclusive education. Key questions this project aims to answer are:
  - How well are learners with disabilities and neurodiversity doing? Including looking at different subgroups (e.g. Māori, Pacific, learners at different life stages).
  - What is the quality and inclusivity of the education these learners are receiving?
- Given that the greatest concerns about inclusivity lie with non-specialist schools and ECEs, the project scope is limited to non-specialist places of learning ("mainstream" schools).
- The project will include site visits (visiting schools & ECEs) to examine teaching practices, literature reviews, and surveys.
- ERO wants to ensure the voices of learners and their parents are included, with a focus on ensuring parents and learners who are less engaged are represented in the survey. Group members emphasised the importance of capturing these voices.
- The project intended to be ongoing, as opposed to being a one-off.
- Terminology currently being used is "learners with disabilities or neurodiversity".
  - Group members suggested changing "or" to "including" and changing "with disabilities" to "disabled learners".
  - This would change the terminology to "disabled learners" including neurodiverse.

- It was suggested the project should look to answer the indicator from the Outcomes Framework: *Disabled students and their whanau are welcomed at the school or education setting of their choice.*
- There was interest from the group about seeing data for learners who have moved schools to get a better education. This would include situations where a parent has moved their child to another near-by school in the same city midway through the school year and the ORS funding has remained with the original school until the start of the next school year.

## **6. Patient Profile/NHI updated & EGL Friendly Admin Data Questions (Ministry of Health)**

### *Paper 2 Accessibility Admin Data Questions*

- The Patient Profile/NHI project has the aims of allowing admin data to be disaggregated by disability status and creating accessibility profiles.
- MOH are using the Washington Group Enhanced Short Set as a starting point for working group discussions.
  - The group discussed the fluid nature of the Washington Group questions, that is, people move in and out of the disabled population.
  - It was noted that survey mode may have an impact on the identification of disabled people.
  - The group was interested in whether the Enhanced Set can mitigate some of the limitations of the Short Set, or whether additional questions are needed.
  - It was noted that terminology needs to be used carefully when it can sometimes be used interchangeably, e.g. 'reasonable accommodations'.
- Questions on accessibility requirements do not currently exist so MOH have drafted some (see Paper 2). They are now seeking feedback on these questions.
  - Accommodations and accessibility requirements change, so questions need to be re-asked.
  - The point was made that when a person is asked about their reasonable accommodations and accessibility requirements, there is an implied promise that they will be provided with these.
  - It was suggested that succinct guidelines could be provided to DHBs, primary care service providers along with the accessibility questions.
- It was also raised that admin data for disabled children is scarce but much needed. Children with high health needs are identified in the

MOE database, but these are only children who have accessed funding and therefore doesn't capture many disabled children.

## **8. Communication approach to admin data (Ministry of Social Development)**

- Regarding the collection of disability status data to be carried out by public sector workplaces, the 6 monthly report showed that 17 agencies have signed the data commitment. Several other agencies have indicated that they would be interested in collecting data if they knew how and what to collect.
- Issues raised included a lack of understanding on what to ask & inconsistency on how data is collected (e.g. medical model approach still being largely used).
- Group decided that the advice to Public Service HR departments should:
  - Recommend asking about required accommodations first, followed by "are you disabled?"
  - Advice letter should be sent by either the Public Services Commission *or* Ministry of Social Development chief executive *or* jointly by Stats NZ and Ministry of Social Development.
- A conversation with the Public Services Commission needs to happen before making any further progress.
- A smaller working group is needed to further this work including members from the 'Improving access to disability data' workstream.

### Action points:

1. Working group will be set up with members from MSD, Stats NZ and ODI. Discussion will include how govt agencies should capture disability status and how to engage.
2. Conversation needed between working group and Public Services Commission.
3. Claire to follow up with Data System Leadership team at Stats NZ to check on what level of involvement they want to have.

## **9. Impacts of COVID-19 lockdown on transport for disabled people (NZ Transport Agency)**

- There is an ongoing research project at Waka Kotahi on disabled peoples' transport experiences, and which lately has had a focus on these experiences during lockdown (Covid level 3 & 4).

- First a survey will be run (aiming for 200 responses, 100 of which are disabled), then a phone interview with a smaller subgroup of volunteers.
- It was discussed that while disabled people are pleased that the government wants to carry out research, they are also disappointed that often this doesn't result in any implemented change. This is especially relevant to a lockdown context, whereby the time the research is completed, lockdown is likely to be over.
  - There is again the implied promise that comes with a survey or data collection: asking about transport difficulties implies a change will soon be made. A lack of implemented change following this survey would risk a negative reaction by the disabled community.
  - Surveys do not reach disconnected people.
  - Focus on surveying is impacting work on other issues/work programs (e.g. review of total mobility scheme, transport availability to disabled people), and causing survey fatigue among respondents.
- The following transport difficulties for disabled people during lockdown were mentioned:
  - Limited timetables for public transport meant:
    - Disabled people were limited in their ability to access essential services (including Covid-19 testing and vaccinations).
    - Disabled essential workers may have to pay more to get to work (e.g. having to use a taxi instead of the bus). Financial support for this is available but information about it needs to be more readily available.
  - Front-doors on buses were not able to be used in some cities during lockdown.

**10. Update on Access to disability data workstream, Resources workstream & NZ Disability Strategy Outcomes Framework (Office for Disability Issues)**

- Resources workstream: contractor has been hired by ODI to pull together existing resources on disability data, but they need guidance from existing members of the Resources workstream.

Action points:

1. Resources workstream will have a meeting facilitated by Anne Hawker. Purpose of meeting is to assist new contractor, provide further guidelines and decide how to sustain workstream.

- Access to data and IDI workstream: modules on disabled children and older disabled people drafted.
- Outcomes Framework: further consultation with disabled people is required. A sub-group from the working group will collate consultation feedback.

## **10. Update on 2023 Disability Survey**

- Public consultation is now open and will remain open for two months (closing date Friday 29 October 2021).
- Information is available on Stats NZ website.
- Work group will meet after consultation to discuss submission received.