

29 November 2022

Australia's Disability Strategy Governance and Engagement Section
GPO Box 9820
Department of Social Services
CANBERRA ACT 2601

Via email: disabilityreform@dss.gov.au

Feedback in response to the 'Developing a guide on how to involve people with disability in evaluation – Full Consultation Paper'

Thank you for the opportunity to comment on this consultation draft in relation to the development of a guide for the involvement of people with disability in evaluation as part of Australia's Disability Strategy 2021-31 (the Evaluation Guide).

As the Public Advocate for Queensland, I undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making ability.¹

People with impaired decision-making ability are a broad and diverse group, due to the range of conditions that may affect a person's decision-making ability. These include intellectual disability, acquired brain injury, mental illness, neurological disorders (such as dementia) or alcohol and drug misuse.

While not all people with these conditions will experience impaired decision-making ability, many of them will at some point in their lives. For some, impaired decision-making ability may be episodic or temporary, requiring intensive supports at specific times, while others may require lifelong support with decision-making and communicating their wishes and preferences.

The inclusion of people with disability in evaluation, including people with impaired decision-making ability, is critical from a human rights perspective, and is also important to ensuring that systems, policies and programs are effective and appropriate to meet their needs and preferences.

In relation to the draft Evaluation Guide, I would like to put forward the following comments for consideration.

Principles for best practices for involving people with disability in evaluation

The best practice principles included in the draft Evaluation Guide identify a number of considerations for evaluation processes and outcomes that recognise people with disability as experiential experts and promote respectful inclusion of people with disability in evaluations.

However, to support greater clarity and implementation of the best practice principles, further information could be provided about some of the terms used and how these can be applied within the context of evaluations. For example:

¹ *Guardianship and Administration Act 2000 (Qld) s 209.*

- **Principle B. Promotes wellbeing.** The guide could clarify how the evaluation should contribute to the wellbeing of people with disability, for example if it is intended that this be achieved through the process of involvement, or via the recommendations and outcomes of the evaluation (or both).
- **Principle C. Co-design.** The terms co-design, co-production, collaboration, and joint decision-making should be defined, and a further explanation provided as to how these concepts can be applied in an evaluation context.
- **Principle F. Accessible.** People with disability, including people with impaired decision-making ability, have a diverse range of skills and can face a range of potential barriers to participation in evaluations. Accessibility should therefore be defined to include not only physical accessibility, but also consider cognitive accessibility and how this can be enhanced to support increased participation.
- **Principle H. Ownership.** It is not clear in the Evaluation Guide what 'ownership' means in this context or how this can be achieved. Further information could be provided as to what this might look like in practice, and how this extends beyond participation in the evaluation alone.

Respect for privacy

As noted under the 'Implementation and Analysis' phase in the Evaluation Guide, capturing data that can be disaggregated in order to understand the views and experiences of people with disability with different backgrounds and situations can enable a better understanding of how systems, policies and programs work for a diverse range of people.

However, it is important that this is balanced with respect for privacy and anonymity in data collection and sharing. To achieve this, good practice in data collection and analysis can include strategies such as collecting only the necessary information to meet the evaluation aims, de-identification of data, the ability for participants to opt out of answering particular questions if they are uncomfortable with providing particular information, and reporting on disaggregated data in a way that does not enable identification of individuals (unless they have specifically consented to use of their information as a case study, for example).

It is also important that participants are provided with sufficient information (in an appropriate format) and support, to ensure they understand how the data will be used and consent to this use.

Ethical and quality standards in evaluation and research

When designing or conducting evaluations with people with disability, it will also be important that the evaluations adhere to relevant ethical and quality standards.

The Strategy's Evaluation Good Practice Guide Checklist identifies a number of features that should be considered in the conduct of quality evaluations.

While not all evaluations would be considered research, some evaluations may, and should therefore meet relevant ethical research guidelines and oversight requirements.² This may include seeking approval from a Human Research Ethics Committee prior to the commencement of the research.

For example, the National Health and Medical Research Council's (NHMRC's) *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)* provides guidance on the ethical conduct of research.³ In particular, 'Chapter 4.3: people in dependent or unequal relationships' (e.g., when the evaluation involves a person with disability and their service provider, their carer, or their healthcare professional) and 'Chapter 4.5: people with a cognitive impairment, an intellectual

² National Health and Medical Research Council, *Ethical considerations in Quality Assurance and Evaluation Activities*, 2014.

³ National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*, The National Health and Medical Research Council, the Australian Research Council and Universities Australia, Commonwealth of Australia, Canberra, 2018.

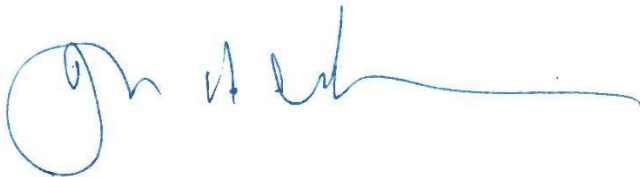
disability, or a mental illness', outline considerations that are relevant to research being conducted with people with disability.

For research involving Aboriginal and Torres Strait Islander people with disability, additional guidance on the conduct of high quality, ethical research can be found in:

- the *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*⁴
- the *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*⁵
- *Keeping research on track II*.⁶

Thank you for the opportunity to provide feedback regarding the Guide on how to involve people with disability in evaluations. If you require clarification of any of the issues raised in this correspondence, please contact my office on 07 3738 9513.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'John Chesterman', with a long horizontal flourish extending to the right.

John Chesterman (Dr)
Public Advocate

⁴ Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*, Canberra, 2000.

⁵ National Health and Medical Research Council, *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia, Canberra, 2018.

⁶ National Health and Medical Research Council, *Keeping research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia, Canberra, 2018.