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| Report |  |
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| Date: | 8 September 2020 |  |  |
| To: | **Disability Data and Evidence Working Group** |

## Workstream 5 – Progressing the disability research agenda

### Purpose of the report

1. The purpose of this report is to get agreement to both the attached report and the next steps to progress the disability research agenda.

### Context

1. Consistent with Article 31 in the United Nations Convention on the Rights of Persons with Disabilities, governments are obliged “to collect information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”.
2. In line with the Disability Action Plan 2019-2023, government agencies are also expected to disaggregate data by disability in the development and implementation of their work programmes.
3. Action 4 in the Health Research Strategy 2017-2027 includes investing in, supporting, attracting and retaining “health researchers with an interest in disability”.

### What is the purpose of the Disability Research Workstream?

1. The purpose of the Disability Research Workstream is to support high quality disability research. The initial focus of the Workstream is on fostering relevant, high quality disability research across government, within the disability sector and elsewhere. This purpose complements the work of the Resources Workstream which is focused on raising awareness of and engagement in the importance of disability research through, for example, the development of guidance and some key resources.

### Who undertakes research?

1. Key organisations undertaking research include:
* universities
* government agencies
* local government
* NGOs, including service providers in the disability support sector
* private research companies
* market research companies, whether procured by a government agency, a corporate, or an NGO.
1. Types of research include:
* peer-reviewed research published in journals and books
* government agencies’ research tied to operational demands
* quantitative research
* qualitative research
* longitudinal research
* monitoring research
* evaluation.

### How to raise awareness of the importance of disability research?

1. It is important to continually affirm the importance of disability research and to provide guidance on how to raise awareness (and ensure the inclusion) of disability research, both independently (ie, as a subject of discrete research) and as part of broader projects (ie, as part of the range of subjects that any project should consider).

### How to gain funding to undertake more disability research?

1. A key objective in the Disability Data and Evidence Working Group’s (DDEWG) Terms of Reference is: “Making recommendations on how the capacity to collect and analyse relevant data and evidence on disabled people can be strengthened, given resource constraints.”
2. Consistent with DDEWG’s objective and given the paucity of disability research, DDEWG is positioned to take a more proactive role in advocating for targeted funding for disability research by initiating dialogue with major research funders such as the Health Research Council of New Zealand and the Royal Society of New Zealand.

### How to ensure demographics include disability in government surveys?

1. Consistent with the Disability Action Plan 2019-2023, there is an expectation that, at a minimum, all government agencies will promote the use of the Washington Group sets of questions on disability in government surveys, and ensure that when demographic data is collected on who is accessing services there is the opportunity for people to self-identify that they are disabled.

### How to ensure community-based dissemination of disability research?

1. Bearing in mind that disabled people usually do not set the research agenda, there is a need to both disseminate and make disability research accessible to the disability community. Options to consider include:
* Ensuring that disabled people are central to setting the disability research agenda.
* Encouraging Stats NZ to release more disability data sets from various surveys (eg, General Social Survey, Household Economic Survey).
* Utilising the Office for Disability Issues as a mechanism for providing regular updates on its website on:
* recently released disability research carried out by agencies (eg, Oranga Tamariki, Ministry of Social Development)
* recently released disability research available via open-access.
* Exploring the utility of reviving the *New Zealand Journal of Disability Studies.*
* Exploring how to achieve greater democratisation of disability research via the work programme of DDEWG’s Engagement and Capability Building Workstream.

### Next steps

1. The meeting of DDEWG (17 September 2020) agrees to:
* Chairs of DDEWG (ie, Office for Disability Issues and Stats NZ) writing to major research funders such as the Health Research Council of New Zealand and the Royal Society of New Zealand to initiate dialogue about various research issues, including:
* need for disability research in New Zealand
* what constitutes disability research?
* need to engage disabled people in setting the research agenda
* is there any ringfenced funding for disability research?
* is there representation of researchers who understand the nature of disability research on decision-making bodies?
* What should be prioritised to ensure the community-based dissemination of disability research?
* Who is going to be involved in the community-based dissemination of disability research initiatives?