

Person-Centered Approaches to Supporting Dignity of Risk for People with Disabilities

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NCAPPS



Welcome to Today's Webinar



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Thank you for joining us to learn about how to support dignity of risk for people with disabilities.

Today's webinar is sponsored by the National Center on Advancing Person-Centered Practices and Systems (NCAPPS).

NCAPPS is funded by the Administration for Community Living (ACL) and Centers for Medicare & Medicaid Services (CMS).

NCAPPS webinars are free and open to the public.

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.





Webinar Logistics

- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English and live interpreted in Spanish.
 - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen.
 - Live Spanish interpretation can be accessed by clicking the “interpretation” button at the bottom of your Zoom screen (world icon). Once in the Spanish channel, please silence the original audio.
 - Se puede acceder a la interpretación en español en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). Una vez en el canal español, por favor silencie el audio original.
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- After the webinar, you can send follow-up questions and feedback about the webinar to NCAPPS@hsri.org.

(Please note that this email address is not monitored during the webinar.)

- The recorded webinar, along with a PDF version of the slides and a plain language summary, will be available within a few weeks at NCAPPS.acl.gov. We will also include questions and responses in the materials that are posted following the webinar.

Who's Here?

“In what role(s) do you self-identify? Select all that apply.”

1. Person with a disability/person who uses long-term services and supports
2. Family member/loved one of a person who uses long-term services and supports
3. Self-advocate/advocate
4. Peer specialist/peer mentor
5. Social worker, counselor, or care manager
6. Researcher/analyst
7. Community or faith-based service provider organization employee
8. Government employee (federal, state, tribal, or municipal)

Meet Our Speakers



SHANNON NEHUS



**MARY LOU
BOURNE**



ELISE MESSNER



SUSAN ARWOOD



CARL LIPFORD

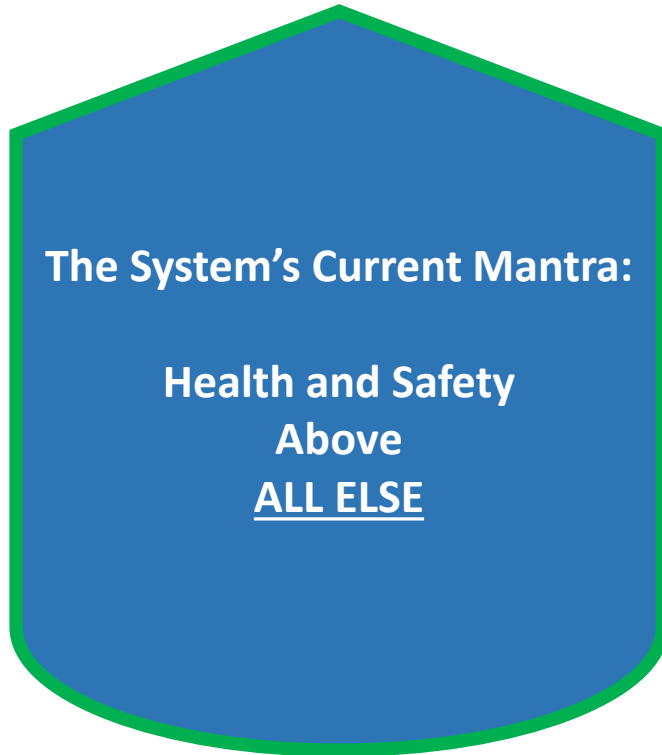
Addressing Risk in Person Centered Services

Sparking Change in
Developmental Disability Systems

Addressing Risk in Person Centered Services

Utilizing an intentional risk identification, planning and implementation approach supports the dignity of choice for people you support.

Why does it Matter?



Risk and Learning are directly related

Learning and self confidence are directly related

Self Confidence and positive self esteem are directly related

Our Systems hide behind the shield of protecting health and safety as a reason to withhold opportunities for reasonable risk and learning

Person Centered Planning in Federal Regulations

Requirements for person centered service plans (Fed. Rule CFR. 42 § 441.301(c)(1) and (2))

1. The plan process must...

(ii) provide necessary information...to ensure...informed choices and decisions.

2 The plan document must..

Reflect the supports ...important for the individual to meet needs identified... and what is important to the individual re: preference for delivery of such services.



Person Centered Planning Rules

Requirements for person centered service plans (Fed. Rule CFR. 42 § 441.301(c)2)

The plan document must

(vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed and

(xii) Prevent the provision of unnecessary or inappropriate services and supports

Key words: Minimize... Prevent... unnecessary ...support



Get Curious: Thoughtful Planning



- What is it that the person does? (*actions taken, behavior observed*)
- What is it about this action that worries others or creates fear? (*risk*)
- What do we understand about the action? (*context or conditions*)
- What are the likely results of the action? (*impact or consequences*)
- What keeps the person from doing it? (*prevention*)
- What do people do when the person engages in the action? (*response*)

Two important questions to discuss:

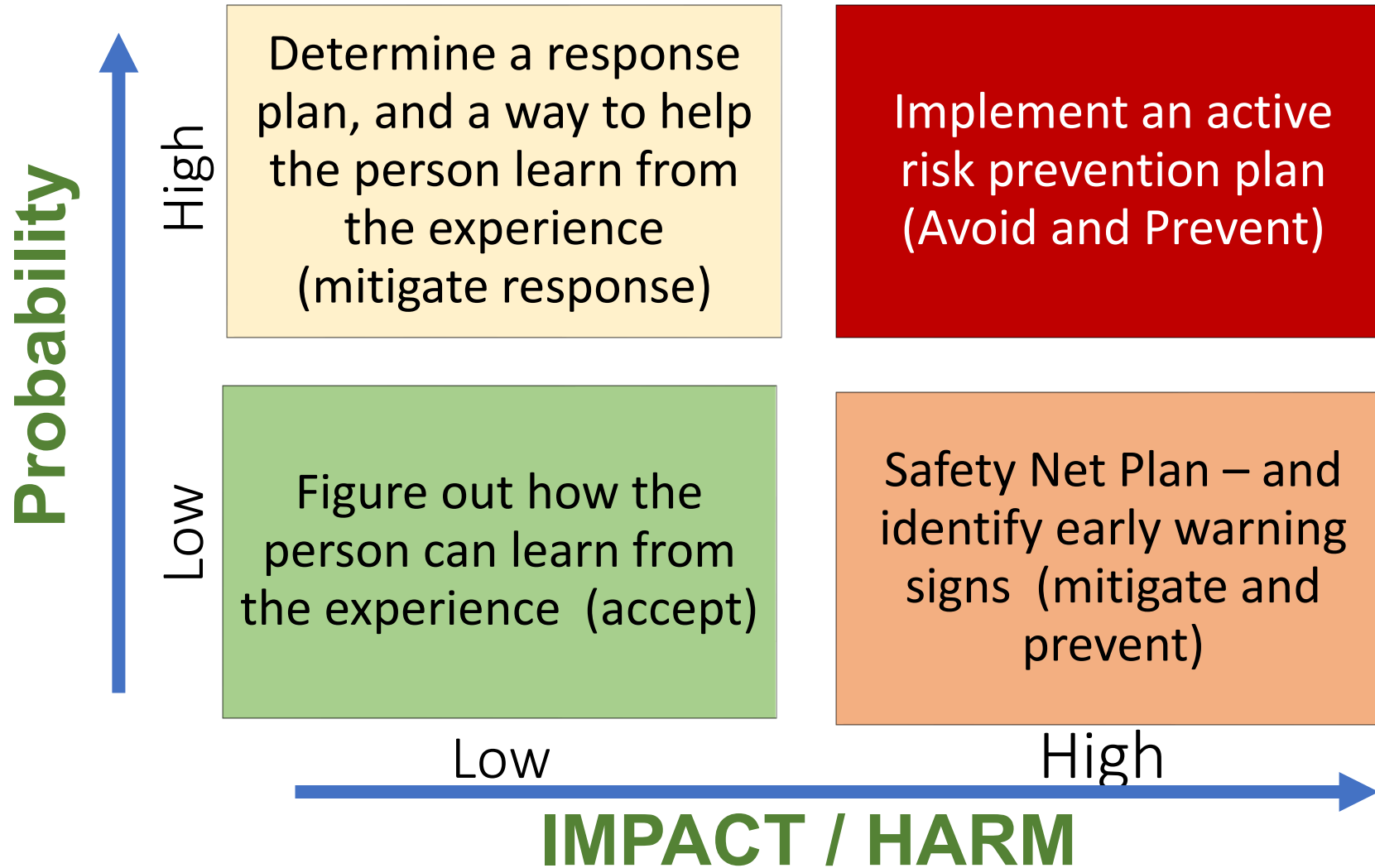
How **likely** is the risk in THIS situation?

- What circumstances contribute to risk?
- In similar settings or circumstances, has the risk occurred rarely, occasionally or frequently?
- What other factors contribute to the likelihood the risk will occur?

How significant is the potential **impact** for the person or others?

- What might happen to the person or someone else as a result?
- Would the results be long or short term?
- Are the results likely to cause trauma, be life changing, life threatening or devastating for this person or others?

Risk Assessment

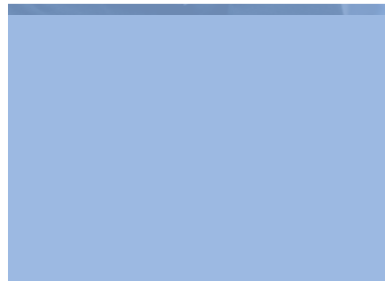
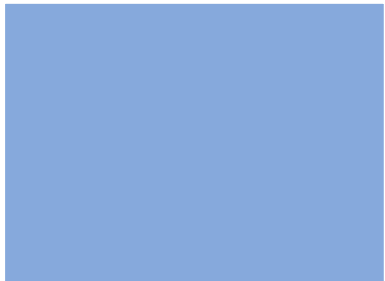
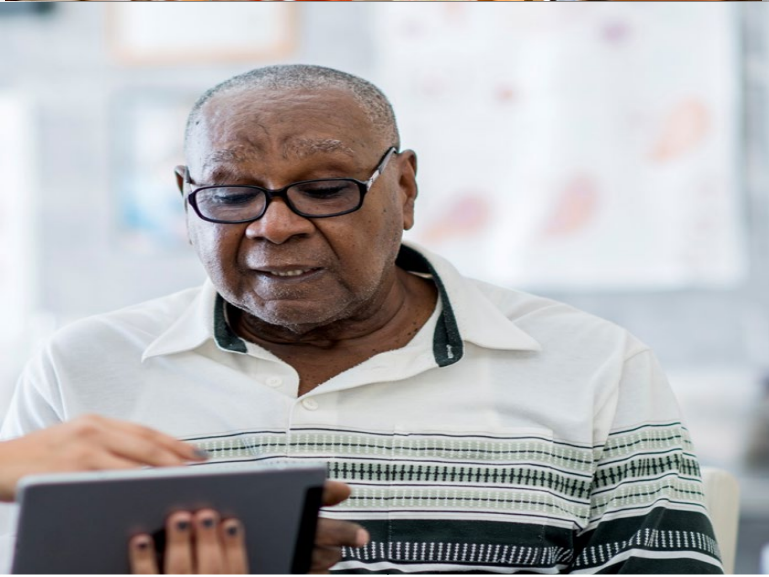


Supporting Paid Staff

- This is hard- and it's scary
- The Risk to staff is real – incident reports, blame if it goes wrong
- Building trust by listening is key
- Strength and courage of leaders
- Graphics help!



Dignity of Choice



Dignity of Choice (DOC) in Tennessee

- 2007 Risk Tool Development
- 2008 Risks identified as part of the PCSP
- 2016 DOC as a System Transformation Initiative
- 2017 Conversations around Dignity of Choice
- 2018 Protocol Development
- 2020 Contract Expectations for DOC
- 2020 Alignment of Reportable Event Management
- 2021 DOC Protocol finalized
- 2021 Training
- 2023 Oversight

Requirements

- Tennessee Dignity of Choice requirements are outlined in:
 - Contract with TennCare Managed Care Organizations
 - National Committee for Quality Assurance Standards for Long Term Services and Supports (LTSS)
 - Federal Home and Community Based (HCBS) Settings Rule
 - Federal Rule – Person Centered Planning
 - 1915(c) ID Waivers
 - Interagency Agreement between TennCare and the Tennessee Department of Intellectual and Developmental Disabilities (DIDD)

Dignity of Choice Protocol

- Sets forth expectations for TennCare Managed Care Organizations, contracted providers, and the Department of Intellectual and Developmental Disabilities regarding philosophies and practices specific to foreseeable risk identification, assessment, and mitigation in HCBS Programs, and identifies a process for addressing dignity of choice through Comprehensive Assessment, the PCSP, and ongoing Support/Care Coordination/Case Management.

DOC Protocol Key Components

- Risk identification
- Person's vision for a meaningful life
- Risk planning
- Proactive approach
- Approach that values dignity of choice is essential
- Commitment to identify, evaluate, and plan for mitigation of risks that come with living life and striving to reach one's full potential

DOC Protocol Key Components

- The Role of the Support Coordinator in addressing risk
- Identifying Risks Unique to the Person's Situation
- Determining Risk Mitigation Strategies
- Determining Tolerable Risks the Person Wishes to Accept/Take
- Developing the Risk Mitigation Plan for Tolerable Risks
- Keeping the Risk Mitigation Plan Current, Relevant, and Effective

Dignity of Choice

Thoughts to keep in mind....

- People need to be able to make choices
- Overprotection might seem kind, but it might smother a person
- Letting people try things that may seem risky or scary for parents or professionals [is important for growth]
- [Dignity of Risk] allows people to “Get Out Of Their Comfort Zone” to try new things Example: moving to a new state or city
- Being able to make choices and live the consequences of choices promotes **Self Determination** and **High Expectations**

Adapted from National Center on Advancing Person-Centered Practices and Systems (NCAPPS). Finding the Balance Webinar. Dec 2019. Available at: <https://ncapps.acl.gov/webinars.html>

What if...

What if your money was always kept in an envelope where you couldn't get it?

What if you spent three hours every day just waiting?

What if you got into trouble and were sent away and you couldn't come back because they always remember your "trouble"?

What if you never got to make a mistake?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed to do any because you weren't able to do all of the shopping?

What if you were never given a chance to do well at something?

What if you took the wrong bus once and now you can't take another one?

What if the only risky thing you could do was to act out?

What if you were always treated like a child?

What if you grew old and never knew adulthood?

What if the job you did was not useful?

What if you couldn't go outside because the last time you went it rained?

What if your only chance to be with people different from you was with your own family?

What if you never got to make a decision?

The Principle of Dignity of Choice

- According to the Center for Medicare and Medicaid Services (CMS), **Dignity of risk** is the idea that self-determination and the right to take reasonable risks are essential for dignity and self esteem and so should not be impeded by caregivers, concerned about their responsibility to ensure health and welfare.

Informed Choice

- Informed choice means the person is well informed to make an educated and voluntary decision about moving forward with his/her goal or planned activity after s/he has had a meaningful discussion about risks and potential outcomes, both positive and negative, that may result.
- Only after the person understands how the identified risks could be mitigated can s/he make a truly informed decision about whether a particular risk is a tolerable risk that s/he wishes to accept/take.

Important Concept: Capacity

Proxy decision-making and conservators:

- The person should be supported and involved in goal setting, risk identification and mitigation to the extent possible. We should not presume that a person with a proxy decision-making arrangement in place has no ability to participate in this process.

Important Concept: Supported Decision Making

A way for a person with a disability to make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to:

- Help understand the issues and choices;
 - Ask questions;
 - Receive explanations in language he or she understands; and
 - Communicate his or her decisions to others
-
- www.tndecisionmaking.org

Successful Citizenship

- The SUCCESSFUL CITIZEN focus group series in Tennessee is intended to ensure people have the opportunity to know things TO DO in order to increase the likelihood of being a successful and valued community member.

Dignity of Choice: Tolerable Risks

Tolerable risks are those risks an individual is willing to accept/take, given their goals, choices and preferences and the risk mitigation strategies that can be applied to avoid potential negative outcomes. Effective risk management processes allow an individual to make an informed decision about which risks are tolerable

- Some risks may be too great to be considered tolerable by the individual
 - Risks with a high probability of death or serious injury
- Other risks are considered a part of everyday life
 - Risks with possibility of minor injury, negative reaction from peers, failure on first try, etc.

Discussion and consideration of specific risks should always balance identifying the potential benefits with the potential harm instead of only focusing on the potential harm that may result from taking a specific risk.

A Risk Mitigation Plan *May* Include:

- Identified **goal**, choice, or preference
- Potential **positive outcomes**
- Potential **negative outcomes**: tolerable and intolerable
- **Impact** of actions toward the pursuit of the goal
- Actions to **address** the intolerable risk;
- **Responsible parties**
- Actions **Timeline**
- What **Successful** risk mitigation will look like for the person
- Document **progress** toward goals
- Possible **multiple** plans in place

Dignity of Choice and Reportable Event Management

- Dignity of Choice supports the idea that self-determination and the right to take reasonable risks are essential for dignity and self-esteem and so should not be impeded by caregivers concerned about their responsibility to ensure health and welfare.
- The overall Reportable Event Management approach must also ensure that people, involved family members, and/or natural supports, as appropriate, are informed about supporting dignity of choice, including informed decision making, tolerable risks, risk mitigation, and how to report an event that compromises the health, safety, individual freedom, and/or quality of life of a person supported.

Implementation

- Tennessee implemented the concept of DOC in many phases. Once the protocol was finalized as part of Tennessee's Aligned Reportable Event Management, TennCare, DIDD, and MCOs worked on multiple levels to train all stakeholders on DOC.
- Training included a comprehensive training that gave examples across HCBS programs in Tennessee.

Things to Consider

- Process
- Time
- Commitment
- Policy and Procedures
- Training
- Philosophy

Lessons Learned

- Statewide initiative
- Guided by protocol and policy
- Alignment across other initiatives and policies
- Person or entity that owns the initiative and is responsible for bringing in all partners and following up
- Collaboration among all partners and stakeholders

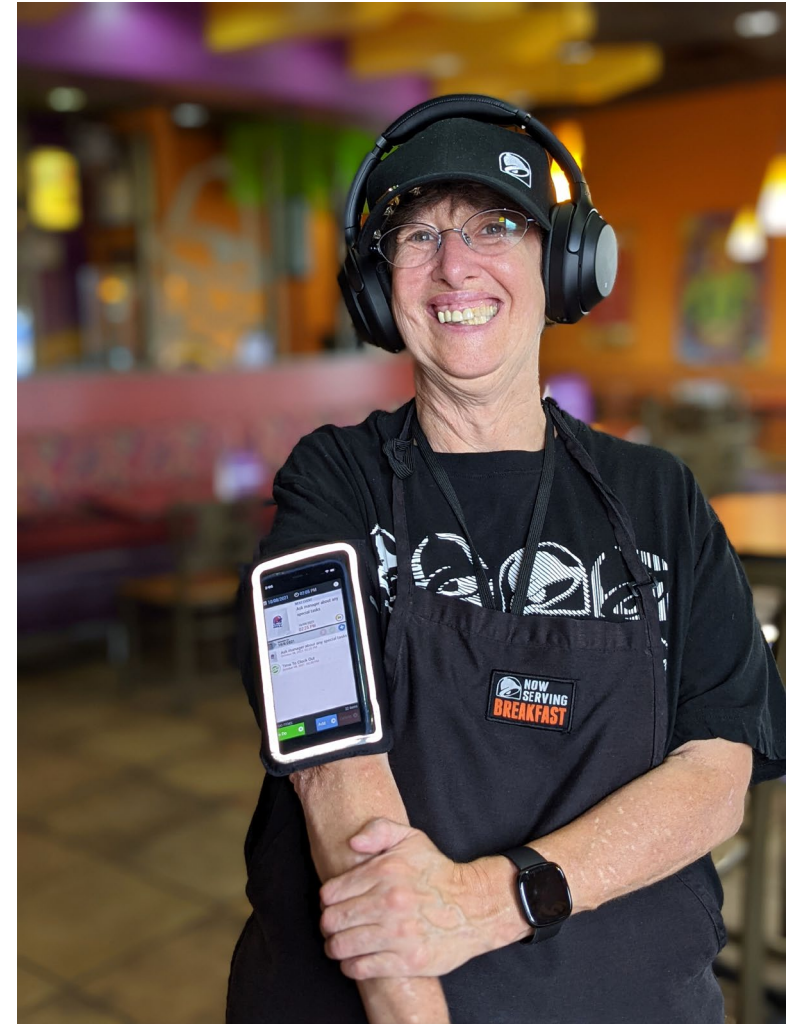
A Provider Perspective on Supporting Risk

- 2017 Tennessee Department of Intellectual and Developmental Disabilities celebrated the dismissal of all federal lawsuits ending a quarter of a century of litigation and court oversight of intellectual disabilities services in Tennessee.
- Despite all the positive changes, what emerged was a **protection from harm model**. A reinforced culture of **heavy staffing** and **risk aversion**.
- Through an Enabling Technology “test project” Tennessee leaders hope to put a toe in the water and feel a way out of the trend of heavy staffing and a one size fits all service model.



TN DIDD Technology Project

- Started in 2018 with a select number of provider agencies and included:
 - Dedicated state dollars to get started
 - An education component-online courses and in-person training for the individuals participating in the project
 - Creative partnerships with technology vendors
 - Training
 - Professional consultation



The “WHY” from an agency perspective

- The “*one size fits all*” model of support, over supports some people and under supports others
- If a person desires more independence, no amount of paid supports, no matter how excellent those supports might be, can provide people with their preferred life
- Technology is all around us and is a natural support for people who can and want to be more independent. Particularly if a person wants less in-person support



*People don't want a lifetime of good services!
People want really good lives!*

Adding Technology to Supports

*Opportunity to break away from a
restrictive service model*

(one-size fits all)

*to a person-centered service model
where the person chooses the type
and level of support they want*



So where do we start?

- Who has been vocal about wanting more independence?
- Who already has a vision of a preferred life?
- Who is motivated for change?



“This is TOO risky!”

Dealing with the naysayers

Breaking away from traditional supports will bring out the naysayers:

“What if they stay up all night”

“Someone will steal their meds”

“Someone is going to get hurt”

“What if they get sick and can’t call for help”

Important to identify who the concerns are important to?

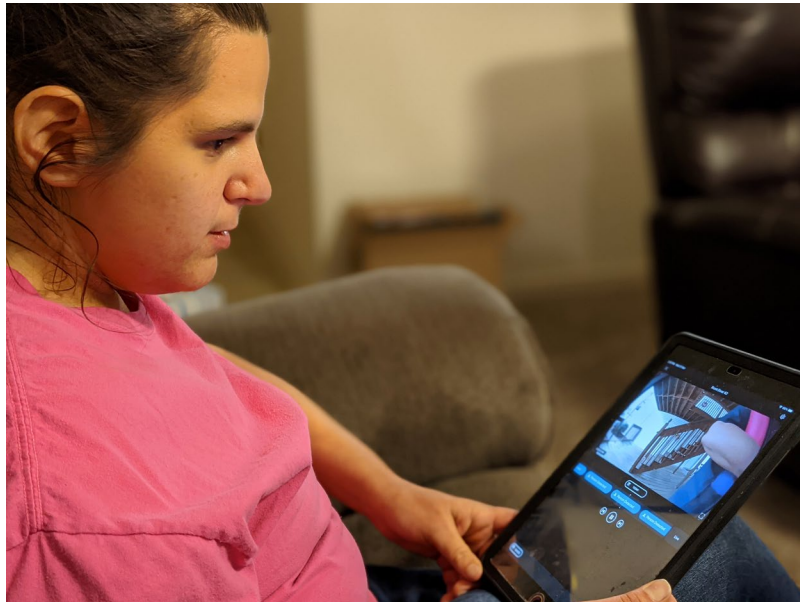
Are you putting protections in place for a true risk?

Are these protections important to the health and safety of the person?

Are these protections important only to the system?



Mitigating Risk by Building Consensus



- Facilitated person-centered planning meetings – bringing the team together.
 - What is the desired outcome? Can technology help achieve a dream that traditional supports can not?
 - Is the person informed to make a educated and voluntary decision to move forward with their dream?
 - What are the concerns/risks? Who are they important to? What risks can be mitigated with technology?
 - Does the person and their COS agree to the Technology Plan?



- Many protections were put in place that were important to the system. We needed those protections, the person supported did not
- Communicate, communicate, communicate. Where there is a hole in communication it will be filled with negativity
- Learn with the person, revisit and adjust the plan often
- Don't get wrapped up in "what ifs" that are not a factor in the persons recent history.
- Beware of naysayers. Natural tendency for the medical field in particular to overcompensate for every possible risk

Significant findings 5 years down the road

- People who choose their supports (technology and/or DSP) are happier and safer as substantiated by Personal Outcome Measures and safety trending data:
 - 57% more likely to have outcomes (POMs) present in their life than people with traditional supports
 - 44% more likely to have support for outcomes (POMs) than people with traditional supports
 - 31% less likely to have a medication error
 - 50% less likely to have a reportable incident
- Agency savings: \$13,500 week in reduced staffing, \$702,000/year

*The Learning Community of PA
Supporting People with Life Choices*



Creating Cultures That Support Success

What is dignity of risk and how does it relate to supporting our DSPs?

- ▶ Dignity of risk is the idea that self-determination and the right to take reasonable risks are essential for dignity and self esteem and so should not be impeded by excessively-cautious caregivers, concerned about their duty of care.

-Wikipedia Definition

Assessing Barriers

- ▶ Poor fit between DSP and person supported
- ▶ Lack of training
- ▶ DSPs not having the right tools or information
- ▶ Punitive agency culture
- ▶ Lack of trust between the DSP and the agency
- ▶ DSPs fear of judgement and negative consequences
- ▶ DSPs feeling unsupported

How do We find the right “fit”?

- ▶ Matching Staff- Asking the right questions
 - What are the supports wanted and needed?
 - What skills are needed?
 - What are the possible common interests between the person looking for support and the DSP?
 - What type of personality matches best with the person looking for support? (Be aware of strengths and possible over used strengths of the DSP)

The right tools and information: The more you know, the more you know

- ▶ Training is crucial and information is the key to success- (tools in the toolbox)
 - Individual Rights
 - Supported Decision Making
 - Person Centered skills
 - Individual Support Plans
 - Behavior Support Plans
 - Supporting Risk-How to educate on choices, give guidance through the process, and support learning using the outcome (positive or negative)
 - Other processing skills in order to understand and provide better support of dreams and mitigate risk

The right tools and information: The more you know, the more you know cont.

- ▶ DSP's need to be a part of the conversation
 - Buy in
 - Synergy
 - To receive information (in real time)
 - To give relevant/crucial information from their perspective
- Remember: DSPs are a part of the information expert team

Creating a supportive Culture: DSPs are our greatest resources

- ▶ “Open door/phone” policy (be available, present and attentive)
- ▶ Words matters (everyone is speaking the same language)
- ▶ Trust is an action
- ▶ “Nothing about us, without us” is not just for people we support
- ▶ Don’t ask for what you wouldn’t do yourself
- ▶ Ask questions
- ▶ Follow through
- ▶ Celebrate the “W’s”
- ▶ Make room for judgement and creativity
- ▶ No room to be judgmental here
- ▶ We all want to feel appreciated!



Questions?

Real-Time Evaluation Questions

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality NCAPPS webinars.
- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at NCAPPS@hsri.org

Real-Time Evaluation Questions (cont.)

- 1. Overall, how would you rate the quality of this webinar?**
- 2. How well did the webinar meet your expectations?**
- 3. Do you think the webinar was too long, too short, or about right?**
- 4. How likely are you to use this information in your work or day-to-day activities?**
- 5. How likely are you to share the recording of this webinar or the PDF slides with colleagues, people you provide services to, or friends?**
- 6. How could future webinars be improved?**

Resources

- TennCare Dignity of Choice protocol:

<https://www.tn.gov/content/dam/tn/tenncare/documents/DignityOfChoiceProtocol.pdf#:~:text=This%20protocol%20sets%20forth%20expectations%20for%20TennCare%20Managed,Plan%20%28ISP%29%20Process%2C%20and%20ongoing%20Support%2FCare%20Coordination%2FCase%20Management.>

Thank You.

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