

**Summary of meeting**

**Disability Data and Evidence Working Group**

**Date:** 28 August 2015 **Time:** 10.00am – 3.00pm

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

**Attendees:** *Government agencies*

* Office for Disability Issues: Megan McCoy (Chair), Catherine Brennan
* Statistics New Zealand: Diane Ramsay, Daniel Griffiths and Phillipa O’Brien
* Ministry of Justice: Patrick Power
* Ministry of Education: Clare Shepherd
* Ministry of Health: Christopher Carroll
* ACC: Julie Shipton-Pasgaard

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

**Apologies:** Ministry of Social Development: Anne Hawker

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

Beasley Institute)

Disabled People’s Organisations: Dr Jonathan Godfrey

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1. **Introduction**

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

1. **Overview of current context for disability data and evidence in New Zealand**

Two papers, “Measuring disability in New Zealand: Current status and issues” (Statistics New Zealand) and “Context for better information on disabled people in New Zealand” (Office for Disability Issues) - informed the discussion of the current context for disability data and evidence in New Zealand. The following were the key discussion points:

* 1. There is no shared understanding of disability in New Zealand. Disability is understood differently in government agencies depending upon the purpose and type of data collection. For example, the Ministry of Health’s Disability Support Services uses a medical diagnosis to determine eligibility for their services. Statistics New Zealand defines disability as an impairment which has a long-term (six months or longer) limiting effect on a person’s ability to carry out daily activities.

The United Nations Convention on the Rights of Persons with Disabilities’ (CRPD) understanding of disability underpins the work of groups like the Independent Monitoring Mechanism (comprising the Human Rights

Commission, the Office of the Ombudsman and the Convention Coalition) and Disabled People’s Organisations.

* 1. It was agreed that it would be helpful to have a shared understanding of disability. There was consensus that, at this stage, the CRPD and the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF) should serve as conceptual frameworks for the Working Group’s understanding of disability. The CRPD and the ICF are the best tools internationally for understanding and measuring disability. It was emphasised that the ICF framework incorporates limitations in body functioning, activity limitations and environmental factors which restrict disabled people’s ability to participate in daily life.
  2. In addition to consistency in the understanding of disability, it is important to have a good understanding of the information needed about disabled people, and how to use resources efficiently to collect this information. It was emphasised that clarity of purpose has to be the driving force behind the collection of data on disabled people. It was suggested that part of our work may be to advise on disability research needed to address some of the knowledge gaps.
  3. There was a discussion of the disability surveys conducted by Statistics New Zealand since 1996 and Statistics New Zealand’s increasing focus on using administrative sources of data. These issues are covered in detail in the paper, “Measuring disability in New Zealand: Current status and issues”.
  4. The collection of qualitative information on disabled people is also important to provide a holistic picture of their lives, their major concerns and experiences. For example, data is required on their experiences of abuse, discrimination, inequalities and so on.
  5. The collection of data on particular groups with the greatest need within the disabled population (for example, Māori) is important.
  6. It was agreed that identifying the purpose of collecting data on disabled people for various stakeholders was important. The availability of robust data on disabled people is not only important for government agencies in the development of policy and the delivery of services. Non-government organisations also need solid data to support their advocacy work. Furthermore, there is a growing demand in local government for data about disabled people. Sound data is also required to support better quality and more efficient monitoring of the implementation of the CRPD, a revised New Zealand Disability Strategy and an updated Disability Action Plan 2014-2018.

1. **Developing a work programme: Some key issues to consider**

The following were the primary suggestions put forward to develop a work programme for the Disability Data and Evidence Working Group:

* 1. Undertake a stocktake of existing data and evidence on disabled people in New Zealand, drawing on tools such as the Domain Plan methodology used by Statistics New Zealand. The Domain Plan methodology includes a stocktake and a process to try and figure out enduring information needs. It, then, enables us to understand where data gaps exist and to develop a strategy to fill them.

The complex and time consuming part of the Domain Plan methodology is finding out what are the enduring information needs. This being the case, it was agreed that it may be prudent to use this methodology in a gradual or staged approach.

Here is an example of a recent Domain Plan done for the environmental statistics domain: <http://www.stats.govt.nz/browse_for_stats/environment/environmental-economic-accounts/environment-domain-plan/snapshot.aspx>

The use of the Domain Plan methodology will enable informed decisions about areas in which there is a dearth of data on disabled people to inform decision-making.

* 1. Identify what the key issues and trends are for disabled people, drawing on evidence from the 2013 Disability Survey, the Convention Coalition’s reports and qualitative research findings.
  2. Undertake further analysis on how using the CRPD and the ICF understandings of disability would work in practice. For example, how would the utilisation of the ICF framework influence who and what to monitor when reporting on the implementation of the CRPD, a revised New Zealand Disability Strategy and an updated Disability Action Plan?
  3. Identify how capability/understanding of data can be built up.
  4. Identify ways to support the work of the Working Group such as establishing contact with the chief science advisors in the various Ministries, the Social Policy Evaluation and Research Unit and iMSD.

1. **Terms of Reference**

The draft Terms of Reference were discussed and the following points noted:

* 1. The statement, “to improve the lives of disabled people”, should be

added to the “Purpose” statement.

* 1. A communication section in accessible formats needs to be included.
  2. The relevant recommendations in both the United Nations Committee on the Rights of Persons with Disabilities’ Concluding Observations and the Independent Monitoring Mechanism reports 2012 and 2014 should be included.
  3. A section outlining the Working Group’s work programme should be added.
  4. Membership of the Working Group will be for one year in the first instance.
  5. Experts on specific issues can be invited to attend meetings, when required.
  6. Protocols around confidentiality will be decided on a case by case basis.
  7. The Office for Disability Issues (ODI) website will be the primary repository of information about the Working Group. Other government agencies can link directly to this website.
  8. A dedicated email address for the members of the Working Group will be set up.

1. **Next steps**
   1. The Office for Disability Issues and Statistics New Zealand will develop a draft work programme for discussion at the next meeting. This will be based on key issues discussed at the next meeting.
   2. The Domain Plan methodology will be shared prior to the next meeting.
   3. The Terms of Reference will be updated and presented to next meeting for discussion.
   4. The next meeting will be held on 1 October 2015 and the following meeting on 9 December 2015.