# Disability, data & evidence working group (DDEWG)

## PURPOSE AND MEMBERSHIP

Purpose of this inter-agency group is to define, clarify and prioritise information needs in order to improve the lives of disabled people and inform better quality monitoring of and reporting on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the New Zealand Disability Strategy and the Disability Action Plan 2019-2023 in future. The group also works to support decision-making on resource allocation.

This group recognises the importance of supporting the Crown in its relationships with Māori under Te Tiriti O Waitangi (the Treaty of Waitangi) by engaging with tāngata whaikaha Māori and understanding the Māori perspective. Collecting data on tangata whaikaha Māori by government agencies will underpin all the workstreams.

Members include Stats NZ, Office for Disability Issues, Ministry of Social Development, Ministry of Health, Ministry of Education, Ministry of Justice, ACC, Ministry of Transport, Oranga Tamariki, Social Wellbeing Agency, Health Quality and Safety Commission, New Zealand Disability Support Network, Disabled People’s Organisations, Universities.

## STRATEGY AND OBJECTIVE

### The strategic focus of DDEWG is to work with representatives from government agencies, Disabled People’s Organisations, and the disability sector to create a structure that supports the collection and dissemination of quality disability data.

### The principal objective underpinning the work of DDEWG’s workstreams is to progressively contribute to closing the significant equity gap between disabled people and non-disabled people through building up a substantial body of evidence to inform policy development and service planning.

### A Māori world view that honours our commitment as a Te Tiriti o Waitangi partner by embedding the collection of tāngata whaikaha data in all workstreams.

## WORKSTREAMS

### ACCESS TO DISABILITY DATA

#### Aims:

* Identify government disability data needs by working through NZ Disability Strategy Outcomes Framework.
* Enable, mediate and advocate for:
  + Improved quality and utility/usability of disability data
  + Improved prioritisation of disability data (i.e. for 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 (including limitations) of disability data across the system.
* Medium/longer term outcome(s) include:
  + Make more disability data easily accessible and available to the public
  + Work on improving data publication, including ensuring government data is available in alternate formats
  + Providing guidance on how to engage with disability information outside of the Outcomes Framework (e.g. unpublished data that could be requested, and how to access this data)
  + Promote accessibility best practice
  + Promote best practice for identifying disabled people within IDI.

#### Projects:

* IDI project (led by Social Wellbeing Agency)
  + The purpose of this workstream would be to share information on how IDI is used, document concerns/limitations, and promote the use of disability data in the IDI. Social Wellbeing Agency could lead development of guidelines as an example.
* Disability Strategy Outcomes Framework Project (Led by ODI Senior Analyst (TBC))
  + Included here is a Māori led focus group on monitoring outcomes against the Disability Strategy. This group will be examining key outcomes that demonstrate progress for tāngata whaikaha.

### ENGAGEMENT, COMMUNICATIONS AND RESOURCES

#### Aims:

* To increase government agencies knowledge of and access to information on disability.
* Provide guidance and advice on best practice for the collection of disability data.
* To promote and support each agency to commit to the collection and sharing of disability data and evidence through specific key messages being disseminated across agencies. The key messages include the need for disability data to be available in accessible formats and ensuring disability status is included when using demographic categorisation.
* To highlight existing resources and develop new disability data resources on:
  + Administrative data
  + Enduring Questions
  + Tāngata Whaikaha (Māori disabled) question sets
  + Washington Group Adult question sets
  + Washington Group Children and young people question sets
  + Choosing the right disability data tools
  + Demographic analysis in disability data
  + Accessible/inclusive survey methodology, collection, and the publishing of results (including for online surveys).
* In future, also contribute to data capability and capacity of agencies.
* To foster the accessibility of disability data sets and disability research findings through dissemination to government agencies, disabled people, the disability sector and the disability community, including in alternate formats.

#### Projects:

* Working on how disability is captured through administrative datasets (led by Dr Adam Dalgleish MoH)
  + NHI and Alert System Project (led by Dr Adam Dalgleish/MOH)
    - Working to include disability support needs information onto the National Health Index
* Disability Data Training Project
  + Develop a training package for government agencies that:
    - encourages the use of existing resources where available (e.g. Washington Group questions)
    - increases awareness and knowledge of the importance of disability data
    - encourages them to embed disability data collection within their work programmes.
* Disability Data and Evidence Consolidation Project Web-based data and evidence consolidation (Synergia)
  + The project is a response to the fact that there is no single place to access the large and diverse body of disability data that is now available. The intent of the Consolidation project is to create linked, practical, and easy to access disability data and evidence.
  + This project will also work to identify and understand the extent of the equity gaps between disabled people and their non-disabled peers.
* To increase DDEWG membership and cross government representation (led by MSD/ODI)

### REPORTING

#### Aims:

* To produce a 6-monthly report under Disability Action Plan 2019-2023 to the Minister for Disability Issues.
* To report back on agencies progress on disability data to Papa Pounamu.

#### Projects:

* 6-monthly report to be sent to ODI, and then published on ODI’s website for public availability.

### RESEARCH (CURRENTLY INACTIVE)

#### Aims

* To foster the development of socially relevant, quality disability research across government, the disability sector, and the tertiary education sector.
* To encourage the participation of disabled people and their civil society organisations from the beginning of the research process, particularly in shaping the research agenda and identifying pressing research needs.
* To promote an extensive range of research about:
  + the kinds of barriers for full and equitable participation of disabled people in society
  + the kinds of strategies and solutions required for the removal of these barriers.
* To encourage different types of research, including:
  + peer-reviewed research published in journals and books
  + government agencies’ research tied to funding demands (e.g., reports)
  + quantitative, qualitative and longitudinal research
  + monitoring and evaluation research

#### Projects:

* Potential future project about guidelines/template documents for researchers applying for funding to undertake disability research.