

Finding the Balance: Person-Centered Supports that Honor Safety and Dignity of Risk

Q: How do you communicate risk/safety to someone with cognitive disabilities?

Marian: Honestly and respectfully with the presumption of competence. When working for someone who has cognitive disabilities, we always presume competence. We approach the person as the expert in their own lives, meaning we believe they know themselves best, and it is our responsibility to understand how they articulate their needs, preferences and aspirations. We have learned, and continue to learn, that just because someone does not use their voice to communicate doesn't mean they don't have anything to say. The fact that we as the professionals may not like what the person has to say is another issue entirely.

We are also learning that the first service we can offer someone is to help them own their own communication. Whether that is using technology or a piece of paper and pen, or some other means, helping someone access the means to express themselves is vitally important.

We also invite the people who know, like and/or love the person to share information from their perspective as we also know that the most important decisions one makes, often means depending on others to help understand the situation and to make the best possible choice even when, and especially when that decision may not be in their best interest.

Q: These are situations in which issues of rights are often more complex for families and providers, including medical professionals. Service providers are held accountable when our participants make choices that result in harm or unfavorable circumstances. How do we balance this?

Nicole: One thing that is good for everyone when supporting adults with I/DD is to weigh the pros and cons of potential decisions. For example, getting wisdom teeth removed as a kid vs waiting till you're an adult and they bother you. We must be there to help them learn through the school of hard knocks. Try and share stories and drawing out the pros and cons, and their consequences.

Marian: I would first suggest that language precedes behavior and so referring to people as 'our participants' may actually be impeding the ability to co-produce solutions

which could potentially mitigate or even prevent choices that result in harm. I would need a clarification on what is meant by 'unfavorable circumstances' to offer an idea on that.

I would also need clarification on what the service provider is being held accountable for, in terms of someone else's choices. Can we use real life examples to further explore this question?

I would also ask for clarification on what is meant by 'more complex'? Is this regarding the person's support needs or a more complex situation for the providers? If the latter, that is our responsibility to work in collaboration with people, their families and medical professionals to work through situations that balance a person's right to choose, and what is indeed important to and for their safety and well-being.

Q: How does a provider navigate the liability/professional insurance provider expectations?

Nicole: On a broader policy level I think this is an area that needs 21st century reform in spirit of the Olmstead decision which says we have a right to live in the community. By closing segregated settings and investing in community-based services it creates an expectation, attitudinal shift in how we view those with I/DD. Society role is not just to "take care of us" But to support to achieve maximum independence in the most integrated setting to the greatest extent possible. Even though we have closed down big institutions, the attitudes of these places still exist. The direct support professionals (DSP) must work with clients on skill building need for greater independence. Use technology or labels to minimize danger in case of someone living alone. Role play what to do if fire alarm goes off and you are alone, for example. Teach clients self-advocacy skills for when they get stopped by a cop. The insurance industry should get training on basic disability awareness.

Marian: Here again, I think it would be most useful to use real life examples of when and where a provider has lost insurance coverage for a decision that someone they support has made.

Our organization carries the same types of coverages as any other provider, as well as the risk assessments that go along with them. In our experience, we have significantly less employee-based claims (workers compensation) as compared to the residential organization some of us worked for previously, and we have not yet had a liability claim (in over 15 years of supporting people in a co-produced manner).

Q: How do we go about navigating regulations and requirements while honoring dignity of risk?

Nicole: Support and teach them skills needed to be as independent as possible. For example, taking one's own meds without having a provider sign off on it. On a policy level, state regulations should be adjusted with the new home and community-based service (HCBS) setting rules to make it truly feel like living in the community. For example, give a key to their own house and teach how to lock, unlock the door.

Marian: If we are doing what we say we are doing, that is supporting people in person centered and individualized manner, in ways that reflect the organization's mission, vision and values statements, then it is our core duty to navigate the appropriate regulations. It's the expertise we bring to the table, if we are truly co-producing services and supports. This requires a total re-thinking of more traditional organizational structures, roles, policies and practices, what we have come to call 'boundaries flexibility'. I am happy to discuss in more detail the lessons we are learning as an organization.

Q: What is the difference between a direct support professional and a nursing assistant?

Nicole: A DSP is someone who provides Home, Community or Job support in the community for a person to have a dignified life in the community. A nursing assistant to me is more medical, physical care for someone with physical disability, chronic conditions due to aging and needs the highest level of care, you would often get in a hospital.

Marian: In our organization, some people choose to hire people who have nursing degrees or nursing assistant certifications to provide direct support, based on their support needs. So, in our experience, the person providing the direct support can have the qualifications and skills sets, experience and characteristics that are important to the person and their family (especially if the services are being provided in the family home)

Q: How can the provider balance... 'physician ordered' with a person's choice to experience risk?

In our experience, we would not contact someone's physician or any medical specialist without their involvement and agreement, so this is a bit challenging for me to picture.

The person would be assisted to talk with whomever they would want to talk to, to make a difficult decision. Perhaps the person has not thought to reach out to their doctors. This could be something we as the provider would suggest/recommend/ urge someone

to do but should not be done without the person being involved, and their preferences and needs guiding the process. Then, it is still the person's decision to follow the physician's orders, or not. Our job is then to create a plan for if/when the person's decision causes illness or some other consequence. We think about that first and part of the support we offer is suggesting consulting with people who have expertise in whatever the area of concern.

Again, I think it would be most useful to use real life examples as every person's situation is unique and should be honored in that way.

Q: How many states have Supported Decision Making as a law in their probate code?

Marian: I don't know the answer to that but I don't know that is matters as long as the process of planning and then implementing the support plan includes the person, their families and other chosen allies.

Q: How do you work through when there are disagreements with a guardian?

Marian: This is best discussed on an individual basis, as each situation is unique, as is the relationship the guardian has with the person, their providers and other team members.

Also, is this a question about disagreements between the person and their guardian? Or the provider and the guardian? Very different approaches in our experiences.

We have learned to ask for the guardianship documentation as there are different types of guardianships.

We have responded to situations differently, but always with respect for all parties involved, and again always sharing and using our expertise in terms of building trust among all team members; inviting others who care about the person to be as involved as the person wants; facilitating circles of support; understanding family dynamics; connecting families to other families for information and support; confirming the importance of self advocacy and supporting people to learn to do this, and continue to do despite non-supportive or challenging conditions; connecting people with I/DD to other people who have experienced similar circumstances and situations.

Q: Any division between our topic and behavioral health...is it one conversation that is applicable to both scenarios?

Marian: Co-production was born in the US civil rights movement. This practice involves universal principles that apply to every single one of us, on the basis of our humanity. Every person has the right to determine their own destiny, and everyone knows themselves best. We believe every person is the expert of their own lives. Professionals who are invited into a person's life, no matter what the 'system', should share their expertise in efforts to support the person to make the best possible decisions for their lives, with the understanding that it is the person's right to disagree and not follow the advice and guidance of others.

Q: Thoughts on our system allowing time necessary for relationship development and trust [with medical professionals]?

Marian: We don't believe any one 'allows' anyone else to do anything. We know that people who are oppressed in the name of treatment, express themselves in ways that are often harmful to themselves and others, and often result in vicious cycles of 'reward and punishment' (again in the name of treatment, aka behavior modification/management plans)

In our system, if we are asked or it is part of the service we are providing, we assist the person and their family to choose from among the best possible medical/psychiatric professionals available to them given their insurance and geographic location. Our role before appointments is to help the person prepare, and ensure we provide the necessary information and data to the doctor. During the appointment, if needed we will amplify (not replace) the person's voice, including their thoughts on their diagnosis and treatment. We will help them advocate for themselves (or on their behalf if given permission). After the appointment, we debrief and help with any decisions such as 'do you understand what the doctor said/prescribed etc....?'

We don't expect that medical professionals will readily change their behavior, so we know we much change ours, and ultimately help the person adapt and respond to the reality of unfair and inequitable health care in our country. This is the reality not just for people with I/DD but for many of citizens who cannot afford 'good insurance' so for us, it is about helping people make the best use of what they have.

Q: Marian, address how the organization works with non-verbal people to identify their dreams and goals:

Marian: We believe everyone communicates and that everyone has a right to their own communication as a human right.

We presume competence, always

From there, we prioritize communication assessment and access for anyone who does not communicate in 'traditional' ways.

We help the person invite and uninvite if necessary, people they want to be a part of their visioning and planning process. For each person and family, the process differs dependent on many things such as how the person communicates, their family dynamics and preferences and where the family is in terms of their life course.

We provide accommodation and support as needed based on the person's preferences and needs:

Framing questions as Yes/No

Paper pencils, crayons markers etc.

Visual aids

Asking the person to demonstrate their thoughts

PATH as a planning tool (graphic representation)

Charting the Life Course Framework as a tool

Q: Nicole/Chester, how do "professionals" support you in making your input heard and used effectively?

Nicole: When it comes to getting input and making our voices heard, you can support us at meetings by making materials plain English-using words everyone can understand. Sending out materials for meetings ahead of time in large print could also help. Actively Presuming Competence and Having High expectations is a big part. Take notes at meetings and go over stuff that was said to ensure I understand it. Providing a supportive environment with natural support from colleagues. Treating us like equals. "I am a person before my disability."

Additional Commentary and Resources provided by Marian

Co-production of services and supports guarantees the full participation of the person(s) effected by any and all aspects of their services and supports. In co-produced services, there is no abandonment of 'patient choice' because all actions are driven by the person, and those they choose to include in their circle or team. Here is a link to basic information on co-production in disability services:

<https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/In-more-detail/what-is-co-production/>

I believe I offered our approach to ensuring people themselves make the decision about whether to follow the 'orders' of a medical professional. I cannot emphasize enough the importance of including the person and their voice, in all aspects of their own healthcare. For example, when a practitioner talks to the professional/paraprofessional instead of the person, the professional/paraprofessional should look to the person and engage with them to respond. Sometimes it's as simple an action as that. Other times, it may mean helping the person present a complaint to the special need's unit of their insurance company. We've seen positive results with that, but it takes courage to do it.

It's important for us to remember that it's never just about the person's choice, it's also about our response to their decision. And that to us is the essence of good support. We can disagree respectfully without us ever having to say the person cannot make that choice, because we can't, and we won't. In a trusting relationship, based on mutual respect and shared power, effective conversations can occur that can lead to a person making a healthier decision of their own accord.

I think for many if not most of us, it's not just about learning from our mistakes as important as that is. It's about the people who stood by us, behind us, in front of us (wherever!) and helped us when we were at our worst, making our mistakes. That's what many people in our system don't have. Think about if we spent as much time helping people find and make friends, as we do trying to get them to behave in ways we find compliant and polite. I believe we would see a huge difference in our work, in each other, and in our system. And that's what we are working to do.

And as we know psychological health is closely linked to physical health. Think also of the health outcomes for many people in our system—they would likely improve with the amount of control they have over themselves, and their destinies. I believe there is research that upholds this.

The question is how do all of us, as stakeholders in this system, work together in a co-produced manner, basically how do we shift from blame to support? How do we treat each other as we expect each other to treat the people using services? As a provider of Support Coordination services in a state where we do not provide direct services, we know how often this role is blamed, yet we often are challenged to find providers who value our role.

Invite guardians in! Our organizations see our role as a direct service provider and as a support coordination provider is to help the person build their network of family and friends. We should be prioritizing trust and confidence in our collective efforts, and our ability to work alongside each other for the good of the person supported.

I agree that Chester and Nicole shared really good examples. Of course, they did! They are the experts of their own lives and have lived experiences most professionals do not. They, like others with similar circumstances, could be seen as dependent on a system of paid support. Instead, they have taken control of their lives. Their efforts have made them leaders, as they show us through their examples, share their expertise and use their power to help others, including providers. I appreciate both of them, and am honored to have been invited to present alongside them.

Families of people with I/DD must be respected for their expertise. They know their family members better than anyone in a paid capacity. What they may not know or understand is the system 'stuff', Medicaid rules, how to find good paid supports, how to navigate their community for resources that every other citizen is using etc..... In a context of co-production, everyone is respected for what they bring to the situation; debate is seen as healthy and is done in a trusting and caring way and ultimately everyone understands that this is about family support, directed by the preferences and support needs of their family member, the person with a disability.

Try to not take feedback personally, but see it as improving on behalf of the person accepting support. Even when unsolicited, we try our best to take feedback from other professionals in an open and accepting manner. When we disagree, we respectfully communicate our disagreement and attempt to collaborate on what would work better for all involved. We try to use every situation as a way to model and demonstrate the importance of co-production.

Attitudes often translate to actions and I agree that we must begin to educate and support families earlier in their life course.

Begin by supporting the families of the people you are supporting. For us, this has made all the difference as we learn about the importance of supported decision making in all situations not just the 'easy' ones. And we learn, we see that someone's easy is another's difficult, so it is all relative.

Here are links to two TED Talks. While not specifically related to I/DD issues, they both speak to the need for professionals to change our own behaviors, and allow our work to be the change we want to see in others and in our world. The first is presented by Cara E Yar Kahn, and she speaks to the balance between courage and fear as being beautiful-interesting! The second features Natalie Fratto, and this spoke directly to me as a service provider. We used this as the basis of our organization's current strategic plan.

I hope you find these helpful, and would welcome hearing from anyone interested in talking about how they received these talks.

https://www.ted.com/talks/cara_e_yar_khan_the_beautiful_balance_between_courage_and_fear?language=en

https://www.ted.com/talks/natalie_fratto_3_ways_to_measure_your_adaptability_and_how_to_improve_it?language=en

Thank you for the opportunity to respond to the questions and reflections. Most of all, thanks to the NCAPPS Team for giving me the opportunity to share the lessons we are lucky enough to be learning alongside people with disabilities and their families who choose to accept services with us.