

#50 - Evidence-based resources for people living with disability

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Objectives/aims

Approximately 4.3 million Australians live with disability. The National Disability Insurance Scheme (NDIS) provides funding to approximately 500,000 Australians who live with permanent and significant disability. The National Disability Insurance Agency (NDIA) administers the NDIS and provides funding to individuals for disability related services and supports.

In 2019 the government commissioned a review of the NDIS Act 2013 which highlighted the need to provide participants access to best available research evidence to inform their decisions about disability-related supports and services.

To identify the best approach to developing evidence-based resources for NDIS participants to support decisions or choices (i.e. decision support tools).

To develop evidence-based resources about disability-related supports to improve access to information and to help participants and their families and carers make informed choices.

Methods

We conducted a rapid review to explore development of decision support tools for people with a disability. This was supplemented by interviews with resource developers and focus groups with NDIS participants to understand their information needs and preferences. These insights were used to design our approach to the development of 'Guides for understanding supports' and a checklist to support evidence-informed choices.

Main findings

The development and effectiveness of decision support tools in the context of disability is not well documented with most research conducted in health care settings. International standards identify the minimum requirements for a decision aid and outline important quality

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criteria. The research noted the importance of facilitating tools to support the use of research evidence.

Participants described how they would like information presented which included plain language, easy read, videos and detailed evidence summaries for further information.

The first Guides were launched in April 2022. These now include Guides for understanding employment supports, early interventions for children who are deaf or hard of hearing and social and community participation. These have been actively accessed by participants. Further Guides are planned for release in 2023. An evaluation framework has been developed to measure the use and usefulness of the Guides.

Guides for understanding supports address an important gap in information provision for people with disability. The evaluation of the Guides will help us to learn more about the use and usefulness of these resources.