

# DECISION-MAKING SUPPORT FOR PEOPLE RARELY HEARD

A workshop by Jo Watson and Gloria Jellif

The right to exercise choice and control in one's life is a central principle for NDIS participants. This can be empowering and enabling for people who can speak for themselves, explain to others what is important to them and what their hopes and dreams are.

However, a relatively invisible group are those people with severe and profound intellectual disability, people who do not have a formal means of communication. How can their voices be heard? How can we support them to have true "choice and control"? This workshop explored those questions and offered some strategies.

Often decisions are made for people who do not have or have not been given a means of communication. These decisions are perceived to be in that person's interests, but are still made without that person's participation. This is termed "substituted decision-making". Article 12 of the UN Convention of the Rights of Persons with Disabilities (UNCRDP) says that substituted decision-making is not sufficient. We continue to violate that right for a large number of people in Australia.

In this workshop Jo and Gloria told us stories and outlined some strategies that can be used to support more inclusive decision-making for people who do not have a formal means of communication.

Supporting true decision-making, choice and control takes time and requires discussions between people who know that person well. Creating a "Circle of Support" - a group of people who support someone to build and act on their decisions, is a key strategy. The Circle of Support works together to determine the person's likes and dislikes, brainstorms a range of possible activities the person may like, videos the person during these activities, and discusses the person's responses to form an opinion of their preferences. Preferences can be developed into expressions of choice, and choices then become decisions about the activities that person wants in their life. This can be a time consuming process, and lack of funding for this is one of the biggest barriers to it becoming a more common practice.

Sensory preferences can also be the building blocks of decisions. We all respond to what we experience and a Sensory Profile can provide valuable information about a person's preferences and dislikes. Telling stories is how we share our lives and let others know about who we are. People without a formal means of communication can be supported to do this through multi-media profiles or Personal History books.

Another barrier is that for many people with severe levels of disability, most if not all the people in their life are paid staff. However we know that the more close and caring relationships a person has, the better their preferences are observed and known. Developing strong and caring social networks for

these people is a vital element in supporting them to make and express their decisions.

This work reminds us that all people, regardless of their level of disability, can and do attempt to communicate. Whether or not they actually succeed at communication depends entirely on the people they are attempting to communicate with. A person's level of capacity is not as important as the support they have.

This work challenges us to follow the lead of the UNCRPD - rather than the various forms of making decisions for people based on their perceived best interests, let's devote more resources to supporting people to make decisions based on their will and preferences.

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