The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to which Australia is a signatory, represents an important step forward for people with intellectual disability in realising their human right to autonomy. In particular, Article 12 of the Convention emphasizes the full and equal legal capacity of all citizens to participate in decisions and importantly to receive appropriate support to make these decisions. Australia’s ratification of the Convention in 2008, coupled with the roll out of Australia’s National Disability Insurance Scheme (NDIS), underscores the Australian government’s commitment to ensuring a national focus on autonomy for all Australians. Supported decision making has emerged as a way of achieving this universal autonomy.

Despite this international and national focus, tension exists around the relevance and application of Article 12 for people whose intellectual disability is at the more severe end of the continuum. Due to the interdependent nature of their lives, decision-making is obviously challenging for this group, however, if signatory nations to the UNCRPD are to live up to their obligations under Article 12 attention needs to be paid to how best to support this population to have their preferences heard and reflected in the decisions that are made about their lives. My work in recent years has focused on the development and evaluation of mechanisms with which to enable this.

In 2011, while employed with Scope in Victoria, I worked with my colleague, Rhonda Joseph, to develop a resource, *People with severe or profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard* (Watson & Joseph 2011). This resource outlines an approach that brings together a group of people who care for and about someone with an intellectual disability who communicates informally (circle of support) to support them in making and acting on a specific decision. The approach involves a combination of training, on-site mentoring, observation, modelling, coaching and provision of feedback over a period of three to six months.

This approach has provided a lens through which I have observed and analysed the phenomenon of decision-making support for people with intellectual disability who communicate informally. These observations and analysis have revealed a number of useful findings deepening my understanding of supported decision-making for people who communicate informally. At the centre of this knowledge is an appreciation that the process of decision making support exists in terms of the existence of two distinct but interdependent roles, played by (a) the person with a disability (supported), and (b) the circle of support (supporters) in the supported decision-making process. The role of the person with a disability in this dynamic is their expression of preference, and the role of supporter is to respond...
to this expression of preference. Within this decision-making dynamic, supporter responsiveness, as opposed to focus people’s expression of preference, is the component that is amenable to change through structured practice guidance, making the enablement of responsiveness a crucial strategy for the realization of Article 12 of the UNCRPD.

Supporters who positively respond to the expression of will and preference of those they support do so through a multi-faceted process, made up of a number of tasks (Watson 2016, 2017). These tasks include acknowledging, interpreting and acting on the expression of will and preference of the people who are being supported. Although each of these tasks are important, none of them in isolation, characterise responsiveness. Rather, supporter responsiveness appears to be reliant on the implementation of these tasks collectively. Supporters acknowledge/notice these expressions of preference, they interpret these expressions of preference, assigning meaning to them, and they act on this meaning.

Considering the importance of supporter responsiveness within a supported decision-making process, I have focused my attention on the key factors underlying this responsiveness. These factors include supporters’ attitudes and perceptions toward and about the person they are supporting, the level of relational closeness shared by supporters and the person they are supporting, the functioning and make up of circles of support, and the characteristics of the service system (e.g. organisational approaches to risk taking). A detailed explanation of these factors can be found in some of my recent publications (Arstein-Kerslake et al. 2017; Watson 2016, 2017; Watson, Wilson & Hagiliassis 2017).

I have been invited by ASID, to run a practical and interactive workshop on April 26th, 2018, for those providing support to people with intellectual disability who communicate informally. I will be joined on the day by Gloria Jelleff, a long-time supporter and her foster son, Michael, a man with an intellectual disability who communicates informally. In this workshop we will be sharing some of our insights around supporting people with intellectual disability who use informal communication. The workshop will focus on supporting this rarely heard group to have their will and preferences acknowledged, interpreted and realised, through the decisions made about their lives.

References


Watson, J & Joseph, R 2011, People with severe to profound intellectual disabilities leading lives they prefer through supported decision making: Listening to those rarely heard. A guide for supporters, Scope, Melbourne.


You might also like to read the following ASID publications on Supported Decision Making for further information.


