# Summary of meeting

# Disability Data and Evidence Working Group

**Date:** 1 October 2015 **Time:** 9.00am – 12.00pm

**Venue:** Statistics House, The Boulevard, Harbour Quays, Wellington

**Attendees:** *Government agencies*

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

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

*Universities*

* Dr. Brigit Mirfin-Veitch (University of Otago and Donald Beasley Institute)

*Disabled People’s Organisations*

* Dr. Jonathan Godfrey

# Welcome

Diane Ramsay (Chair) welcomed members of the Disability Data and Evidence Working Group (DDEWG) to the second meeting.

# Summary of First Meeting

A summary of the first meeting had been distributed by email.

Discussion confirmed that the summary for each meeting will be published on a webpage dedicated to DDEWG documents to be hosted on the Office for Disability Issues (ODI) website. We will aim to have meeting summaries up on the webpage two weeks after each meeting, once they are agreed by DDEWG members via email.

A dedicated email address will be set up for external feedback on documents on the webpage. ODI will manage feedback with the support of Working Group members.

It was agreed that before publication of the first meeting summary the date for the meeting in December needs to be confirmed.

Ministry of Health (MoH) representative noted that the Health Survey could be a potential data source for the work discussed in paragraph 3.2 of the first meeting summary document.

# Terms of Reference

The draft Terms of Reference (ToR) for the DDEWG were distributed by email prior to the meeting. The version under consideration was produced after amendments that were agreed at the July 28th meeting.

It was agreed that the goal of working towards a shared understanding of disability should be made explicit in the Terms of Reference.

It was agreed that ‘evaluation’ should be added to the second bullet point under objectives.

There was some discussion on the agencies represented on the Working Group with particular interest in the inclusion of a transport agency.

It was agreed that the Ministry of Transport (MoT) should be approached for them to suggest someone from their sector (across both MoT and the New Zealand Transport Agency [NZTA]) for the DDEWG. The selection process for the representative from the transport sector would use the same criteria as when current group members were selected.

Agreed that agencies do not need to be around the table to be involved, they can be invited in for discussion of specific issues. Also discussed was the possibility of a reference group to engage all those with an interest in disability data and evidence.

Membership of the Working Group will be reviewed one year from commencement. It was agreed that other agencies should be considered at that time.

Agreed that references to ‘services’ should include both ‘mainstream’ and ‘specialist’, where currently only specialist services are mentioned.

Discussion clarified that recommendations of the DDEWG will go to the Ministerial Committee on Disability issues, as well as to the organisations participating in the Working Group. Recommendations will inform the Statistics NZ (SNZ) strategy for collection of disability data.

Feedback via email from the Human Rights Commission (HRC) on the ToR was summarised. Comments from HRC were made on:

* harmonising definitions of disability
* self-identification of disabled people
* UN Sustainable Development Goals
* international comparability.

Noted that the Sustainable Development Goals apply to all countries (while Millennium Development Goals did not). Ministry of Foreign Affairs and Trade is leading the reporting process for New Zealand on the Sustainable Development Goals with the support of SNZ.

Summary of agreed changes to Terms of Reference (to be made by ODI)

* Add wording to include ‘shared understanding’ /harmonising definitions of disability as goal
* Add sustainable development goals to objectives, bullet point one.
* Move ‘improve the lives of disabled people’ up within purpose, bullet point one.
* Reference to specialist services should also include mainstream services.
* Change ‘support’ to ‘inform’ in first bullet point under purpose.

The Terms of Reference will be distributed via email, with changes highlighted, for final approval before going online.

# Draft Work Programme

The Chair introduced the paper on the proposed work programme of the DDEWG and said that timeframes are not fixed, but aim to keep workflows progressing. The programme is intended to be a living document.

## Enduring Questions

The first item on the table of activities called, ‘environment scan’, should not be grouped as part of ‘identifying enduring questions’. Discussion followed on what is required by this piece of work and whether it should be called an environment scan. ODI have called it an ‘Information Assignment’. The purpose of it is to ensure that the Working Group has a shared understanding of the key issues facing disabled people. It is a scene setting document and not a direct input into defining the enduring questions. It is meant to bring together issues identified from a number of sources to help build a shared understanding of the key issues by members.

Discussion followed on when and how to begin engagement with Disabled People’s Organisations (DPOs) regarding the enduring questions. It was agreed that engagement should begin early in order to allow for a co-design approach. ODI will put the DDEWG on the agenda for a meeting with DPOs in two weeks’ time. ODI and DPO representative to meet separately and discuss the engagement with DPOs.

## Understanding of conceptual framework

The DDEWG needs to understand the meaning of disability in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and the International Classification of Functioning, Disability and Health (ICF).

ODI are investigating bringing some international expertise to help build understanding within the Working Group.

## Stocktake

Agreed to confine the initial stocktake to the government agencies around the table at the Working Group (including the transport agencies.) Coverage would then be reviewed at a later date. Administrative data would be the starting point. First draft of the stocktake to be available for the December meeting. Achieving the tight timeframe will be made possible by the role/work of the representatives on the Working Group.

A set of questions based on the 2007 stocktake will be made available by SNZ. Barriers to, and processes for, sharing data were discussed and information on this should be part of the stocktake.

Discussed the scope of the stocktake and whether to include national and regional sources of information. It was agreed that ideally region, like ethnic group, would be a characteristic of data identified.

## Monitoring Framework

The last entry in draft work programme was discussed. This refers to the monitoring framework for reporting against the UNCRPD.

The DDEWG will provide input into this ODI-led framework as well as into the revision of the New Zealand Disability Strategy and the Disability Action Plan 2014-2018. ODI aim to prepare a brief paper about the monitoring framework which they will develop in conjunction with the Independent Monitoring Mechanism (IMM) for the UNCRPD.

The work programme paper will be revised and distributed. It was agreed that a summary of the planned pieces of work for the Working Group would be put on the webpage without deadlines.

# Terms of Reference for contractor

Agreed that this is not an environment scan but an ‘information assignment’ to inform the Working Group and establish a common understanding of key issues. It could also be thought of as a ‘desk review’.

It was agreed that coverage includes published material and information already prepared by agencies. Agreed to remove ‘2013’ from Disability Survey and broaden the named sources of information. Must include the voice of disabled people and draw together qualitative and quantitative sources. Terms of Reference should include a lived experience perspective.

The DDEWG agreed that this piece of work is useful and should proceed.

# Other Business

It was suggested that a set of FAQs would be useful. In particular to clarify the role of the DDEWG and the future of the Disability Survey. The decision to run one post-censual survey after each census and for Te Kupenga (Māori social survey) to be the post-censual survey in 2018, was made well before the decision to set up the DDEWG. Recommendations of the DDEWG will inform future decisions about the collection of disability data by SNZ, including the requirement and timing of a specialist disability survey.

# Action Points from this meeting

1. ODI / DPO representative to discuss engagement with DPOs.
2. DDEWG to be on the agenda of next meeting of ODI with DPOs.
3. MoT to be approached about a transport sector representative for the DDEWG (ODI).
4. DDEWG webpage, on the ODI website, to be available next week (ODI).
5. Dedicated email address for external feedback to be set up (ODI).
6. SNZ to send out to members a question set for the stocktake.
7. December meeting date to be finalised.
8. Summary of first meeting, with December meeting date, to be posted on the webpage (ODI).
9. ToR for the DDEWG to be amended, emailed for approval and posted online (ODI).
10. Work programme to be amended and emailed for discussion at December meeting (SNZ).
11. Summary of work programme to be prepared for the webpage (SNZ).
12. Terms of reference for information assignment to be amended and circulated for agreement (ODI).
13. Disability service providers’ representative and university representative to consider how to draw on expertise in their sectors.
14. Government agencies represented on the Working Group to begin draft stocktakes of disability data sources at their agency for discussion at December meeting.

# Next meeting

The next meeting of the DDEWG will be held on December 9th. The meeting will be chaired by Megan McCoy from ODI.