

Editorial

Supported health care decision-making for people with intellectual and cognitive disabilities

The United Nations Convention on the Rights of Persons with Disabilities is the first international treaty to recognize that people with intellectual and cognitive disabilities have a human right to legal capacity. Article 12 calls for supported decision-making to replace substituted decision-making such as power of attorney or guardianship. Substituted decision-making transfers responsibility to make decisions to a third party. Supported decision-making allows people with intellectual and cognitive disabilities to name trusted supporters to assist them with making decisions and to assist with communication. This enables the person to direct their own life to the greatest extent possible (1).

Nowhere is this support more important than in making informed decisions about one's own health and end-of-life care. Good communication is essential for accurate diagnosis, for negotiating treatment plans and for adherence. It is a key to patient safety. However, supporters can be both facilitators and barriers to accurate health information exchange. In their article, 'Experiences of patients with intellectual disabilities and carers in GP health information exchanges: a qualitative study', Mastebroek *et al.* describe some pitfalls. Trusted supporters are not always available when needed. They may not be sufficiently proactive in checking for symptoms. Supporters may not relay critical information accurately to those with a need to know. Caregivers can take over the conversation. They may also have competing demands on their time, causing them to rush appointments. Also, having a caregiver in the room can result in doctors using less plain language (2). It can be challenging for professionals to understand a patient's wishes, and to distinguish them from pressure from others (3). Also, attitudes can be a barrier when people assume that people with cognitive disabilities are unable to consent (4).

These problems also manifest where legal capacity to make decisions is transferred to another person. The supported decision-making paradigm does not create these tensions. But it is still important to recognize that supported decision-making is an emerging practice (5). We have yet to fully develop and study models and standards for providing effective support (6). Infrastructure, funding, training, and legal and clinical tools will be required to maximize self-direction for people with cognitive and developmental disabilities. However, legal models to support this process have been developed. There have been some pilot implementations (7).

Model legislation was developed by the Autistic Self Advocacy Network <http://autisticadvocacy.org/> for Supported Health Care Decision Making Agreements. These agreements legally formalize support arrangements and introduce a variety of protections for both patients and health care providers. The agreements define who can be

a supporter and which conflicts of interest are disqualifying. They outline the procedure for executing an agreement with witnesses, a notary public and signatures from both the patient and the supporter. They allow the patient to specify the type of support desired and authorize access to confidential medical records. They clarify the support role to allow supporters to accompany people with disabilities in medical settings such as emergency rooms. It also protects health care providers who act on informed consent decisions made with support (8).

A key protection with Supported Health Care Decision-Making Agreements is that a person can select their own supporter and can change supporters at any time, for any reason. A Supported Health Care Decision-Making Agreement is an authorization to provide support. To implement, it typically requires less capacity than a contract. It is also less enduring if the relationship or needs change such that the supporter selected is no longer appropriate. A new Supported Health Care Decision-Making Agreement can be executed at any time without court involvement or other expensive and complex procedures.

A person can retain legal capacity to direct their own life, even when they lack mental capacity to make a specific decision with or without support. Legal capacity means the legal right to consent and to enter into contracts. Mental capacity is the ability to understand choices, risks and benefits, weigh them against each other and communicate a choice. The same person can have capacity to make decisions with support even though they are unable to do so without support. They may have mental capacity to make some decisions and not others. The type and amount of support needed can fluctuate with time and situation. Nobody is born with mental capacity. Supported decision-making takes into account the fact that capacity can improve with experience and education. People learn from their choices, both good and bad. This allows people with functional limitations to retain legal capacity and to maximize their right to self-determination using the capacity to make decisions which they have at any given time.

People with visible disabilities often have their capacity overlooked because of their appearance, diagnosis or the way in which they communicate. People with invisible disabilities may have their need for supports overlooked. Supported decision-making allows a person to retain legal capacity even when a supporter provides assistance with understanding options; communication; and determining their intention, will and preferences. In supported decision-making the patient's preferences are primary. The patient makes the final decision, even if it conflicts with their supporter's preferences or judgement.

Training materials in supported decision-making have been developed by the Office of Developmental Primary Care in the

Department of Family and Community Medicine at the University of California, San Francisco. They can be accessed at <http://odpc.ucsf.edu/supported-health-care-decision-making>.

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