# Summary of meeting

# Disability Data and Evidence Working Group

**Date:** 5 October 2016 **Time:** 9.00am – 3.30pm

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

**Attendees:** *Government agencies*

* Statistics New Zealand: Diane Ramsay (Chair), Litia Tapu, Phillipa O’Brien, and Elodie Green
* Office for Disability Issues: Megan McCoy, Catherine Brennan
* Ministry of Education: Brian Coffey (afternoon only)
* Ministry of Justice: Patrick Power
* Ministry of Social Development: Anne Hawker
* Ministry of Transport: Kevin Eames (afternoon only)
* Human Rights Commission: Douglas Hancock (morning only)

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

*Universities*

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

*Disabled People’s Organisations*

* Jonathan Godfrey (Disabled People’s Organisations)

**Apologies:**

* Ministry of Education: Clare Shepherd
* Ministry of Health: Christopher Carroll
* ACC: Lance Fowler

# Welcome and introductions:

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

Douglas Hancock replaced Paul Gibson (Human Rights Commission) and Brian Coffey replaced Clare Shepherd (Ministry of Education) for this meeting.

# Summary of previous activities

Diane outlined the three events that have happened since the last meeting in March:

1. The workshop on Enduring Questions in May 2016
2. The DDEWG workshop on the International Classification of Functioning, Disability and Health (ICF) with Ros Madden (University of Sydney) in June 2016
3. The three days of consultation on Enduring Questions and the ICF (and Health Research Strategy) held in August 2016

**Enduring Questions workshop**
A workshop was held on 5 May 2016 where Working Group members brainstormed ideas for enduring topics and questions.

**Ros Madden’s International Classification of Functioning, Disability and Health workshop**
Ros Madden presented a workshop on the International Classification of Functioning, Disability and Health (ICF) in late June 2016. It included an introduction to the ICF and sessions on how the ICF could be applied.

**Enduring Questions consultation**
Public consultation on the Enduring Questions document took place in August 2016. It included three workshops with government agencies, independent organisations, Disabled People’s Organisations (DPOs), service providers and universities. There was also an online survey that was open to the public and the Working Group email was also promoted as a point of feedback.

Megan McCoy then provided an update from the Office for Disability Issues (ODI).

**Consultation on revision of New Zealand Disability Strategy**Consultation on the revision of the New Zealand Disability Strategy occurred in April/May 2016 and August 2016. Megan described the work ODI have done on the new Disability Strategy. She stated that the draft Disability Strategy would go to Cabinet in October 2016. Consultation on the revision of the Disability Strategy emphasised the need to ensure that information and evidence is available for decision making.

The **information paper**, *Key issues for disabled people in New Zealand,*commissioned when the DDEWG was set up, has now been circulated to DDEWG. The paper provides a brief overview of major issues for disabled people in New Zealand, drawing on data from Statistics New Zealand’s (SNZ) 2013 Disability Survey and qualitative research contained in the New Zealand Convention Coalition Monitoring Group (Convention Coalition) reports. Patrick Power noted that we should ensure the information paper issues are covered in the Enduring Questions document.

Megan provided an update on the Convention Coalition research which is used in the paper. She noted that the management of the research will be undergoing a review to inform next steps, but that the appropriation was on-going (that is, there have been no changes to the funding allocation).

# Enduring Questions consultation feedback

Three documents informed this discussion:

* Feedback from public consultation on the enduring questions
* Memo on the changes made to the Enduring Questions from public consultation
* Enduring Questions document (with amendments made from consultation feedback).

Elodie Green summarised what had been done and the issues that needed to be discussed today (from the memo)

**United Nations Convention on the Rights of Persons with Disabilities mapping**
Feedback was given about how the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is reflected in the Enduring Questions document. While the Enduring Questions are informed by articles in the UNCRPD, the relationship is not explicit. A mapping exercise of the Enduring Questions to the UNCRPD articles will be carried out and included as an appendix item in the document. This appendix will be noted in the Introduction to the Enduring Questions document.

**Terminology used**Feedback on the use of various terms prompted a discussion on what are the best terms to use. It was noted that something was often not included in the questions when it was within another question. For example, there is no question on voting, but voting sits within Types of Civic Engagement. Therefore, a glossary of some key terms will be added to the Enduring Questions document. An explanation of why these terms are used, their limitations and benefits will be included.

The use of “disabled people and others” was contested. The use of this term was taken from the UNCRPD and suggested that data would be collected that enabled comparisons in a multitude of ways. For example, comparing the disabled population with non-disabled, but also the disabled population with the total population. It will be changed from “others” to “other groups” and an explanation will be given.

**The use of ICF terminology**
Feedback from consultation requested definition of terms. The Enduring Questions document uses the ICF as a framework so that there is a coherent, shared understanding of disability and impairment. Every framework has benefits and limitations, and a section on the ICF has been added to the Introduction. The Working Group discussed the ICF to arrive at an agreement about the framework to go forward – to help the DDEWG complete its work – and be explicit about the limitations. It was agreed that the ICF could be used as a framework for discussion in the Enduring Questions document, but the classifications will not be used as this level of detail was not considered necessary. The DDEWG provided further feedback to refine the section on the ICF in the Introduction to increase transparency.

**Cross-cutting topics**
Feedback from consultations revealed that it was not clear that certain topics were cross-cutting. These topics included Personal Characteristics and Disability, Impairment and Limitations. Cross-cutting topics were separated from the other topics, which were labelled core topics. It was agreed that further elaboration should occur, and a question on personal autonomy would be added to all core topics. Accessibility is addressed in core topics in barriers and facilitators. Attitudes and Awareness are also included in the core topics as they can also be barriers or facilitators.

**Cost of disability**
A question on the cost of disability and/or impairment will be added to the Disability, Limitations and Impairment topic. A discussion took place on how this question would be posed. Conversion costs and opportunity costs were examples of proposed approaches. Brigit Mirfin-Veitch will forward a piece of Auckland University of Technology work on the subject to the Working Group.

**Bioethical Issues**
Examples: Sterilization/screening. It was discussed how to frame questions about bodily integrity, issues of personhood and personal autonomy, informed consent, changing attitudes and legal arrangements. Medical and legal procedures that are applied to disabled people were also discussed. How well do legal frameworks and current interpretations meet the needs of disabled people? Examples of questions were recorded and will be distributed to the Working Group for further discussion.

**Other points raised**
Habilitation/rehabilitation, health literacy, and the right to express sexuality were other points that were discussed and will be incorporated into the Enduring Questions document. In the Health topic, need to change ‘medical’ to ‘health’ and drop words before ‘determinants of health’. Change ‘effect’ to ‘impact’ in document. Rehabilitation and habilitation will be discussed in Services topic. Health literacy is a barrier and facilitator for health outcomes, and will be discussed in the Health topic. These changes will be highlighted so that particular attention can be focused on them when the amendments are reviewed by the DDEWG.

# Proposed approach to develop Outcomes Framework and Disability Data and Evidence Plan

ODI presented an approach to develop the New Zealand Disability Strategy Outcomes Framework and the Disability Data and Evidence Plan as a single programme of work. This will include joint meetings between the New Zealand Disability Strategy Reference Group and the DDEWG.

This is to streamline engagement with government agencies and the disability sector, and consideration by government. There is a need to specify the roles and responsibilities of all the groups involved in work on the Outcomes Framework and the Disability Data and Evidence Plan.

The goal of the single programme of work is an initial draft Outcomes Framework and Disability Data and Evidence Plan to be considered by the Chief Executives’ Group on Disability Issues and DPOs meeting in mid-February 2017. The draft Outcomes Framework, the Disability Data and Evidence Plan (as well as the draft updated Disability Action Plan 2014-2018) would then be considered by the Cabinet Social Policy Committee at the end of February before going out for public consultation in March 2017. It is expected that the Cabinet Social Policy Committee will consider the final Outcomes Framework, Disability Data and Evidence Plan and the updated Disability Action Plan in April/May 2017.

It was noted that further work on the stocktake from academic institutions was required to ensure it was fit for purpose.

ODI to update the overview table in the memo, *Proposed approach to develop Outcomes Framework and Disability Data and Evidence Plan,* with firmer dates and to include roles and responsibilities of the New Zealand Disability Strategy Reference Group and the DDEWG. Both groups to attend meeting in October/November 2016.

# Gaps Analysis

The memo, *Proposed approach to develop Outcomes Framework and Disability Data and Evidence Plan,* and the paper, *Gap analysis: A process review,* informed this discussion.

The process for the gap analysis was discussed. An initial gap analysis will be carried out by the DDEWG in a workshop in late October / early November when enduring questions will be mapped to either survey, research, or admin data. ODI will set up and chair, SNZ and ODI will plan content.

A more in-depth analysis will take place in December and January which will involve consultation with stakeholders and experts on the data sources.

# Action points and next steps

1. Update the Enduring Questions document based on feedback
* ODI will map UNCRDP articles to enduring questions
* ODI will elaborate further on ICF in Introduction.
* SNZ will further elaborate on cross-cutting topics
* SNZ will make references to CRPD consistent and remove reference to ‘disability community’ in the document.
1. SNZ will lead further discussions and refine proposed points to be incorporated in Enduring Questions document:
* Cost of disability
* Inclusion of bioethical issues
* Further elaboration of rehabilitation and habilitation
* Questions/details on expression of sexuality and on families/relationships
1. Brigit will find and distribute the AUT piece on cost of disability.
2. DDEWG and New Zealand Disability Strategy Reference groups need to get up to speed with what the other is doing.
3. ODI will send out proposed date by close of Friday the 7th for the initial gaps analysis workshop.
4. SNZ will send out details on the gaps analysis workshop process, information required by attendees, and proposed approach (including values).