

**Summary of meeting**

**Disability Data and Evidence Working Group**

**Date:** 9 December 2015 **Time:** 9.00am – 2.15pm

**Venue:** Thorndon Hotel, Hawkestone Street, Wellington

**Attendees:** *Government agencies*

* Office for Disability Issues: Megan McCoy (Chair), Catherine Brennan
* Statistics New Zealand: Diane Ramsay, Litia Tapu, Phillipa O’Brien, Elodie Green
* Ministry of Justice: Patrick Power
* Ministry of Education: Clare Shepherd
* Ministry of Health: Christopher Carroll
* Ministry of Social Development: Anne Hawker
* Ministry of Transport: Jennifer McSaveney

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

*Disabled People’s Organisations*

* Jonathan Godfrey

**Apologies:** ACC: Julie Shipton-Pasgaard

Universities: Dr Brigit Mirfin-Veitch (University of Otago and Donald

Beasley Institute)

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Megan McCoy (Chair) welcomed all participants to the third meeting of the Disability Data and Evidence Working Group.

1. **Summary of second meeting**

A summary of the second meeting had been distributed by email. It was confirmed that the summary of the meeting was accurate.

1. **ODI and Statistics New Zealand updates**

Megan McCoy’s (Director, Office for Disability Issues) update included:

* The updated Disability Action Plan 2014-2018 includes an action (9E) relating to implementing the work programme of the Disability Data and Evidence Working Group (DDEWG), including a focus on Māori and Pasifika. This will increase the profile of DDEWG and make reporting lines clearer.
* Given that membership of the DDEWG will be reviewed in mid-2016, Minister Wagner has asked that the Working Group approach the Māori Centre for Excellence when asking for a new university representative in 2016.
* The Office for Disability Issues (ODI) has been unable to progress the draft of the Information Assignment. The Disabled People’s Organisations (DPOs) are interested in having an input into the draft.

Diane Ramsay’s (Manager, Labour Market and Households Unit, Statistics New Zealand) update included:

* One of the members of the Labour Market and Households Unit recently went to Tonga to speak about the New Zealand Disability Survey. The focus was on disabled children. The visit to Tonga was sponsored by UNICEF.
* Statistics New Zealand (SNZ) has been testing the Washington Group Short Set of Questions in the General Social Survey (GSS). The testing has been successful. SNZ is planning to add these questions to the GSS in April 2016, although the final decision has yet to be made.
* SNZ is still engaged in consultation on the content of the 2018 Census. The feasibility of including disability questions in the forthcoming Census is under consideration.
* SNZ has been speaking to Grant Pittams (Manager, New Zealand Health Survey) about whether SNZ can get access to the disability data in the Health Survey.

1. **Stocktake of government data on disabled people**

The paper, “A stocktake of government data on disabled people”, informed the discussion. The Working Group reviewed the initial stocktake prepared by Statistics New Zealand with input from the Ministries of Health, Education, Justice and Social Development. They agreed that this was a good start. The following were the key discussion points:

* ACC disability data is currently being gathered for the stocktake.
* It was agreed that it would be a good idea to add a question in a revised stocktake questionnaire on whether government agency disability data sources have been added to SNZ’s Integrated Data Infrastructure (IDI). For example, Ministry of Social Development data is being integrated into the IDI and matched up with Corrections.
* It was agreed that it is important to add the Ministry of Transport to the stocktake of government data on disabled people.
* It was agreed that ODI and SNZ would jointly co-ordinate adding to the stocktake of government data already collected. The following will be consulted:
  + Child, Youth and Family
  + Corrections and Police
  + Transport
  + Ministry of Health (i.e., District Health Boards)
  + Ministry of Business, Innovation and Employment (i.e., employment and accessibility)
  + Universities/research institutes
  + DPOs
  + Convention Coalition Monitoring Group
  + Service providers (New Zealand Disability Support Network and Inclusive New Zealand)
  + Human Rights Commission
  + Office of the Ombudsman
  + Health and Disability Commissioner.
* It was emphasised that the collection of data and evidence must be informed by the following question: What kind of data and evidence is required to have an impact for disabled people? It is crucial to compare the experiences of disabled and non-disabled people.

1. **Monitoring framework for New Zealand**

The paper, “Monitoring framework for New Zealand”, informed the discussion. The following points were noted:

* The Government has mandated responsibility to monitor the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in New Zealand. Government agencies, in turn, have a responsibility to deliver commitments made by State Parties.
* Some concern was expressed about government agencies being both sources of information for monitoring and objects of monitoring.
* It was noted that the Independent Monitoring Mechanism (IMM) is broadly supportive of the monitoring paper. It is the intention of the IMM to align as much as possible with the Government in the development of monitoring indicators etc. However, the IMM monitors independently of the Government and retains the right to critique the Government.
* DDEWG will act as the primary advisory group in the development of the monitoring framework.
* A Terms of Reference (TOR) for the process of developing a monitoring framework will be drawn up, specifying the roles and responsibilities of the parties involved.
* The development of the enduring questions to inform the ongoing collection of data and evidence on disabled people will be informed by the need to regularly monitor progress against the CRPD, the New Zealand Disability Strategy and the Disability Action Plan.
* It was observed that the integration, where possible, of the Better Public Services (BPS) targets into the monitoring framework is important. For example, the focus of BPS1 is reducing the number of people who have been on a working age benefit for more than 12 months.

1. **Updated work programme**

The paper, “Framing the work programme as a disability domain plan”, informed the discussion. The discussion revolved primarily around how DDEWG can develop an understanding of the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework for measuring disability.

* Megan McCoy contacted Dr Alarcos Cieza in the Disability and Rehabilitation Unit at the World Health Organisation. Dr Cieza has agreed to come to New Zealand in 2016 to run workshops on the ICF. She is also planning to bring the Technical Officer for the Western Pacific Region.
* DDEWG has not yet decided to adopt ICF as a conceptual framework. However, it was agreed that organising ICF workshop sessions for DDEWG members, government agency officials, researchers/academics, DPOs and service providers would be very useful to build up knowledge of the ICF conceptual framework. Particular interest was expressed in how the ICF framework could:
  + facilitate the development of the enduring questions to underpin the collection of data and evidence on disabled people in New Zealand
  + be translated into the New Zealand cultural and linguistic context.
* The IMM would also be interested in building up knowledge of the ICF framework.
* It was agreed that ODI and SNZ would put together a list of questions and outcomes required from the proposed ICF workshops.
* Megan McCoy advised that the Australian Institute of Health and Welfare (AIHW), Australia’s national agency for health and welfare statistics, has not yet been approached about coming to New Zealand to share their knowledge and expertise about disability data and evidence.

1. **Next steps**

The following action points arose from the meeting:

* Letter to be written to the Senior Manager Customer Focus 2018 Census on behalf of DDDEWG, recommending that the Washington Group Short Set of Questions on Disability be included in the 2018 Census.
* A draft of the Information Assignment to be sent to the DPOs for comment in February 2016.
* The “Monitoring framework for New Zealand” paper to be turned into a Terms of Reference for the process of developing a monitoring framework.
* SNZ to update the Summary of work programme for DDEWG 2015/16 one-pager before publication on DDEWG website.
* “A stocktake of government data on disabled people” document to be updated to version 2 before publication on the DDEWG website in the New Year.
* ODI and SNZ to co-ordinate adding to the stocktake of data already collected from government agencies represented on DDEWG. Organisations to be contacted about data and evidence available on disabled people will include: more government agencies, universities/research institutes, DPOs, service providers, IMM and the Health and Disability Commissioner. A timeframe for requesting information to be decided upon.
* The next meeting will be held in early to mid-March 2016.

Ref: A8543355