

Project Fact Sheet: Effective decision-making support for people with cognitive impairment

The Public Advocate

The role of the Public Advocate is to protect and promote the rights, autonomy and participation of Queenslanders with impaired decision-making capacity through statutory systems advocacy. The Office of the Public Advocate is committed to an evidence-based approach that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for these vulnerable Queenslanders.

The Public Advocate is firmly committed to ensuring that Australia's responsibility under the United Nations *Convention on the Rights of Persons with Disabilities* is upheld in Queensland. The Public Advocate therefore supports the right of people to be supported in the least restrictive way to exercise maximum autonomy in making decisions.

Background

Over one million Australians have a cognitive impairment due to intellectual disability or acquired brain injury and some require assistance with making decisions. To date, Australia's legal response has been in the form of substitute decision-making, most commonly through the appointment of attorneys, guardians and administrators. Under this paternalistic approach, people are often disempowered and lose their legal capacity.

The provision of decision-making support, particularly support that is provided freely and voluntarily by a trusted person, is critical to upholding the right of a person to make their own decisions. It can also prevent the imposition of intrusive interventions such as guardianship and administration.

Further, the National Disability Insurance Scheme (NDIS) is being phased in across Australia and is scheduled to achieve full implementation by 30 June 2019. The NDIS is based on the presumption that everyone has the capacity to make their own decisions. It is therefore possible that people with cognitive impairment who require decision-making assistance may experience difficulties in accessing the NDIS, e.g. accessing and analysing information, assessing available options and communicating decisions. It is important that those who experience difficulty in making decisions are provided with appropriate and adequate support to enable them to navigate the NDIS.

Australian research has highlighted the lack of guidance afforded to the people who practically support the decision-making of others. Many supporters are constrained by contextual factors and face practical dilemmas in providing support, e.g. expressed views versus best interests, and balancing risk and protection.

About the project

Researchers and industry partners from Queensland, New South Wales and Victoria are collaborating on a unique research project that seeks to address the gaps in knowledge, expertise and resources that exist in respect of providing support for decision making. The four-year project, commencing in July 2015, is supported by funding from industry partners representing government, non-government and statutory agencies from these three Australian jurisdictions, in addition to a Linkage Grant allocation from the Australian Research Council.

The aim of the project is to develop and evaluate the effectiveness of an education program that trains people who provide decision-making support so that the quality of their support improves and results in better outcomes for the person who requires decision-making assistance. While the project will specifically explore this for people with intellectual disability or acquired brain injury who require decision-making assistance, the findings are expected to have applicability to a broader range of people with cognitive impairment.

The first phase of the project involves the development of the evidence-based education program and resources that will be delivered and evaluated. The education program will be based on Australian research and pilot projects on decision-making support. These pieces of work have revealed the factors that impact the provision of 'successful' decision-making support and a positive experience for the people who require support.

The second and third years of the project will involve delivering the education programs and gathering evidence to assess the effectiveness and impact of the education program. Research participants will be interviewed before and immediately after taking part in the education program, then again at three, six and twelve months after the program. The interviews will be conducted with the people who require decision-making support and with their supporter. Research participants will be recruited in Queensland, New South Wales and Victoria.

The final year of the project will involve analysing and reporting on the research.

Project partners

The Chief Investigators for the project are Professors Christine Bigby and Jacinta Douglas (La Trobe University), Emeritus Professor Terry Carney (University of Sydney), Dr Ilan Wiesel (University of New South Wales) and Dr Shih-Ning Then (Queensland University of Technology). The Partner Investigators are Dr John Chesterman (Office of the Public Advocate-Victoria), Ms Jodie Cook (Office of the Public Advocate-Queensland) and Ms Imelda Dodds (New South Wales Trustee and Guardian).

Queensland's Public Advocate will chair the Queensland advisory consortium, which comprises the Office of the Public Advocate, the Office of the Public Guardian, the Public Trustee and the Queensland Mental Health Commission. All of these agencies are partner organisations and have made cash and in-kind contributions to the project. Other Queensland agencies may also contribute to the project through in-kind support.

Other partner organisations include the Endeavour Foundation, Summer Foundation Ltd, Melbourne City Mission, Inclusion Melbourne, the New South Wales Public Guardian and the New South Wales Department of Family and Community Services.

Further information

Updates about the project will be published on the Office of the Public Advocate website at www.publicadvocate.qld.gov.au as they become available. For more information about the project, phone 07 3224 7424 or email public.advocate@justice.qld.gov.au.