



Submission to NSWLRC on draft proposals to the Assisted Decision Making Act

We are a collaboration of academic researchers and industry partners from Queensland, New South Wales and Victoria on an Australian Research Council (ARC) Linkage Project involved in developing and trialling an evidence based education program that trains people to provide better decision-making support to adults with cognitive disabilities. The program was developed by La Trobe University and aims to improve the quality of the decision-making support and test whether it results in better outcomes for the person who requires support in decision-making. The continued roll-out of the National Disability Insurance Scheme (NDIS) highlights the need that many people with cognitive disabilities have for support with decision making in order to ensure that they can execute 'choice and control' over decisions that affect their lives.

While this Project focusses on people with intellectual disability or acquired brain injury who require decision-making assistance, it is anticipated that the findings will be applicable to a broader range of people with cognitive impairment, such as people with mental health issues and those with age-related conditions such as dementia.

We note that the recommendations of the NSWLRC are part of a noticeable trend globally, and domestically, of seeking to incorporate supported decision-making into law, policy and practice. This trend has been driven by the introduction of the UNCRPD and the change in philosophy as to how adults with decision-making difficulties ought to be treated, listened to and respected by our societies. Our team is concerned with the question of how best to provide support to adults with decision-making difficulties.

The NSWLRC recommendations seek to further formalise the practice of support for decision-making by providing the option of legal recognition of supporters. The potential need for legal recognition, rather than just implementation in practice without formal legal recognition, was identified as something that may need to occur in our



previous research (Bigby, Douglas, Carney...& Smith, 2017). However, it should be stressed that these findings were preliminary in nature. This is because, to date, there has been very little rigorous academic research into how supported decision-making works in practice, and how to ensure that people know how to provide good support to adults requiring support in decision-making. Given the very limited empirical research in the area of supported decision-making, we think it imperative to recognise the **need for further research** and **mechanisms to promote rigorous research** in this area to ensure that the goals of any legislation (based on the recommendations) are realised in practice.

Research conducted by members of our team has shown that certain factors are needed for a 'successful' supporter and decision-maker partnership (Douglas, Bigby, Knox, & Browning, 2015). While these factors may naturally occur between some supporters and decision-makers, it is likely that many appointed supporters will themselves need to have access to education, training and support, if they are to successfully fulfil their role. For the goal of a legally recognised supported decision-making model to be realised, those in the role of supporters need to have a commitment, knowledge and respect for the preferences and rights of the person they are supporting. This requires a supporter to be aware of and reflect upon their biases or preferences that may negatively influence their actions as a supporter. These types of issues can be better dealt with by providing supporters with tailored evidence-based education programs like the one our team is evaluating (Bigby & Douglas, 2016). A full understanding of what the supporter role encompasses and the practice necessary to carry it out, seems particularly important where such supporters are legally recognised, given powers and burdened with duties under legislation. This clarity is important as formal recognition should also be accompanied by mechanisms for monitoring quality of support and for accountability.

Members of our team have previously suggested that programs are needed to 'train and support' supporters (Bigby, Douglas, Carney...& Smith, 2017). Consistent with that view, we suggest that the NSWLRC make a specific recommendation in relation



to **funding evidence-based education programs and support** of those who take on a legally recognised supporter role.

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