
Supported Decision-Making: A Parent's Perspective

By Janice Fitzgerald, May 2019

Decisions guide us in achieving dreams and avoiding what we fear.

As adults, we make decisions multiple times a day. Decisions are made to solve problems, to select choices and to make plans. Successful decision-making builds confidence and strengthens experience. Sometimes decisions are made in concert with others, to gain perspectives and to increase the likelihood of success. We've learned that guidance and experience lead to well thought out decisions.



Doug, Janice and John Fitzgerald

When I was the parent of a young child with intellectual and developmental disabilities, I was an expert at worry and fear. I lived with fear for what might happen and fear for John's future. At first I worried about a relapse of the seizures he experienced as an infant. Would he speak? Would he learn? Would he read? The things I felt the need to fear were endless. I tried to protect and control John's environment. It didn't occur to me to consider, "How can anyone learn and enjoy life in an environment of fear and control?"

Facing Fears

When I feared for the future, I lost time living in the present. Gradually, I began to reflect on the parent I was for John. For the first 10 years of his life, I worried about his safety. It was painful knowing he was teased at school. How could I protect John from the tough stuff? Some of the fears were valid. Over time, I shifted from fear and the sense of needing to control John's actions, to an approach where I saw John for who he was and the strengths and gifts he brought to us and to others. He did learn to speak, and he learned to read. He is joyful and a unique thinker. He has a great sense of humor. As with any of us, the more experience John has with different situations, the more personal growth he has accomplished. He has learned skills for making decisions and the impact of his decisions. Helping a child make decisions is what parents organically do.

When we focus on the lessons children and young adults learn, we can break the cycle of being catapulted back into concentrating on fears.

Love and fear are opposing emotions; they are not compatible. When living with fear, decisions are likely made to control a situation. When decisions are grounded in care and love, sound judgments can be celebrated. These qualities are needed in Supported Decision-Making.

For John, as with most children and young adults, decisions started small. He learned and gained confidence, and with that his skills in making decisions grew. John now lives independently and makes decisions daily about his activities, care of his apartment, meals and

self-care. They may be different from your choices or mine, and that is okay. They are *his* choices and to be celebrated for what they mean to John.

When the risks are higher

When it comes to complicated situations and decisions, John admits he needs help sorting out the issues and options. He acknowledges he needs help managing and making financial decisions. It is a sign of maturity and a comfort in knowing that John accepts assistance and support.

John wants others in his life to help explore consequences and impact. Last year, he was quite ill and hospitalized. Surgery was one option. I respected the doctor who came to talk with John. He spoke directly with him and laid out his recommended options. He ended this conversation by advising John to discuss the options, and then he would come back to finalize plans. It was a wonderful approach in that the doctor did not talk to me; he spoke to John. We talked about the options, and John made the final decision.

We cannot be in in our children's lives forever. Our goal should be to position our sons and daughters as well as possible for when we are not in their lives. This includes learning and participating in making decisions. Families have differing challenges and children's disabilities present differently. No matter what, with guidance, support and deep listening, everyone can participate in decision-making. By guiding and mentoring a person in making sound decisions, skills will develop gradually. Remember, the younger the practice starts, the more experience a person will gain.

As a child exits high school, and as part of transition planning, parents are sometimes steered toward pursuing Guardianship. Guardianship is a legal process that assigns a person to be the decision-maker for a person with disabilities. Guardianship takes away a person's right to make their own decisions. This means that a person with a disability who has a legal Guardian does not make decisions about where they live, what medical treatments they receive, or how their money is spent.

Does it have to be that way? Are there other options? Supported Decision-Making (SDM) is emerging nationally and internationally as an important support alternative to more restrictive options such as Guardianship. There are tools used with SDM, such as Power of Attorney, Living Will and Health Care Proxy. These alternatives to Guardianship can provide a person who has disabilities with opportunities to assess life situations and make decisions, with needed support.

Learning Supported Decision-Making is not complicated. It can be utilized in simple day to day activities or it can be formalized as an alternative to Guardianship. Put simply, a team (sometimes parents are the team) assist and guide a person to reach a decision.

The most important skills used in SDM are actually qualities.

Objectivity, care, concern and respecting a person's right to make decisions are attributes subscribed to in supporting a person in decision-making. *And, all forms of communication are respected and honored.*

Important strategies include breaking down an issue into manageable parts. Recommendations can be offered, and concerns expressed. For young learners, starting with

small choices can lead to sound decisions. As we help guide a person in this process, we can teach how to examine decisions for their impact and effects.

Final steps in Supported Decision-Making include review and reflection. While supporting a person in decision-making, review the steps taken and issues considered. Reflect on the decisions and their impact. Not all decisions work out as anticipated, and, that is an important learning lesson.

For those interested in guidance and information on Supported Decision-Making the NRC-SDM website is a wealth of information. Local Parent to Parent organizations may be able to refer to state specific policies and information on SDM.

From The National Resource Center on Supported Decision-Making

<http://www.supporteddecisionmaking.org/>

The **National Resource Center on Support Decision-Making (NRC-SDM)** has an abundance of information, knowledge and experience.

The NRC-SDM began in 2014 under a five-year grant from the U.S. Administration on Community Living to The Quality Trust for Individuals with Disabilities. NRC-SDM is dedicated to advancing the “Right to Make Choices” of people with disabilities and older adults, through training, information-sharing, technical assistance, research, and promotion of promising practices in Supported Decision-Making (SDM). Project partners include The Burton Blatt Institute of Syracuse University, The Kansas University Life Span Institute, The American Bar Association Commission on Law and Aging, The Autistic Self Advocacy Network, Family Voices, and Parent to Parent USA.

Supported Decision-Making guides us in making choices

Supporters/advisors help and assist a person to:

- Discover, understand and explore options,
- Know the risks and benefits of those options,
- Get guidance and recommendations,
- Make and communicate a choice, and
- Carry out that choice, with help when needed.
- Reflect and review steps and decisions and impact.

Supported Decision-Making: Why?

SDM has “strong potential for promoting favorable outcomes in the lives of people with disabilities and older adults.”

Supported Decision-Making and Human Dignity

- Recognize the inherent value and worth of a person as a human being.
- Honor that person’s unique identity.

- Ensure access to accommodations as needed.
- SDM mirrors how everyone makes decisions.
- SDM is an emerging nationally and internationally recognized alternative to adult guardianship.

Supported Decision-Making: How?

- There is no “one size fits all” method.
 - SDM is a paradigm, not a process or program.
 - It means working with a person to identify where help is needed and how it can be provided. Check out <https://www.aclu.org/other/when-do-i-want-support>
 - The key question is: “What will it take?”
- SDM can include, as needed and appropriate:
 - Informal support,
 - Written agreements, and
 - Formal Micro-Boards and Circles of Support.

Person-Centered, Person-Driven

- SDM is Person-Centered
 - Person-Centered Planning ensures that decisions are focused on the individual.
 - Person-Centered Services and Supports focus on assuring the individual feels safe and secure and enabled to achieve goals and aspirations.
 - Person-Centered Health Care includes treating an individual with dignity and respect for their health needs and values.
- SDM is Person Driven
 - Person-Driven Planning is based on aspects of life that are most important to the individual.
 - Person-Driven Services and supports enhance an individual’s life.
 - Person-Driven Health Care addresses physical and emotional needs of the individual.
- Always–always-always ask the person what they want.
- Everyone has the Right to make choices.
- Everyone has the “capacity” to make choices.
- As long as a person can communicate in any meaningful way, they have the ability to make choices.
- People have the capacity to make good choices for themselves with support.

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