



Scan for
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Disability Data and Evidence Working Group

Date: 23 June 2023

Time: 9.00am-11.50pm

Venue: Online via Teams

Attendees

Government agencies:

- Office for Disability Issues: Brian Coffey (Co-Chair), Catherine Brennan, Michelle Gezentsvey, Alan Ryan
- Stats NZ: Robbie Blakelock (Co-Chair), Katy Auberson, Alexandra Ferguson
- Ministry of Health: Bridget Murphy
- Health Quality and Safety Commission: Joanna Swanson
- Ministry of Education: Annie Chenery
- Ministry of Social Development: Sonja Eriksen
- NZ Police: Christine Aitchison
- Waka Kotahi: Samantha Eastman
- Whaikaha: Dr Adam Dalglish, Alex Dixon
- Corrections: Elyse Taylor

Independent agencies:

- Public Service Commission: Paul Vance
- New Zealand Mortality Review Group (NZMRG) - University of Otago: Rachael Lawrence Lodge, Nick Bowden
- Te Tāhū Hauora – Health Quality & Safety Commission (HQSC): Rosie Pears

Disabled People's Organisations Coalition:

- Jonathan Godfrey

Apologies

- ACC: Ben Lucas, Tina Cronshaw
- Ministry of Health: Shari Mason, Kelly Palmer, Laura Cleary
- Health Quality and Safety Commission: Richard Hamblin
- Ministry of Justice: Tadhg Daly
- Oranga Tamariki: Elodie Green, Dr James McIlraith
- Human Rights Commission: Frances Anderson, Kerri Kruse
- NZDSN: Peter Reynolds
- Office of the Ombudsman: Andrew McCaw, Olivia Soesbergen
- Stat NZ: Sophie Flynn, Phillipa O'Brien
- Social Wellbeing Agency: Andrew Webber
- Donald Beasley Institute: Brigit Mirfin-Veitch
- Social Wellbeing Agency: Craig Wright
- Education Review Office: Juvena Jalal
- Ministry of Transport: Olivia Kitson
- DPO Coalition: Tristram Ingham
- Waitemata DHB: Wesley Pigg
- Supported Life: Monica Munro
- Tika Tangata: Frances Anderson

Meeting opened with karakia at 9am.

1. Administration

- Minutes from previous meeting (10 March 2023) approved by group for online publication.

2. Household Labour Force Survey (HHLFS) – Proposed change to the publication of disability labour market statistics.

Stats NZ - Alex Ferguson

HHLFS Labour Market data on disabled people in employment is currently released two weeks after the core Labour Market employment data release.

This allows for Labour Market disability data to be released together with the HHLFS Income data which includes disability income data.

Stats NZ has proposed that Labour Market data on disabled people in employment be released in the core Labour Market data release from 2024.

Disadvantage of delayed/separate disability data release

- creates the perception that disability labour market data is deliberately separated from core data
- concern that delayed release results in less public/media commentary and economic analysis of disability data.

Advantage of delayed release

- Allows all disability data to be aggregated in one release (more data points)
- Allows for single commentary on full disability data set
- Allows for better quality analysis of disability data prior to release including intersectional analysis.

A decision on same day release has yet to be made. If same day release is approved customers will be advised in advance.

Infoshare as the HLFS data tool

Stats NZ intends to replace Infoshare and NZdotStat with a single accessible data tool. The new tool and go live date have not been decided.

If Infoshare is still live in 2024 Stats NZ may be limited/selective re the number of new data series that can be released on the legacy system.

Discussion

- It was noted that a separate disability data release allowed for focused and dedicated discussion on that data. Stats NZ responded that media have better access to Stats Analysts on same day release, whereas a separate release is not resourced to the same extent, and/or does not receive the same media attention.
- There is concern that a same day release will overwhelm already under resourced disability organisations, particularly as same day release will be in the excel format, not on an accessible platform.
- Wider issue is to ensure that the disability sector receives best quality data, regardless of release time, in a format that is most accessible and usable to the sector (action point below).

3. HQSC - Quantitative research on mortality risk among children and young people with neurodevelopmental conditions

New Zealand Mortality Review Group (NZMRG) - University of Otago
 Rachael Lawrence Lodge
 Nick Bowden

Te Tāhū Hauora – Health Quality & Safety Commission (HQSC)
 Rosie Pears

NZMRG will soon assess the mortality risk among children and young people with neurodevelopmental conditions (NDCs).

This planned research study is part of the current work programme of HQSC's Child and Youth Mortality Review Committee (CYMRC). It involves matching data in the CYMRC database (a secure database hosted and managed by NZMRG that combines mortality data from a range of sources) with other administrative health and disability services datasets.

The study plans to use population level data to examine the mortality risk for children and young people diagnosed with NDCs compared to those without NDCs. It is intended that this research, which is due to be completed by 30 June 2024, will help to determine factors that will prevent and reduce premature deaths among children and young people with NDCs and improve health, disability, and social services' systems and practices.

Data drawn from:

- the Maternity Collection (to determine the birth cohort)
- the National Minimum Dataset (NMDS), the Programme for the Integration of Mental Health Data (PRIMHD), Socrates, and the Pharmaceutical Collection (to identify individuals with NDCs)
- the CYMRC database (to determine mortality).

NZMRG and HQSC acknowledge that the data work and the analytical methods used for this research are underpinned by the medical model of disability. This is due to the nature of the data the researchers are able to access. The social model of disability will inform the framing of the project and the discussion on interpretation and implications of the findings.

Discussion

- Questions to the presenters focused on potential follow-up research and exploration areas, including repeating the study and looking in more depth at educational experiences, psychosocial elements, and critical life events.
- DDEWG suggested linking this research to existing longitudinal studies, such as the Dunedin Study. Presenters stated that a birth cohort study is not possible at this stage as useable disability data is only available from 2010 onwards.
- It was noted that CYMRC data has limited use value due to clinical data being subject to delays.

4. DDEWG updated draft Terms of Reference (ToR) – Robbie Blakelock (Stats NZ) and Brian Coffey (ODI)

- Updated draft ToR presented to DDEWG for comment/approval.
- Agreed that DDEWG will move from being a 'working' group to an 'advisory' group with the aim of advising agencies on collection, aggregation/disaggregation, and dissemination of data.
- DDEWG is now Disability Data and Evidence Advisory Group (DDEAG)

Discussion

- While an 'oversight' role for DDEAG was seen as desirable, there is no mandate or resourcing for this role.
- Concern was expressed that an 'advisory' role does not compel agencies to seek advice from DDEAG (see action point below). In response, the ToR was updated to confirm that DDWAG would/should be informed of agency and organisation data and evidence work programmes as follows:

To be informed on disability data and evidence work programmes being progressed across government agencies and sector organisations (p2).

- Brian noted DDEAG advice would focus on quality processes and standard setting – which was not incorporated in the ToR. Discussion on whether 'standards' are tools to achieve purpose of measurables re strategic intent – this was confirmed.
- The ToR have also been updated to reflect this as follows:

Purpose

The Advisory Group is convened to assist government agencies to:

- define, clarify, and prioritize data, evidence¹ and information needs for and about disabled people to improve their lives
- encourage and inform:
 - the gathering and reporting of survey data collections,
 - within agency/across agency collection and use of disability administration data
 - disability evidence and research
 - best and future practice in data and evidence collection including processes and standard setting (tools to achieve strategic intent).
- use data and evidence to enable effective decision-making, policy development and service provision for disabled people.

The Advisory Group will also:

- be informed on disability data and evidence work programmes progressing across government agencies and sector organisations

Appendices

- Agreed that appendices were useful, appropriate, and could be updated/amended as required.

¹ This includes qualitative and mixed-methods research.

Community of Practice (CoP)

- Clarity was sought on role and function of proposed CoP and the relationship between DDEAG and the CoP
- It was proposed that CoP would inform DDEAG of its work programme in the first half of future meetings, with comment and support offered by wider group in second half
- CoP might hold monthly meetings, be more accessible, take up a peer advisory role at practitioner level
- Where DDEAG has been established by Ministers to improve Government/agency capability, CoP may have mandated role to improve sector capability.

5. Quarter 3 Meeting

- Set for 13 September 2023 10am – 12.30pm

6. General Business

- Update on Public Service Census raised as a possible item for Q3 meeting.

7. Action Points

Household Labour Force Survey (HLFS) – Proposed change to the publication of disability labour market statistics

- Whaikaha to work with Stats NZ to communicate any changes to the sector.
- Whaikaha to ensure that awareness of disability data is maintained through, for example, Ministerial press release on release day.

HQSC - Quantitative research on mortality risk among children and young people with neurodevelopmental conditions

- NZMRG: Present to DDEWG on analysis phase in 2024 (TBC)
- Stats NZ and Whaikaha: Assist/provide relevant data if available on request.

DDEWG updated draft Terms of Reference (ToR)

- Stats NZ/Whaikaha to circulate updated ToR
- DDEAG to clarify role of CoP.

***** Karakia to close meeting 11.50am *****