

Supported Decision-Making in Practice

Tina M. Campanella

Supported decision-making (SDM) is emerging as an approach to provide decision making assistance for adults with disabilities and other functional challenges without imposing any long-term legal limitations on their rights or personal liberties. This promising practice has the potential to enhance, advance, and transform the current approach to daily support for people if it is successfully integrated into routine practices. In simplest terms, we are talking about supporting children and adults with disabilities to experience the natural process of maturation—learning how to make better decisions over time through real-life experiences. Increasing opportunities for people with disabilities to participate in decision making follows the typical process of growth and development and has the potential to result in reduced reliance on more restrictive approaches for support over time.

The ideas behind supported decision-making are not entirely new. They build on a long tradition of research and implementation around person-centered planning and the concept of self determination. Person-centered practices, self determination, and support for individual choice have been seen as best practice for decades in the field of disabilities. Yet, the reality is that these practices are used for only a small percentage of the people with disabilities receiving formal support. Figuring out how to use these principles for all people and making this an integral part of day-to-day support interactions remains a challenge.

The person-centered support model blends with an supported decision-making approach because it is built on respect and uses the person's expressed will and preferences to guide action. Support teams are directed to learn about each person's unique characteristics and desires and use this knowledge to design individualized interactions and activities. The goal of true “support” is to nurture gifts and talents and assist the person to develop as a person—not just teach “skills.” Working *with* the person, assistance is provided to explore and experience options related to a given choice. For example, if the choice is related

to where to live, support starts with seeking to understand what experience the person already has and the preferences he or she expresses. Additional activities are then planned to help the person learn about other various living options that are available and assess which option is preferred.

For some people, this process is relatively easy. What they want and desire is consistent with what other people typically want and does not conflict with established community norms. For others, the goals and activities they want to pursue challenge our beliefs about right and wrong, health and safety, and what is possible for people with different disabilities. In these instances, it is common to see support for individual preference diminish as the attention of “supporters” shifts to thoughts about redirection and protection. Our desire to help can limit our capacity to see consequences we may not be able to control. It may be difficult, if not impossible, to stop a person who is determined to pursue a relationship, activity, or life path that others can clearly see is not healthy or leading to positive outcomes. The application of simple logic does not stop people—with or without disabilities—from smoking, overeating, biting fingernails, or drinking too much, for example. There are multiple theories about why people behave this way, and not all strategies work well with all people. In these situations, sometimes our best option is to maintain a positive relationship with the person so we are available to assist when (and if) the person is ready to change or pursue a different path.

Although health and safety are important elements in and for life, most people accept that some risk is inherent in the daily living process. Crossing the street, riding in a car, or coming in contact with large numbers of people all contain potential threats to our personal health and safety. We can mitigate these threats with our personal choices and behavior, but we cannot eliminate all possibility of harm. The same is true for people with disabilities. Addressing this mental “road-block” is essential for advancing practice in

support of children and adults with intellectual and developmental disabilities. Our primary responsibility is to be sure we provide people with the opportunity and individualized support needed to develop the skills and abilities needed in different situations and to not knowingly abandon people to make choices and pursue activities for which they are poorly equipped.

To be most effective, the role of support must remain focused on the person AND what the person wants. This does not mean that the support provider stands by and “allows” the person to do whatever he or she wants. Effective support requires a relationship of give and take with the person. This relationship would also be characterized by the presence of trust, reliability, and mutual respect. As such, the person is free to express his or her desires without fear of judgment or consequence. The support “provider” is equally free to make independent determinations about how to be most helpful—including, in some situations, respectfully declining to assist the person to pursue certain goals. Assessment, opportunity to develop as a decision maker, and direct support are three areas where the principles of respect and support for personal preference can be infused to make practice more consistent with a supported decision-making approach.

Capacity and Assessment

Predictive assessment of children and adults with disabilities as a practice can lead to limitations in experience that negatively impact learning opportunities—especially those related to decision making. When a diagnosis of disability is made, the tendency to project what the future may hold for the child and family is all too common. Many professionals extrapolate what future abilities are possible based on the presence of a developmental delay or functional limitation in early life. A disturbing danger associated with this practice is the potential for real limitations emerging as a result of limited or low expectations and reduced support for growth and development. Known as the “self-fulfilling prophecy,” children not expected to learn are not provided with or engaged in meaningful learning activities and, therefore, do not learn, confirming the original prediction.

Much emphasis is placed on assessing decision making capacity for people with intellectual and developmental disabilities or other functional

challenges. Formal assessments about whether people have developed the “capacity” for decision making are often completed and considered when determining individual learning or support plans. The best assessments are based on an evaluation of the person’s past experience and opportunity with decision making and acknowledge that limited capacity is often directly related to deficits in experience, learning support, and opportunity for a broad range of life experiences. Less useful assessments reflect observations in current environments without consideration of personal history, and often link conclusions to a diagnosis and/or psychological evaluation as a basis for determining capacity. These assessments are not helpful in understanding the person’s unique circumstances with decision making or in determining how to assist the person to develop capacity to direct their lives over time.

Capacity for decision making is not easily assessed. There is no formal test that can be used to measure capacity. At its best, capacity assessment measures what the person has learned (the past) and what is demonstrated in the present. Human capacity is not static and may change over time based on learning and the accumulation of personal experience. Lack of life experience or opportunity to make decisions can prevent people from developing capacity. Variance in capacity can also be experienced relative to different situations. For example, a person may be very comfortable and capable when making decisions about their home and personal routine, yet not as confident or capable when making decisions about health-related treatment or care issues. A combination of different supports is required to provide the best assistance.

Clinical judgment and critical-thinking skills are essential to sound and functional assessment. As Schalock and Luckasson (2014) emphasize in their book, *Clinical Judgment*, all professional practices must start from a perspective of profound respect for the person. This encompasses many areas, such as supporting individual rights (especially the right to choice), embracing person-centered practices, and assisting the person to direct their own life. Clinical practice in intellectual disability has shifted to describing the assistance needed at a given time instead of categorical diagnoses, as reflected in the American Association for Intellectual and Developmental Disabilities’s (AAIDD) *Supports Intensity Scale*. It has been recognized that even the diagnosis of

intellectual disability itself can lower expectations for future accomplishments. Skilled professionals use their expertise to describe what has been learned and accomplished by an individual and make recommendations to enhance opportunities for future growth and learning, always embracing the potential for capacity development over time.

Choice and Decision Making

Choice and decision making are a routine part of daily life for people, making it something we too often take for granted. Each day we make many choices without engaging in a deep thinking process. Simple choices about when to get up, what to wear, what to eat, and many others are made based on past experience and highly developed preferences. These preferences reflect our life experience and our concept of who we are as people. Major life choices and decisions are usually made through a more deliberate process of exploration and evaluation. Decisions about a place to live, a job or career, or a life partner are considered life-defining choices requiring more careful deliberation. Of course there is no “official” requirement that these decisions be made thoughtfully—and many people make these choices quickly and impulsively, preferring to learn through trial and error during real-life experience.

Research pertaining to how people make decisions has steadily increased. There are many popular books on patterns of human behavior related to decision making in both the personal and business context. Specific and common barriers to good decision making have been identified and explored. For example, the tendency to focus on information that confirms our existing beliefs is often called “confirmation bias.” This bias and other human traits, such as overconfidence, access to limited information, emotionality, or reliance on intuition, are now commonly recognized as barriers to better decision making.

In his book, *Thinking Fast and Slow*, psychologist Daniel Kahneman (2011) studied how the human mind works and wrote about the different ways people make decisions. He described two different thought processes—one fast and instinctual, one slow and deliberate. Although we often associate good decision making with the second type of thinking, Kahneman proposed that both

systems work together and that this is often the source of flawed or irrational decisions. Dan Ariely (2010) described in detail the many variables that influence human decision making, challenging the notion of rational decision making in *Predictably Irrational: The Hidden Forces That Shape Our Decisions*. In his follow-up book, which was published in 2011 and entitled *The Upside of Irrationality*, he examined both the positive and negative effects that irrationality has in our lives, noting that

From a rational perspective, we should make only the decisions that are in our best interest ... We should be able to discern among all of the options facing us and compute their value—not just in the short term but also in the long term—and choose the option that maximizes our best interests. (p. 45)

The goal of these authors is to raise awareness about how people make decisions and provide tools for improving the quality of decisions being made.

The conclusions for practice from these and other authors addressing this subject are clear. On one hand, people are not very conscious about decision making, leaving them highly vulnerable to influences from forces they do not understand. On the other hand, we can get better at decision making by using specific practices. Decision making related skills are learned and highly influenced by our life experience. The quality of decisions can be improved by learning more about human tendencies and developing a disciplined process to use when faced with important life decisions. Helping people with disabilities develop as decision makers requires this same awareness of how people make decisions and the experiences that influence this process. What these and other authors have learned about improving human decision making are valuable resources to inform specific decision making support strategies for people with disabilities.

The Role of Direct Support

Direct support professionals have a profound impact on choice and decision making. Opportunities for expressing personal choice can be expanded or diminished based on the beliefs and actions of the people providing day-to-day assistance. How service organizations define and manage people in the direct support role also

matters. If direct support professionals are given few tools or limited involvement in developing support plans, outcomes for the person will be negatively impacted.

Improving support for individual choice and decision making may require rethinking and diversifying the direct support role. Although the current service model emphasizes “levels of supervision” that must be adhered to by direct support workers, day-to-day interactions that support choice and decision making more closely resemble the role of a “coach.” Supporting choice making requires following the person’s lead. In coaching, the coach seeks to help the person discover the best path or strategy for themselves through questions and reflection.

The personal outcome approach defined by the Council on Quality and Leadership (n.d.) provides an excellent model for balancing individual preferences and support responsibilities in practice. It is based on a process of learning about the person and her priorities as the foundation for all other activities. Emphasis is placed on understanding the world through the eyes of the person without filters or judgment. Until the person’s situation is understood, effective and responsive services that are tailored to the person’s unique needs cannot be developed. Once the person’s perspective is understood, strategies to assist and support the person can be considered. In this way, the supports are uniquely responsive to the person and her situation.

The 2001 Code of Ethics published by the National Alliance for Direct Support Professionals (NADSP; <https://www.nadsp.org/library/code-of-ethics.html>) also outlines a set of principles for action consistent with supported decision-making. It recognizes the critical questions and dilemmas faced by direct support providers every day, and the positive or negative impact the choices made can have on the quality of support for people with disabilities. The preamble to this code rightly notes that “people who assume the support role must examine and call upon values and beliefs, as well as creative vision, to assist them in the complex work they perform.” Although staff training programs address elements included in the code such as person-centered practices, respect, confidentiality, relationships, responsibility, advocacy, and self determination, much more support and ongoing assistance is required to help direct support workers integrate these principles into practice in truly individualized ways. The

NADSP has developed credentialing and training programs to facilitate implementation. At present many states still do not have active chapters and membership touches only a fraction of the workforce. The room for growth and expansion in this area is great.

Conclusion

Decision making is part of everyday life for everyone—including people with disabilities. Accordingly, everyday support for people with disabilities must embrace the best practices most consistent with assisting people to become better decision makers over time. Given our strong traditions of supervision and protection, this will be not an easy task, but it is the right goal and wholly consistent with the ideals and principles of person-centered support and self determination. It will involve accepting responsibility for defining the best type of assistance for every person we support. The realities of how personal choice and decision making operate in life means strategies will look very different for different people. Strong partnerships with people that acknowledge, respect, and honor each person’s unique presence and power will help us to achieve this goal in practice.

At its core, supported decision-making is about seeing every person with a disability or functional challenge as just another person trying to live a life full of challenge as well as promise. Professionals at all levels supporting people must accept responsibility for finding ways to assist those in need of support to experience life fully consistent with their personal goals, vision, and preferences. Although there are many promising practices upon which to build, embracing and actualizing the concept of supported decision-making requires expanded use of these practices in all types of interactions and with people with all different abilities.

References

- Airely, D. (2010). *Predictably irrational: The hidden forces that shape our decisions* (2nd ed.). New York, NY: HarperCollins.
- Airely, D. (2011). *The upside of irrationality: The unexpected benefits of defying logic at work and home*. New York, NY: HarperCollins.
- Dinerstein, R. D. (2012). Implementing legal capacity under Article 12 of the UN Conven-

- tion on the Rights of Persons with Disabilities: The difficult road from guardian to supported decision making. *Human Rights Brief*, 19(2), 8–12.
- Kahneman, D. (2011). Thinking fast and slow. New York, NY: Farrar, Straus and Giroux.
- Lovett, H. (1996). *Learning to listen*. Baltimore, MD: Paul H. Brookes Publishing Co.
- National Alliance for Direct Support Professionals. (2001). *Code of ethics*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.
- Quinn, G. (2010, February). *Personhood and legal capacity perspectives on the paradigm shift of Article 12 CRPD*. Presented at the Legal Capacity Conference, Harvard Law School Project on Disability, Cambridge, Massachusetts. Schalock, R. L. & Luckasson, R. (2014). *Clinical judgment* (2nd ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- The Council on Quality and Leadership. (n.d.) *Personal outcome measures*. Towson, MD: Author.
-
- Author:**
Tina M. Campanella, Quality Trust for Individuals With Disabilities Director, National Resource Center on Supported Decision Making.