

Informed Decision Making: It Takes More Than Practice

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Members of Self Advocates Becoming Empowered (SABE) and Green Mountain Self Advocates (GMSA) had the opportunity to review a paper written by the National Association of State Directors of DD Services (NASDDDS) on informed choice and decision-making. This paper is our response.

Making decisions is not just about our skills. It is essential to take a close look at the amount and variety of opportunities being presented to people with intellectual and developmental disabilities. Always ask, “Are these the same possibilities available to people without disabilities?”

The system is eager to measure our capacity. We recommend focusing on assessing the ability of teachers and support staff to be effective communicators and providers of reasonable accommodations. A person’s capacity to teach as well as learn is fluid and changes all the time. Whether or not we have disabilities, we learn from our mistakes and become more and more competent through our life experiences along the way.

“I would like to tell you what having autism is like when taking a trip into the community. It can be painful. People look at me with so much doubt that I have any intelligent thoughts. When in the community, we with disabilities stand out. I quietly watch all of society believe that we are empty spaces. What we really are, is full of intelligence.”

–Kristofor Medina

Supporting us to state our desires works in our best interest and leads to getting what we need. We hope you understand that when our supports are strong, we are able to work toward our life’s goals.

Disability Double-Standard

Often when a person without a disability makes a mistake, it’s not as big of a deal in comparison to when a person with a disability messes up. Plus, there is the

expectation that we must master certain life skills to get a chance to try certain things like working, dating, or living on our own. When we live in a world of low expectations, our hopes and dreams are stripped away.

“Presuming competence” is a popular term in the disability rights world. One of our favorite quotes by Rosemary Crossley is, “Not being able to speak is not the same as having nothing to say.” A lot of people believe that verbal speech is a showcase of the intelligence that people possess, holding onto the theory that if a person cannot speak verbally, then they can’t possibly receive information to process and understand. This way of thinking can be deadly to people’s growth personally and intellectually. It limits opportunity and decreases overall quality of life. Always believe in everyone’s intelligence and the amazing things that people can accomplish. You, yourself can provide support by just believing.

“I want people to move into the light by taking one step at a time. Think about what you want personally for yourself is the first step; that will provide you with direction. Always keep each person that truly supports you close by. It is important to not isolate yourself when trying to move forward with your goals. Talk to people representing your interests with confidence, be proud of yourself and many doors will open.”

–Kristofor Medina

Stop and Think- Is Guardianship at 18 Necessary or Are There Other Options?

The attitude of many educators is that students with disabilities need help and lack the capability to do things on their own. There is a “panic” when the legal authority to make special education decisions goes from parent to student. Parents want to stay in charge of education decisions. Often, this is not meant to limit a student’s self-determination, but is because parents may not trust the school system.

How To Promote Supported Decision-Making

People need to be in charge of selecting who will be at their planning meetings. Too often this is not paid any attention. People with intellectual and development disabilities may not have as many friends as people without disabilities, and may be easy to influence. They often want to please the people on their team because they rely on them for everyday support. People may not have the self-advocacy skills to speak up for themselves. One way to explain this to self-advocates is to talk about the difference between what others think is “important for” you and what you say is “important to” you. Having a team meeting where a person does not get to select the members of their team results in the room filled with “important for” comments. This can easily drown out the “important to” comments. It is really important to have a neutral person outside of the agency help a person with planning.

Supported Decision-Making is Not a “Program”

Supported decision-making takes opportunities, skills, and practice for all involved. It is not realistic to think that every action staff take in a day will be empowering. Some days will be good and some not. We are dealing with human beings, their relationships, and outside pressures and influences. Although supported decision-making is not a program, states do need a system to train, monitor, and supervise staff to make sure that staff are continuing to learn and practice good supported decision-making strategies. This will keep the service system focused on our strengths.

Presuming competence is not about what we can't do.

It is about respecting people for their abilities!

Green Mountain Self-Advocates and Self Advocates Becoming Empowered

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The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities. The contents of this brief were developed by our partners at Self Advocates Becoming Empowered (SABE) under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR Grant # 90RT5028-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this brief do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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