

Service, Support and Success

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Supporting Informed Decision Making: Something Every Direct Support Professional Should Do!

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Each day, direct support professionals support scores of thousands of people with intellectual and developmental disabilities whose needs and desires are as multiple and varied as is their number. Central to this effort is a vast direct support workforce whose members have diverse ethnic, racial and educational backgrounds and whose different life experiences shape what they bring to the job. Our personal beliefs and values certainly guide each of us in our personal lives, but it gets really tricky once we enter our place of work because what we believe is “right or wrong” and what the person we support believes is “right or wrong” is often quite different.

As a direct support professional, being “person-centered” is more than an ideal or the next mandatory training. It is the heart and soul of the work of a direct support professional. Being “person-centered” is a yardstick against which all other activities we perform must be measured. In the National Alliance for Direct Support Professionals’ (NADSP) Code of Ethics, we define person-centered supports, “as a direct support professional, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.” Of course, this presents a significant challenge because, as we write in the Preamble to our Code of Ethics, “there are numerous pressures coming from organizations, government, social policy, and societal prejudice that can shift focus and allegiance away from the people who are being supported. Direct Support Professionals face ethical decisions on a daily basis and consistently feel the tension between the ideals of the profession and its practice.”

Often times, our duty and responsibility to protect people from harm is the highest priority, but that often puts direct support professionals in the position of imposing our values, judgment and concerns before those of the person being supported. It also can create a potential train wreck via a perception of power and control over another person. Where do we draw the line? How do we promote the dignity of those we support to assess and take risks, understand the consequences of a bad decision and learn from those mistakes? After all, that’s how everyone learns!



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In January of 2014, the United States Centers for Medicare and Medicaid Services, the federal agency that is responsible for funding the states in supporting people with disabilities, came out with new rules. Basically, if a state wants that federal money to support people with disabilities (and they do), it must comply with these new rules where there is a new emphasis on personal autonomy and greater access to integrated settings. The regulation also will ensure that people who receive the supports will be able to make informed choices. Given that direct support professionals will have a major role in ensuring that people with disabilities will be better prepared to understand the choice-making process, as well as associated risk and responsibility that goes along with making ones' decision, the NADSP created a training program that is geared towards educating direct support professionals to support the Informed Decision Making (IDM) process.

People with intellectual and developmental disabilities can be helped in how to make informed decisions, but have been traditionally limited in the opportunities to make their own choices. In many cases, the people we support are 'experience poor' and need to have opportunities to experience different options in order to establish a preference. The NADSP believes that people with disabilities should be given information about the IDM process. Through the use of scenarios and real life experiences, everyone will be able to learn how to make informed choices, as well as understand the risk and responsibility that goes along with decision making - big decisions and little decisions, the process is the same.

Until now, service systems across the world have been geared towards overprotection, which is counter-productive to allowing for the dignity of risk. In order to be truly person-centered, service settings will have to balance associated risk that is part and parcel of decision making, with its traditional regulations on incident management regarding abuse and neglect. We think you'll agree that, in many service settings, direct support professionals will be key in meeting these new guidelines.

In all regions of the world, people with disabilities report that having control in their lives is essential to being seen and treated equally in the community. Perhaps the self-advocates from Inclusion International say it best in their ["Global Report on the Right to Decide" \(2014\)](#), "Making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?"

Lastly, the report states this seemingly obvious but powerful assessment on the Right to Decide, "When people are supported to make decisions for themselves, they are seen as more capable by others. When we are not allowed to make our own decisions or when someone else makes our decisions for us, we are seen as less capable and as having less value in community."

In our experience, aside from family members, direct support professionals are often the lynchpin to helping people make decisions on a regular basis, and frankly, what's more important than helping someone direct the course of his or her own life?

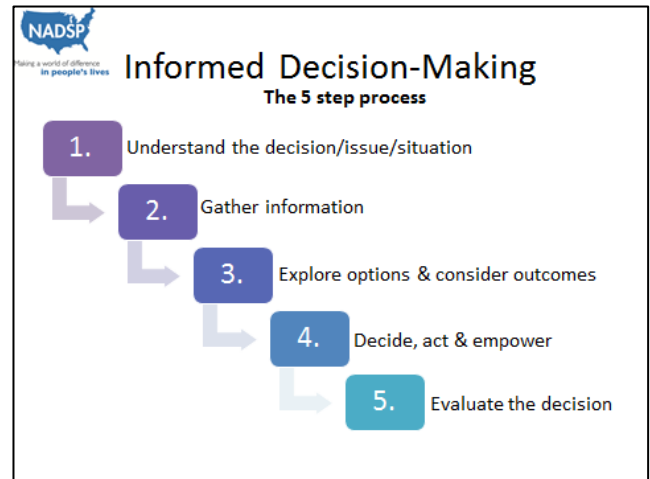
Understanding the Five Step Process to Making Decisions

To support the rights of people with disabilities to make informed decisions, the National Alliance for Direct Support Professionals (NADSP) has created a train-the-trainer curriculum which can be used by support organizations to help DSP's learn how to best support someone

when they are making a choice. The purpose of this training is for participants to develop an understanding of why supporting people with disabilities to make their own choices is important, for participants to demonstrate an awareness of how their attitudes and values toward choice can enhance or suppress the decision-making capacity of those they serve, and for participants to build the skills needed to support decision making in a manner in that balances choice and risk. This rich curriculum can take up to a full day of training, but here are the five core steps in NADSP's Informed Decision-Making (IDM) process for you to think about and discuss:

1. The first, and arguably the most important step in the IDM model is to identify the decision/situation/issue. A DSP will need to help individuals frame their issue/problem to understand if and how best to proceed in the process.

- What decision is being made?
- Is the person's choice clear and consistent?
- Does the person have experience/knowledge/understanding to support their choice?
- Is the choice being made voluntarily?
- Can the person be accountable/responsible for the consequence?
- How much risk is involved?



2. The second step is to gather information and resources. This is where DSPs will guide individuals on how to research and gather as much information and as many good alternatives regarding the issue as possible. This step could also include having the individual discuss the situation with peers, family and/or other trusted sources.
3. The third phase is to list options/choices and weigh them. Narrow the list of options that best fit the individual's values, goals and desires. This is where the DSP will assist the individual to rank the alternatives. Determine options by considering what is realistic and possible for the person. The options should seek to lower the risk of the choice, add to or reflect experience that the person has to base a good decision upon, and/or help the person gain clarity about what they want.
4. The fourth phase is to make a decision and a plan of action. Implementation will require a lot of support from the DSP in the beginning and, depending on the decision, on an on-going basis, until the individual has garnered sufficient experience. Therefore, it is important for the DSP to empower the person to act on the choice and provide support throughout the process to make the decision a reality.
5. The last phase of the process is to evaluate or reflect on the decision to determine how well it went for the person. Evaluating the decision should provide clarity to both the person who made the choice and supporters to inform future choices.
 - What did you (the DSP and the person) learn?
 - What are you (the DSP and the person) pleased about?

- What are you (the DSP and the person) concerned about?
- Given this, what will you do next?

Here are some things to consider. There is a big difference between decision and outcome. You can support someone to make a good decision based on the information at hand and still have a bad outcome. The decision is within your control, but the outcome may not be. If a decision does not have the outcome you expected, you can start the process over.

The Staff Training Video on How to Support Informed Decision Making

An integral part of the NADSP all-day training program is a video that demonstrates how staff support individuals in making informed decisions. The video can also be used as stand-alone training. It is available for free on the workforcetransformation.org website which is part of the New York State Office for People with Developmental Disabilities (OPWDD) workforce transformation initiative. The video shows seven scenes of challenging situations where direct support professionals (DSPs) have difficulty in supporting a person's informed decisions. As previously stated by Carol in the preceding section of this article, the five step decision-making process is continuously demonstrated. Additionally, a three step process for active listening (repeat, ask, validate) is emphasized. The actors in all the scenes are actual DSPs and the individuals with disabilities that they support. We tried to demonstrate how all people, regardless of the level of support required, can make informed decisions. Below are examples:

In the first scene, an individual wants to buy expensive sneakers at the mall. If he buys those sneakers which cost \$140, he will not have enough money to join his family on an outing the next day. The video asks, "What should the DSP do?" This is not an easy situation for the DSP. We first show the DSP handling the situation in a way that does not respect informed decision making. He tells the person that he doesn't have enough money to buy the sneakers because he is going on a trip with his family the next day and needs the money for the trip. Why is this wrong? The person did not have support in making an informed decision. Rather, the staff made the decision for him. Why? The staff may have thought that the sneakers were too expensive and that he would never buy them for himself. The staff may have been concerned that the family and his supervisor would blame him for allowing the person not to have enough money for the outing. The person might be upset the next day because he realized he cannot go on the outing with his family. The video next shows a better way for the DSP to support the individual following the five step informed decision-making process that was reviewed in the preceding section. Rather than try to influence the person to make the 'right' choice of buying less expensive sneakers so enough money remains for the outing, the staff person reviews a short list of options and outcomes from each option. At no point does the DSP try to persuade the individual. In a calm, emotionless manner, he enables the individual to truly make an informed decision.

Another scene shows a woman who requires a great deal of support shopping in a department store. She is in a wheelchair, cannot speak or move her arms and communicates through eye gaze. The video shows how the DSP can support her in choosing what dress she truly wants. The other scenes are also very thought provoking.

The video was made at programs run by the Center for Disabilities Services in and around Albany, New York. The scenes were suggested by direct support professionals and front line supervisors. Leading the project were three outstanding administrators: Tom Gillespie, Barbara Pettengill and Nancy Champlin.

Conclusion:

We realize that focusing on helping people understand the human decision-making process is another new skill that will be required of direct support professionals as their roles evolve from care giving to providing support and building bridges to a full life in the community – this is a new paradigm that requires a different mindset that focuses on equity and support. While doing this, we must always remember a few important things: human decision making is a flawed and complex process. It doesn't matter if you have a disability or not, it's messy work! As direct support professionals, we must always be mindful of our own values and never let them influence the person that we support, or interfere in their decision-making process. Of course, if someone wants to make a decision that would harm themselves or others, we would immediately intervene, effectively communicate with our team and supervisors, and document, document, document! Good luck and we hope that you go out and empower people in their decision making – big ones and small ones.

About the authors:

Joseph M. Macbeth is the Executive Director at the National Alliance for Direct Support Professionals (NADSP) and has worked in the field of intellectual and developmental disabilities for more than 30 years - beginning as a Direct Support Professional. Macbeth is recognized as a national leader in the advocacy and advancement the direct support profession and is a highly sought after speaker on the workforce crisis affecting human service provider organizations. He has co-authored the series of publications titled "Voices from the Frontlines", produced an award winning Realistic Job Preview titled "Working as a Direct Support Professional: We Get It Done," and has partnered with the State University of New York (SUNY) and assisted more than 500 direct support professionals advance their college education through the Disability Studies Certificate. He currently sits on the board of directors for the Council on Quality and Leadership (CQL), the College of Direct Support and Relias Learning's National Advisory Boards and most recently was appointed by New York Governor Andrew Cuomo as a Member of the Advisory Council for the New York State Justice Center for the Protection of People with Special Needs. He lives in Albany, NY.

Dr. Carol Britton Laws is a Clinical Associate Professor and Interdisciplinary Training Director for the Institute on Human Development and Disability (UCEDD) at the University of Georgia where she coordinates the Disability Studies Certificate program at the undergraduate and graduate levels. She is a Fellow of the American Association for Intellectual and Developmental Disabilities and former President of NADSP. She has worked in the disability field in roles that range from direct support professional to state-level program design. She lives in Athens, Georgia with her wonderful husband Jason and two fat cats.

Perry Samowitz has an M.A. in Rehabilitative Counseling from the University of South Florida. He is currently the Region 3 Leader for the OPWDD Centers on Workforce Transformation. He has been in the field for over 40 years. Perry started as a residential supervisor for YAI and

subsequently, for over three decades, was the YAI Director of Education and Training. Perry was responsible for training over 5000 staff, including DSPs and managers. He has created over 50 training videos in the field for both staff and for people with developmental disabilities. The training videos include:

- How to Enhance the Ability of People with ID/DD to Think and Problem Solve
- How to Teach People with Profound ID/DD
- Nine videos for people with ID/DD on Relationships and Sexuality
- How to Work with Adults on the Autism Spectrum
- How DSP's can empower individuals with ID/DD by "Listening, Supporting and Empowering"

Perry is one of the co-authors of the NYS DSP Core Competencies Curriculum as well as the PROMOTE curriculum.

Perry has lectured and trained in over 20 states, as well as in Canada, Iceland, Finland, Israel, Jordan, Saudi Arabia and the United Arab Emirates. His expertise is in preparing staff to work with various populations of people with developmental disabilities.

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