

Deep Connection with Ordinary "Community Life"



IDEA 3: EMBRACING EXPERIENCE AND SUPPORTING THE DIGNITY OF RISK

Life is a succession of lessons, which must be lived to be understood.
-Ralph Waldo Emerson

IN A NUTSHELL:



We often talk about people with developmental disabilities having the same opportunities and choices as everyone else. And as people lead fuller lives in their communities, those experiences often come with risk. As a result, the conversation about "dignity of risk" becomes increasingly relevant.

As we all know, conversations about people with disabilities experiencing "risk" can be uncomfortable. These conversations often reveal two things: 1) we all have individual ideas about and comfort levels with *risk*; 2) when a person uses services, the circumstances and the approaches to decision-making *do* change--there are more people involved who all share some level of responsibility for the person's welfare. This creates an awkward but potentially inevitable struggle in our heads that probably goes a little like this:

"I really want [insert name of person using services here] to have a full life and do the things she wants to do. I totally get that there is risk involved sometimes and that we all learn from mistakes. But I just don't want anything bad to happen to her...especially (gulp) not on *my* watch."

SUCCESS STORY

"C. met a friend online in a chat room. After talking for few weeks, our client decided she was going to on the bus to meet her in California. We had a team meeting with C. and talked about the dangers of going. We had the police talk to C. We gave C. our phone numbers. We called and talked to the friend in California before C. went. We knew the address and phone to where she going. C. went on the trip against everyone's better judgment. She stayed 3 days and called staff and was unhappy. Staff sent her a ticket and she returned home."

Ironically, protecting people from experiences may actually make them MORE vulnerable and potentially put them at GREATER risk of being in dangerous situations. Given that human beings *learn* through experience, we may best address people's safety by thoughtfully supporting them to have the experience of living a full, engaged life.

Despite the fears about supporting people to have typical life experiences, many New Mexicans with disabilities *are* leading full lives and receive the thoughtful, respectful support they need to do so.

Supporting people to have typical experiences and navigate potential risks is never easy and each situation poses a unique set of questions and considerations. There are no "quick and easy" answers for how to support people to live a full life. Therefore, the most important thing we can do is encourage thoughtful dialogue between the person and those who know the person best. In an effort to encourage conversation, this paper has been written as a series of questions to help people, teams and other entities have thoughtful conversation about typical experiences and the dignity of risk.

BRINGING IT TO LIFE **THOUGHTS AND IDEAS**

THOUGHTS FOR EVERYONE

Aren't We Talking About Dignity of *Experience*?

"Risk" is defined as "a situation involving exposure to danger." Yet the everyday dreams and wishes of most people are not usually described as "dangerous"— the desire to own a home, to have friends and a social life, to go on a date and have a relationship, to participate in worship services, to try a new job, and to travel.

Certainly any activity has potential risk (or even danger) in it, but most people are not prevented from having the experience because of these potential risks. However, often the discussion about the wishes, dreams

and desires of an individual with disabilities focuses on the “risks” involved without first valuing the importance of the larger experience. As we support people with developmental disabilities to navigate risk, we must first commit to supporting people to have rich, full lives, filled with typical experiences.

What if We Committed to Using our Common Sense and the Typical Public Standard of Experience to Guide our Decisions and Supports?

If a person wants to try something, here are some questions to consider...

- Is this something that other people do?
- If my friend/my sister/my mother/my wife said she wanted to do this, what would my advice be?
- How can I both support this idea and give this person the information he needs to make an informed decision?
- Are there any special safety considerations we need to think about, given this person has a developmental disability and may be more vulnerable in some ways?

How Can We Keep Talking? The Importance of Conversation

Ongoing conversation about the concepts of *typical experiences* and *dignity of risk* is essential to individuals having fuller, richer lives.

Some ways to keep conversation going....

- Widely share stories about successful experiences.
- Create an organizational and team culture where people are encouraged to talk about challenges they are facing in supporting people to have typical experiences.
- When an experience doesn't go well, invite people to talk about lessons learned and if anything could have been done differently, instead of looking to assign blame.

- Facilitate opportunities for providers to talk to providers, family members to talk to family members, case managers talk to case managers, etc.

THOUGHTS FOR FAMILIES, GUARDIANS and TEAMS

Do we understand that our function is to support adults to have typical experiences?

Some ways to ensure team's support for a person's right to have a typical experience:

- When staff pose new ideas or ways of supporting typical experiences, acknowledge and celebrate the initiative and creativity BEFORE editing or critiquing the idea. Consider asking questions like:
 - "HOW can we make this happen?"
 - "What can we do to help?"
 - "How can the organization do more of this?"
- Teams should assume a permissive approach to supporting the person and her staff to try new things and enjoy typical experiences. Support people to "just go do" within the framework of 1) the activity being guided by the person's interests and 2) the person and his/her staff being thoughtful about mitigating the risks involved in the activity.
- When the person we support wants to try something new, do we talk about the "pros and cons?" Do we come up with a plan for what happens if the experience doesn't go well?
- If we are struggling with a person's desire to have a particular experience, have we asked for help to figure it out rather than simply saying "no"?

When an accident occurs in the course of doing a typical activity, can we work to ask “What can we learn?” instead of “Who’s at fault?”

Sometimes accidents happen. Sometimes the accident is a result of poor planning, a flawed organizational practice, a lack of training, or an error in judgment. And sometimes, despite the best preparation, mishaps still happen. Formal investigations, while sometimes necessary, create anxiety among staff and foster a “fault finding” organizational culture. As teams and organizations respond to accidents, consider asking the following questions and incorporating the following approaches:

- Are we ethically or legally required to conduct a formal investigation? Can we learn about what happened through less formal channels?
- Do we ask the person directly if s/he thinks the incident could have been avoided? Are any future prevention measures acceptable to the people using services?
- Whenever possible, informalize the debriefing. Think through what happened with both the staff and the person directly involved in ways that everyone is comfortable being open and honest. Have the conversation over food, or in an informal space—like a living room.
- If staff were directly involved in the incident, consider inviting a group of fellow direct support staff to participate in the conversation and offer input and feedback about the incident and whether it could have been avoided.
- Are we at peace with the idea that sometimes NOTHING could have been done differently to avoid an accident? That sometimes, in the course of living a full life, unfortunate events that are beyond our control happen?

Does a person's Individual Service Plan ("ISP") reveal a robust, passionate vision for a person's life?

In New Mexico, a person's ISP is considered the foundation on which services are built. By this logic, the ISP needs to be full of information about who a person is, what s/he enjoys doing, and ideas for new experiences.

While a document can never truly capture a person's life experience (the fuller a person's life, the more difficult to reduce it to paper!), a thoughtfully developed, "possibility-oriented" ISP can provide a formal endorsement for supporting a person to try new things and have typical experiences.

When developing an ISP, consider asking...

- Have we encouraged the person and his/her direct support staff to "take the lead" on developing the ISP?
- Does this ISP work to expand a person's life by including new ideas for experiences based on what we know about this person?
- Have we included language in the ISP that supports a person to "try new things?"

THOUGHTS FOR PROVIDERS

Do we know this person well and are we doing our best work in our efforts to support typical experiences?

The better we know a person, the more thoughtfully we can prepare the person for a new experience. When we know a person well, we have a good understanding of things like:

- How a person best receives information (verbally, with pictures, etc.);
- Specific personality traits that may influence the outcome of the experience;
- Unique safety and support considerations that need to be considered when organizing the experience.

While we are always working to deepen our understanding of who a person is, it is really important to have a trusting, informed relationship already established with a person when supporting him or her to have new experiences. Some basic ways to get to know the person:

- Prioritize opportunities for getting to know the person, BEFORE services begin.
- Ensure that support staff knows the person well, has good judgment and can give the person his/her undivided attention.
- Create informal opportunities for a person, her staff and family to tell stories about the person and debrief on activities and experiences.

How can the organization's mission and vision be used to support typical experiences?

Most organizations that serve people with disabilities have value-rich language in their mission, values statements and vision. Organizations often are publicly committed to supporting people with disabilities "to achieve their dreams" or "to achieve their goals." These articulated values are intended to guide the supports the organization provides and can be used to leverage additional support within the organization, on teams and within the communities.

Some questions that explore how organizational values can facilitate typical experiences...

- Are the lives of the people served by the organization consistent with the organization's values?
- When unsure how to best support a person who wants to try something, what does the organization's values call staff to do?
- What if an organizational donor or board member was invited to share her social network and time with a person using services in lieu of a financial donation?
- Are the organizational values widely distributed and discussed with families, community members, regulators, teams and staff?

Do we talk about our organizational values regarding typical experiences with people and their families/guardians BEFORE services begin?

As we all know, families and staff often have different ideas of what is possible for a person with disabilities. By engaging in conversation about the typical life experiences *before* services begin, people, families and organizations are able to create a foundation of common values on which to build future supports, decisions and experiences.

Some language that may be useful...

- “We all agree to work together to thoughtfully explore how this person can enjoy a rich life full of typical experiences.”
- “We know that there may be times when we’re nervous about supporting a person to have a particular experience. When these situations arise, we all agree to talk about how to ensure the person has the best experience possible.”
- “We all understand that because of disability or circumstance, this person may require additional preparation or support when having a particular experience.”
- “We agree to not limit the person or our thinking with concepts like “mental age” but will work to respect the person’s adulthood and to acknowledge that people grow and mature through life experience.”

Do we prioritize hiring staff with good judgment (even over experience in the field or certifications)?

Some ideas for how to hire quality staff...

- Invite talented direct support staff and people who use services to help identify staff candidates, both through recruitment and interviewing.
- Ensure the recruitment and interview process highlights and reflects an organization’s commitment to typical experiences.

- Include a number of “what if” scenarios about a person and a typical experience in order to assess the candidate’s judgment and other important skills.
- For more ideas on hiring staff, check out the paper “Finding Good Fits between Direct Support Staff and the Person Served,” located in the *Supporting Individualized Access* section of the *Meaningful Day Idea Book*.

Do we create an “open door” organizational culture, so that staff feel comfortable asking for help?

Thoughts about how to create this culture...

- Do organizational leaders ask direct support staff for their guidance and thoughts on how to improve the supports to people?
- Do organizational leaders emphasize the importance of constant learning and asking questions, including questions that respectfully challenge the status quo or poor outcomes?
- Do we prioritize a staff person’s critical thinking skills (fundamental for problem solving) over her expertise?
- Do we acknowledge that when engaged in the tricky, nuanced work of supporting people to have typical life experiences, “I don’t know” is often the most honest response to a question and usually reveals an opportunity for critical thinking and conversation?
- When staff ask for help, is the organization responsive?

Have we scrutinized any internal policies that summarily restrict experiences that the general public would deem “typical?”

Some thoughts about policy development...

- Develop policies in partnership with the people who use services and their staff.
- Before developing policies, explore the questions:
 - Does this proposed policy help or impede people’s ability to have typical experiences?

- Is this policy consistent with common sense?
- Is this policy easy to remember?
- If you were receiving supports under this policy, would you be ok with it?
- Avoid drafting reactive policies—policies that result from an unfortunate outcome of a typical experience. Use unfortunate outcomes as an opportunity to think about how the outcome could have been prevented and whether the outcome reflects a systemic issue or an isolated incident.
- Acknowledge that all policies will have unintended effects once they are executed. Be open to revising policies quickly and as needed.

How do we ensure any concern about liability doesn't get in the way of supporting people to have typical experiences?

Just as thoughtful risk-taking is an essential element of having a full life, perhaps an organization's fullest potential is realized when it is not driven by fear of liability but rather by an openness to possibility by thoughtfully and respectfully supporting typical experiences in the lives of the people it serves.

When bad things happen, do we always respond in a way that:

- 1) encourages dialogue about what happened;
- 2) nurtures typical experiences; and
- 3) doesn't discourage trying new things in the future?

THOUGHTS FOR EXTERNAL ENTITIES

Do we recognize that the more people have typical, community experiences, the greater chance of real life happening—trips, falls and all?

✓**CHECK IT OUT:**
GOOD RESOURCES

- For a collection of articles about experience, self-determination and dignity of risk, look at “A Few Words About Dignity of Risk” in the *And Yet More Section*. Special thanks to Lorie Ellison for compiling this information.
- Dignity of Experience Workgroup’s Report to the ACQ, go to the *And Yet More* section.
- Consent Handbook for Self-Advocates and Support Staff. AAIDD, available through Quality Mall at <http://www.qualitymall.org/products/prod1.asp?prodid=3659>
- For discussion of liability, take a look at “Risks in Providing the Least Restrictive Environment in a Litigious World, Question and Answer Session with Chris Lyons, defense attorney.” Available at: www.dhs.state.mn.us/main/dhs_id_057572.doc