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**SUMMARY**

**Disability Data and Evidence Working Group**

**Date:** 23 March 2021 **Time:** 2.00pm – 5.00pm

**Venue:** Room 1.7, Aurora Centre, 56 The Terrace and Virtual

**Attendees:** *Government agencies*

* Office for Disability Issues: Brian Coffey (Chair), Shama Kukkady and Dr Catherine Brennan
* Stats NZ: Dr Claire Bretherton, Sophie Flynn, Katy Auberson and Chelsea Dickson
* Ministry of Social Development: Anne Hawker
* Oranga Tamariki: Elodie Green
* Ministry of Health: Shari Mason, Bridget Murphy and Dr Adam Dalgleish
* ACC: Tina Cronshaw
* New Zealand Transport Agency: Samantha Eastman
* Ministry of Transport: Seb Brown
* Ministry of Justice: Tadhg Daly

*Independent agencies*

* Human Rights Commission: Frances Anderson and Kerri Kruse

*Disabled People’s Organisations Coalition*

* Dr Jonathan Godfrey and Dr Tristram Ingham

*New Zealand Disability Support Network*

* Monica Munro

*Universities*

* Associate Professor Brigit Mirfin-Veitch

*Guests:*

* Ministry of Social Development: Tessa Thompson and Lauren Innes-Hill
* Public Service Commission: Paul Vance

**Apologies:**

* Ministry of Education: Matt Frost
* Oranga Tamariki: Dr James McIlraith and Dr Ann Walker
* Health Quality and Safety Commission: Richard Hamblin

**1 Introduction**

Brian Coffey welcomed all participants to the meeting of the Disability Data and Evidence Working Group (DDEWG).

Sam Murray, the Zealand Disability Support Network representative on DDEWG, has resigned. His contribution to DDEWG, since its establishment in 2015, was noted.

**2 Approve December 2021 meeting summary and papers for uploading to Office for Disability Issues website**

Members approved.

**3 Engagement and Reporting workstreams (Anne Hawker)**

**Paper 1 *Engagement and Reporting report***

* The Ministry of Social Development (MSD) has received positive replies from 18 Chief Executives to the letter about disability data, signed by Debbie Power.
* It was noted that officials in various agencies have been inquiring about resourcing for information about disability data, disability data collection and so forth.

**4 Resources workstream (Catherine Brennan)**

**Paper 2 *Resources report***

* Funding has been secured from MSD and Oranga Tamariki to employ a contractor to design, consolidate and publish resources on disability data and evidence.
* The Office for Disability Issues (ODI) has collaborated with MSD to draw up a procurement plan to employ a Disability and Data Resources Contractor for six months. It is anticipated that the contract will commence in early April 2021.
* Given Sam Murray’s departure, a new lead is required for the Resources workstream.

**5 Access to Government Data, including Integrated Data Infrastructure workstream (Part 1)**

**(I) Paper 3 *Access to government data, including IDI report*****(Shama Kukaddy)**

* The Data and IDI workstream is to merge with the Access to Government Data workstream.
* The Data and IDI workstream met with members of the Strategic Advisory Group on IDI (SAID). SAID indicated that increasing the integration of data (e.g., disability data) into the IDI is not currently one of their objectives.
* SAID has referred the Data and IDI workstream to the Datalab Community Group (hosted by Stats NZ, but led by the community). The focus of the Datalab and Community Group is to enable and support the research community to use the IDI, such as providing resources.
* The Data and IDI workstream met with Māori disabled representatives to consider how to analyse disability data from a te ao Māori perspective.
* The Ministry of Health (MOH) has requested some time in the next month to discuss the inclusion of disability in the National Health Index (NHI). MOH is seeking guidance from DDEWG. The NHI is currently used for:
	+ statistical purposes
	+ service provision
	+ prevalence of population groups in the health system.

**(II) NZ Disability Survey 2023 (Stats NZ)**

**Paper 4 *NZ Disability Survey 2023: Purposes and Objectives***

* The purpose of Paper 4 is to outline a proposed statement of the overarching purpose and primary objectives of the 2023 Disability Survey. The proposed survey objectives listed in priority order are:
	+ to understand the size of the disabled population usually resident in NZ, and describe the characteristics of that population. More specifically, to produce reliable national estimates of the disabled population by demographic characteristics (such as age group, gender, and ethnicity), and produce reliable national estimates of the disabled population by functional domain.
	+ to understand the extent to which social and economic outcomes for disabled people differ from those for non-disabled people, and how these outcomes differ between groups within the disabled population
	+ to understand the level and type of support disabled people need to perform activities of daily living
	+ to understand what facilitates or hinders participation by disabled people in important aspects of life such as work, education, and recreation.
* Comments noted on the proposed objectives include:
	+ An interactive lens on disability needs to underpin Objective 2 (e.g., if Māori, low income, inequitable access to health services etc. mean disability will have a different effect on outcomes).
	+ Objective 3 also needs to focus on life-expectancy and unmet (which may be unfunded) need.
	+ The important aspects of disabled people’s lives may not be work, education and recreation (Objective 4). A focus on wellbeing may be more appropriate, such as social isolation and social relationships.
	+ Accessibility needs to be highlighted in Objective 4, given that lack of access to education, health and the like is the process through which disablement occurs in NZ society.
	+ A broader definition of rights needs to underpin the proposed objectives, for example, socio-cultural rights, civil and political rights.
	+ Cultural identity is crucial to include in a survey of the disabled population. The Disability Survey needs to be “culturally robust”.
	+ An objective on carers should be included.
* There will be future discussion on the content of the 2023 NZ Disability Survey. Consultation will take place online and in workshops.
* A separate piece of work will be undertaken on the residential component of the 2023 Disability Survey.

**Paper 5 *Identifying Disabled People in the 2023 NZ Disability Survey***

* Comments noted include:
	+ Comparability with previous disability surveys should not be an important feature, given the lack of comparability over time. In other words, longitudinal data is secondary. Our understanding of disability is unlikely to remain unchanged in a ten-year period.
	+ Other features the Disability Survey needs to consider are factors such as the association of the environment and identity with disability.
	+ In addition to the inclusion of one of the Washington Group question sets on disability, the following was suggested:
		- Include a self-identifier question.
		- Lower the threshold (to the lowest level of “no difficulty”) to be identified as “disabled”. (The Washington Group recommends a threshold that requires an individual to have “a lot of difficulty” undertaking at least one activity to be identified as “disabled”.)
	+ Questions need to consider individual needs (i.e.,”are you” vs. “do you want to be”, unmet needs vs. unfunded needs).
* Stats NZ are considering adding a “catch all” style disability question to the 2023 Census (in addition to the Washington Group Short Set) to inform the sample for the 2023 Household Disability Survey (HDS). The additional question would be used only to boost the sample of disabled people for the 2023 HDS, and results from this question would not be output.
	+ Suggested wording for this additional question was: “Do you have a disability, or physical or mental health condition, which limits your ability to carry out day-to-day activities?”
	+ DDEWG discussed removing the word, physical, and the importance of not placing the ownership of the disability on the person.

**6 Access to Government Data, including Integrated Data Infrastructure workstream (Part 2)**

**(III) Feedback on the “Working Matters” dashboard (Tessa Thompson and Lauren Innes-Hill)**

**Paper 6 *“Working Matters” dashboard***

* It was noted that:
	+ NEET rate has a high standard error, and potentially is based on a very small sample size for disabled people. The consensus was that it is best to avoid using the standard error, unless it can be pooled over time without double counting.
	+ It is imperative to report on the work composition of employees.

**(IV) Guidance to agencies on the use of the disability administrative question(s)**

* It was noted that DDEWG, the Independent Monitoring Mechanism (including the DPO Coalition) and the Disability Action Plan 2019-2023 work programmes, all have an expectation that government agencies use administrative data to understand:
	+ How many disabled people are accessing public services?
	+ What has been the disabled person’s service experience and outcomes?
	+ What support may a disabled person require to access a service with dignity?
* It was observed that agencies cannot be encouraged/expected to improve their collection and use of disability administrative data, if appropriate guidance cannot be given on the question(s) to ask.
* Various disability administrative questions were suggested, including:
	+ Do you have a disability? (This question will be used in the forthcoming Public Service Census alongside the Washington Group Short Set.)
	+ Are you a disabled person?
	+ Are you a person with a disability?
	+ Do you have a disability, including a health condition or mental health condition? (It was noted that many people with health conditions are not disabled.)
	+ Has your health or wellbeing made achieving your desired life outcomes harder?
	+ Do the life circumstances in which you find yourself disable you?
* The support needs question(s) posed, include:
	+ What help or support do you need to access a service?
	+ Do the services meet your needs?
* It was pointed out that framing needs questions need to be more aspirational (e.g., ability to carry out daily activities vs. full and effective participation in society on an equal basis with others).
* It was observed that support need questions are quite different from reasonable accommodation questions.

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| **Action**ODI will provide some resourcing to bring disabled people together to develop a few disability administrative questions for later testing with a wider group of disabled people.  |

**(V) Public Service Census (Paul Vance)**

* A survey of 36 core government agencies (60,000 people approx.) will be undertaken in May 2021. The survey is currently being piloted.
* An external research provider has been contracted to run the Public Service Census.
* Separate data sets will be made available for each agency, and each agency will have access to a reporting portal.
* The Public Service Commission plans to conduct the Census every two years across the public service.

**(VI) New datasets**

* *Child Poverty Statistics*
	+ Data for the year ended June 2020 is only for nine months, to March 2020, due to being unable to collect data for the *Household Economic Survey* during the COVID-19 lockdown.
	+ Child poverty statistics have, for the first time, been disaggregated by disability.

**7 Disability Research workstream (Catherine Brennan)**

**Paper 7 *Disability Research report***

* The letter drafted to research funders seeking information about the funding of disability research is ready to be signed out by ODI, Stats NZ and the Human Rights Commission.
* The assessment of the data sources available to answer the questions in the *Enduring Questions on Disability* (October 2016) is in process.

**Note**

Next meeting will be on 8 June 2021 (2.00pm-5.00pm).