



**SUMMARY**

**Disability Data and Evidence Working Group**

**Date:** 17 September 2020 **Time:** 1.00pm – 4.00pm

**Venue:** Room 1.2 Kākā, Aurora Centre, 55 The Terrace and Virtual

**Attendees:** *Government agencies*

* Office for Disability Issues: Brian Coffey (Chair), Shama Kukkady and Dr Catherine Brennan
* Stats NZ: Dr Claire Bretherton, Chris Harty-Eugster and Chelsea Dickson
* Ministry of Social Development: Anne Hawker
* Ministry of Justice: Tadhg Daly
* Ministry of Health: Shari Mason
* Ministry of Transport: Bonita Gestro
* Oranga Tamariki: Dr James McIlraith, Dr Ann Walker and Elodie Green
* Social Wellbeing Agency: Alistair Mason

*Independent agencies*

* Human Rights Commission: Frances Anderson and Kerri Kruse

*Disabled People’s Organisations Coalition*

* Dr Jonathan Godfrey and Dr Tristram Ingham

*New Zealand Disability Support Network*

* Sam Murray

*Universities*

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

**Apologies:**

 Ministry of Health: Christopher Carroll and Bridget Murphy

 Ministry of Education: Matt Frost

**1 Introduction**

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

**2 Engagement and capability building**

Paper 1, *Key messages and processes*, informed the discussion. It was noted in the report back from the Engagement and Capability Building Workstream that government agencies should focus on the progressive realisation of the following:

* commit to the collection of disability data (surveys, administrative data etc.) and evidence, including in an emergency such as a pandemic
* share the findings and outcomes of disability data and evidence activities widely and in a range of forms, ensuring accessible formats are available
* report at six-month intervals on disability data and evidence collection and use
* include the collection of most quantitative and qualitative disability data and evidence, when gathering information on policies and services
* ensure every data collection exercise is accessible and complies with WCAG 2.1 AA
* use as a minimum the Washington Group Questions on Disability (Short or Extended)
* ensure that there is a proven need not to include disability data indicators, if demographic categorisation is undertaken
* require external agencies contracted to collect data and evidence to include and adhere to the above list of factors in the procurement documentation.

It was acknowledged that agencies are at different stages in the collection of disability data and evidence. What is important going forward is that agencies are committed to the process.

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| **Decision**DDEWG agreed to the paper, *Key messages and processes,* on the understanding that agencies are at different starting points in the process of collecting disability data and evidence and, hence, this process will be progressively realised.  |

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| **Actions**Statistics NZ and the Office for Disability Issues will decide where the key messages relating to disability data and disability data resources are to be housed.Anne Hawker (Principal Disability Advisor, Ministry of Social Development) will write a report informing Papa Pounamu about the key messages relating to disability data and next steps in building up disability data resources in government agencies.  |

*How to ask service clients about their disability*

The questions that government agencies could use to respectfully ask service clients about their disability for the purposes of collecting administrative data were raised. It was noted that consideration needs to be given to different groups, including children, people in a vulnerable situation such as those experiencing mental distress and the like.

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| **Action**The Disabled People’s Organisations Coalition (DPO Coalition) will use their networks to seek advice on how government agencies should ask service clients about their disability. Once the feedback has been collated by the Office for Disability Issues, the DPO Coalition will share their agreed position with DDEWG at the December 2020 meeting.  |

**3 Resources**

Paper 2a, *How to collect disability data,* and Paper 2b, *Suggested areas for resources,* informed the discussion. It was observed that patchy knowledge about the practicalities of collecting and publishing quality disability data in the state sector needs to be addressed. The following areas for resources were proposed:

* general principles and advice for collecting disability data in administrative data sets
* explaining the nature of the enduring questions developed by DDEWG in 2016
* how to choose between and use the three Washington Group Adult Questions Sets on Disability (Short Set, Enhanced and Extended)
* how to choose between and use the Washington Group’s Child Functioning Question Set and Stats NZ’s shortened version
* how to select the correct disability data tools
* when and how to disaggregate or standardise disability data by demographic categories: ethnicity, gender, age and sexuality
* how to ensure inclusive and accessible methodology so that everyone has the opportunity to participate in surveys (including online surveys) and access the results
* providing guidance on the New Zealand Disability Strategy 2016-2026 indicators.

It was noted that Stats NZ’s Design Questionnaire Team are putting together guidance on gender, age and disability status.

It was pointed out that the Washington Group Question Sets on Disability do not consider the socio-cultural context of disability.

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| **Decision**DDEWG agreed to the proposed body of resources. |

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| **Action**Agencies will consider whether they can provide some funding to develop the resources proposed by DDEWG’s Resources Workstream and come back to the Office for Disability Issues’ Director. |

**4 Data and the Integrated Data Infrastructure**

Paper 3, *Data and IDI,* Paper 4a, *Enduring Questions on disability,* Paper 4b, *Questions about the “enduring questions”,* and Paper 5, *Draft NZ Disability Strategy Outcomes Framework* informed the discussion.

*Data and IDI*

It was stated that the key aims of the Data and IDI Workstream are to enable, mediate and advocate for:

* improved quality and utility/usability of disability data
* improved prioritisation of disability data (ie, for NZ Disability Strategy Outcomes Framework)
* increased incorporation of disability datasets within the IDI
* more frequent and timely updates of disability data onto IDI
* more transparency and understanding of the complexities and limitations of disability data across the system
* use of best practice for identifying disabled people within the IDI.

It was noted that the Ministry of Health is undertaking research (which is in the planning stage) on the health of disabled people. The purpose of the research is to gain insights into the health inequities of the disabled population. The research will focus, in particular, on the characteristics, health outcomes and service use of the population that receives disability-related services (including Ministry of Health disability support services, disability-related benefits, education support or other government services).

It was stated that the Social Wellbeing Agency is working to make the IDI more open to community organisations.

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| **Decision**DDEWG agreed to the aims of the Data and IDI Workstream and the next step to meet with agencies with expertise on IDI and existing metadata such as the Strategic Advisory Group for Integrated Data. |

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| **Action**A one-page draft summary of the Ministry of Health’s disability research projects will be provided to DDEWG. |

*Draft NZ Disability Strategy Outcomes Framework*

It was observed that more measures are now available for indicators. The focus is on indicators on which data is regularly collected.

It was pointed out that the accessibility of the *Draft NZ Disability Strategy Outcomes Framework* document is an issue.

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| **Actions**The most up-to-date *Draft NZ Disability Strategy Outcomes Framework* document will be distributed.An *Outcomes Framework* dashboard will be prepared. |

*Enduring Questions*

It was pointed out that the *Enduring Questions* document (October 2016) needs to be tidied up, including:

* reference the *Convention on the Rights of Persons with Disabilities* and the *NZ Disability Strategy* more frequently
* include an Identity and Culture topic
* identify more questions
* consult with the DPO Coalition for feedback on the current document.

It was agreed that revisions of the current *Enduring Questions* document would sit mainly with Stats NZ and the Office for Disability Issues.

As to the relationship between the *Enduring Questions* document and the *NZ Disability Strategy Outcomes Framework* document*,* it was noted that the *Strategy* has its own unique set of indicators based on the *Strategy’s* outcomes and to report on the impact of the *Strategy* over time. Some of the indicators and measures may be the same or similar to the *Enduring Questions.*

**5 Access to government data**

It was stated that the scope of the Access to Government Data Workstream is limited to quantifiable data. The Workstream’s aims are:

* how to make government data accessible for disabled people (ie, attaining disability data access for everyone and ensuring data is available in accessible formats)
* how to improve access to and accessibility of data across three layers:
	+ published raw data (eg, table builders, excel spreadsheets)
	+ published analysed reports (eg, Stats NZ)
	+ available on request/data lab (eg, customisable, Official Information Act).

It was observed that examples of good practice include:

* Washington Group Sets of Disability Questions in many surveys (eg, Stats NZ’s Household Economic Survey)
* Education Counts (includes three layers, as above)
* United Nations Principles on data use.

This Workstream has a focus on both immediate and long-term outcomes:

* Immediate outcomes are:
	+ knowing what data is available and where to get it from
	+ tying the availability of current data to the *NZ Disability Strategy Outcomes Framework.*
* Long-term outcomes are:
	+ increasing access to disability data for the public (eg, NGOs)
	+ working on improving government data publication (eg, three layers of publication as above) and ensuring the data is available in accessible formats
	+ directing people to the means of accessing disability information outside of conventional channels (eg, knowledge of unpublished data that could be accessible and how to request such data)
	+ promoting accessibility best practice.

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| **Actions**Seek wider feedback from DDEWG on the *NZ Disability Strategy Outcomes Framework*Clarify with the Ministry of Social Development Accessibility Team potential areas of overlap and how the Access to Government Data Workstream can support (but not duplicate) their work. |

*Stats NZ report*

The following information was noted:

* A Wellbeing Supplement was added to the Household Labour Force Survey (HLFS). The first release was available in mid-August 2020.
* The Washington Group Short Set of Questions on Disability will also be included in the December 2020 quarter of HLFS.
* Given the COVID-19 pandemic, the General Social Survey (GSS) has been delayed until 2021.
* The Household Economic Survey was back in the field on 16 September 2020. This includes the slightly longer Washington Group Extended Set3 questions set for adults, and an adapted set of questions based on the child functioning module for children.
* The report, *Measuring equality for disabled New Zealanders 2018: A comparison of outcomes for disabled and non-disabled people in Aotearoa*, will be released in October 2020. Data from the 2018 Census, 2018 GSS and 2018 HLFS is included in the report.
* Consultation regarding content for the 2023 Disability Survey will begin in 2021, and work is beginning on how to identify disabled people in the Survey.
* There will be a major focus on accessibility in preparation for the 2023 Census. A fixed-term role with a focus on accessibility has been created. The key responsibilities of the role include:
	+ identifying barriers to participating in the forthcoming Census (eg, how Census staff will operate in the field)
	+ forming strong relationships with government agencies and the disability sector
	+ understanding disability support systems
	+ focusing on the appropriate use of language and translation into accessible formats.
* An operational test of field processes for the 2023 Census will take place in March 2021, concentrating on 20,000 households.
* Te Kupenga (the Māori Social Report) will be released on 9 November 2020.

**6 Progressing the disability research agenda**

Paper 6, *Progressing the disability research agenda,* informed the discussion.

Although Point 8 in the paper addressed the importance of disability research being part of research generally (or included as part of a range of subjects to consider), it was agreed that it could also be emphasised in the subsequent points in the paper.

Other comments relating to the paper included:

* Identity and violence and abuse should be priority research topics.
* The work programme of the Disability Research Workstream should line up with that of the Resources Workstream.
* The Office for Disability Issues website should:
	+ include (or have links to) current research and reports on disability
	+ provide a process for the general public (eg, academics, university students) to publish research documents.

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| **Decision**DDEWG agreed to the paper, *Progressing the disability research agenda.* |

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| **Action**A letter (about disability research issues) will be drafted to various research funders (eg, Health Research Council) and signed out by Stats NZ and the Office for Disability Issues. However, the *Enduring Questions* document and the Office for Disability Issues website will need to be updated before sending out the letter.  |

**7 Reporting**

It was stated that when agencies are reporting on the progressive implementation of the Accessibility Charter, they are now also being asked to report on how they are progressing the disability data and evidence agenda.

**Note**

It was pointed out that the publication of DDEWG agenda and papers should be resumed.