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**SUMMARY**

**Disability Data and Evidence Working Group**

**Date:** 5 October 2017 **Time:** 11.00am – 4.00pm

**Venue:** 2.3 Tui, Aurora Centre, 56 The Terrace, Wellington

**Attendees:** *Government agencies*

* Office for Disability Issues: Brian Coffey (Chair), Jacinda Keith and Dr Catherine Brennan
* Statistics New Zealand: Diane Ramsay, Calli Seedall, Phillipa O’Brien and Elodie Green
* Ministry of Social Development: Anne Hawker
* Ministry of Education: Shiona Beverstock
* Ministry of Health: Lauren Jones, Chloe Lynch and Sue Jansen

*Independent agencies*

* Human Rights Commission: Paula Tesoriero and Douglas Hancock

*New Zealand Disability Support Network*

* Sam Murray (CCS Disability Action)

*Disabled People’s Organisations*

* Dr Jonathan Godfrey

**Apologies:** Ministry of Justice: Patrick Power

Ministry of Education: Clare Shepherd

ACC: Julie Shipton-Pasgaard

Ministry of Transport: Kevin Eames

University of Otago and Donald Beasley Institute: Dr Brigit Mirfin-Veitch

1. **Introduction**

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

1. **Current situation: New Zealand Disability Strategy and disability data**

Paper 1, *New Zealand Disability Strategy Outcomes Framework: Development of proposed indicators for the eight outcome domains,* and Paper 2, *A3: Initial stocktake of disability data sources,* informed the discussion. The following were the key discussion points:

* Disability data needs will now be framed by the development of indicators for the eight outcome domains in the New Zealand Disability Strategy 2016-2026 (the Strategy). However, it was agreed that this will not totally define the work of the Disability Data and Evidence Working Group (DDEWG) going forward.
* The work undertaken by the DDEWG in 2016 on the development of Enduring Questions (designed to identify long-term data needs relating to disabled people in New Zealand), will remain relevant in identifying and prioritising initiatives to address gaps or deficiencies in meeting disability data needs.
* The draft indicators presented in Paper 1 do not encompass everything valuable in disabled people’s lives. Rather, these indicators represent a sub-set of what might be chosen as important by disabled people.
* It was emphasised that the ultimate goal of collecting data on disabled people was to use the data to bring about equity between disabled and non-disabled people on all outcomes.
* It is necessary to establish consistency across the indicators (for example, wording, refining concepts).
* It was emphasised that decisions about indicators to include in the Strategy Outcomes Framework cannot be made on the basis of available data alone. Resourcing for the collection of data required to measure certain indicators may have to be broached.
* It was noted that a data dictionary will be developed against which the indicators will be measured. The dictionary will include:
  + a narrative of intent
  + who is responsible for collecting data
  + the data source
  + frequency of reporting.
* A mixed methodology will be utilised to assess progress in the implementation of the Strategy. In other words, both quantitative and qualitative data will be utilised. Possible sources of qualitative data could include reports prepared by: the Human Rights Commission, the Office of the Ombudsman and disabled people-led monitoring.
* There was agreement that coordination across government was important in the collection of disability data. Such coordination is dependent upon building up a shared understanding of “disability” across government agencies (for example, in administrative datasets and surveys). In this regard, it was suggested that the use of the Washington Group Short Set of questions on disability (WG-SS) in surveys carried out by government agencies could ensure survey comparability. The WG-SS has been included in the piloting of the Crime and Victims Survey and will also be included in the New Zealand Health Survey 2018-2019.
* The role of the Integrated Data Infrastructure (IDI), managed by Stats NZ, in providing comparable disability data was discussed. It was observed that the IDI which is comprised of a series of integrated datasets from different government could be used more. For example, Census 2018 (which will include the WG-SS measuring module) will be put into the IDI.

1. **Role of Disability Data and Evidence Working Group**

Regarding the role of the DDEWG going forward, the following were the key discussion points:

* The DDEWG could, possibly, coordinate the collection of disability data across government agencies.
* The DDEWG could play a valuable educational role in the promotion of:
  + International Classification of Functioning, Disability and Health (the conceptual framework underpinning the disability measuring instruments developed by the Washington Group on Disability Statistics), and
  + Washington Group’s disability measuring instruments (for example, WG-SS).
* The DDEWG may have a role to play in building up a data map relating to data needs for the Strategy, the Disability Action Plan and the Sustainable Development Goals.

1. **Paula Tesoriero – New Disability Rights Commissioner’s emerging priorities**

Paula Tesoriero is the first dedicated Disability Rights Commissioner appointed under the recently amended Human Rights Act 1993. Paula presented an overview of her emerging priorities.

Paula commented on the fact that disabled people are considerably behind other population groups. She outlined her five top priorities for action:

* promoting education outcomes of disabled people
* increasing employment of disabled people, given that 42 percent of young disabled people, for example, are not in employment, education or training
* shifting hearts and minds of New Zealanders, given that attitudes toward disabled people extend from indifference to discrimination
* building up data to provide a better picture of disability in New Zealand, given that disabled people who are not counted do not matter
* supporting a stronger disability sector.

Paula listed a second list of priorities, including but not limited to the following, that she will take every opportunity to speak out on:

* housing
* accessibility
* violence and abuse
* mental health
* seclusion and restraint
* bioethical issues
* state abuse
* neuro-disability.

In respect of her working style, Paula commented that her key objective is to work in collaboration and partnership with the disability sector, decision-makers, business, Non-Government Organisations and community groups.

1. **Next steps**

* The Office for Disability Issues, Stats NZ and the Human Rights Commission will meet to develop a draft work programme for the DDEWG going forward.
* A Ministry of Health (Client Insights and Analytics) official will raise the possibility of using the WG-SS in government agencies’ surveys at the next Questionnaire Design forum.