

Case Management Redesign

Dignity of Risk

January 17, 2024



HEALTH MANAGEMENT ASSOCIATES

Public Meeting Notice

- Please note this meeting is open to the public and is being recorded.
- Anything said during this meeting may be part of the public record.

Agenda

- **Introductions, Recording, & Meeting Guidelines (5 min)**
- **Poll: Who is here? (2 min)**
- **Presentation: Dignity of Risk (43 min)**



Poll #1:

Who is Here Today?



Presenters



Sharon Lewis
she | her



Courtney Thompson
she | her



Deborah Rose
she | her



Megan Beers
she | her

Today's Learning Objectives



- Participants will learn the concept and definition of Dignity of Risk.
- Participants will be able to identify two reasons why Dignity of Risk is important.
- Participants will be able to describe two ways to incorporate Dignity of Risk in case management.

Poll #2:

Your Experience



Concept of Dignity of Risk

- People have the right to make decisions and choices – and mistakes
- Key part of person-centeredness: balancing safety and risk
- Need for choice and control: inherent in HCBS requirements
- Overprotecting people prevents growth, connections and dreams
- Taking reasonable risks and living with consequences promotes self-determination
- Empowerment and self-advocacy skills allow people to recognize and resist abuse and exploitation

What if you never got a chance?

Dignity of Risk



“Overprotection...can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity. Overprotection can keep people from becoming all they can become. Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try.”



Dignity of Risk – Not a New Idea

- Older Americans Act (1965) “Older people of our Nation are entitled to... freedom, independence, and the free exercise of individual initiative in planning and managing their own lives.”
- Developmental Disabilities Assistance and Bill of Rights Act (1984) People with developmental disabilities should be enabled to “to achieve their maximum potential through increased independence, productivity, and integration into the community ...” defining independence as the chance to “exert control and choice over their own lives.”
- Americans with Disabilities Act (1990) “Physical or mental disabilities in no way diminish a person’s right to fully participate in all aspects of society.”
- Convention on the Rights of Persons with Disabilities (2006) Principles include “Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.”

Federal HCBS Rule

- **Medicaid person-centered planning requires that the person has choice and control:**
 - The process “(1)(ii) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible and is enabled to make informed choices and decisions.”
 - The plan “(2)... must reflect... what is important for the individual to meet the needs... as well as what is important to the individual.”
 - The plan shall “(2)(vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.”
 - The service setting “(4)(iv) “Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.”

Video: This Isn't An Institution!



Barriers to Exercising Dignity of Risk

- **Systems, staff and/or family protecting health and safety in ways that overly restrict opportunity for reasonable risk-taking. Risk aversion focus that benefits systems and processes more than the person being supported**
- **Historical reliance on medical model**
- **Too much decisional power removed from the person**
- **Staff concerns about liability and being blamed if things go wrong**
- **Fears of family members, guardians and caregivers (real or perceived)**
- **Lack of time and capacity to adequately support informed decision-making**
- **Limited training for staff, family, guardians, caregivers**
- **Focus on potential harm instead of potential benefit**
- **Low expectations, limited commitment to supporting individual choice**

Poll #3:

Dignity of Risk and Safety



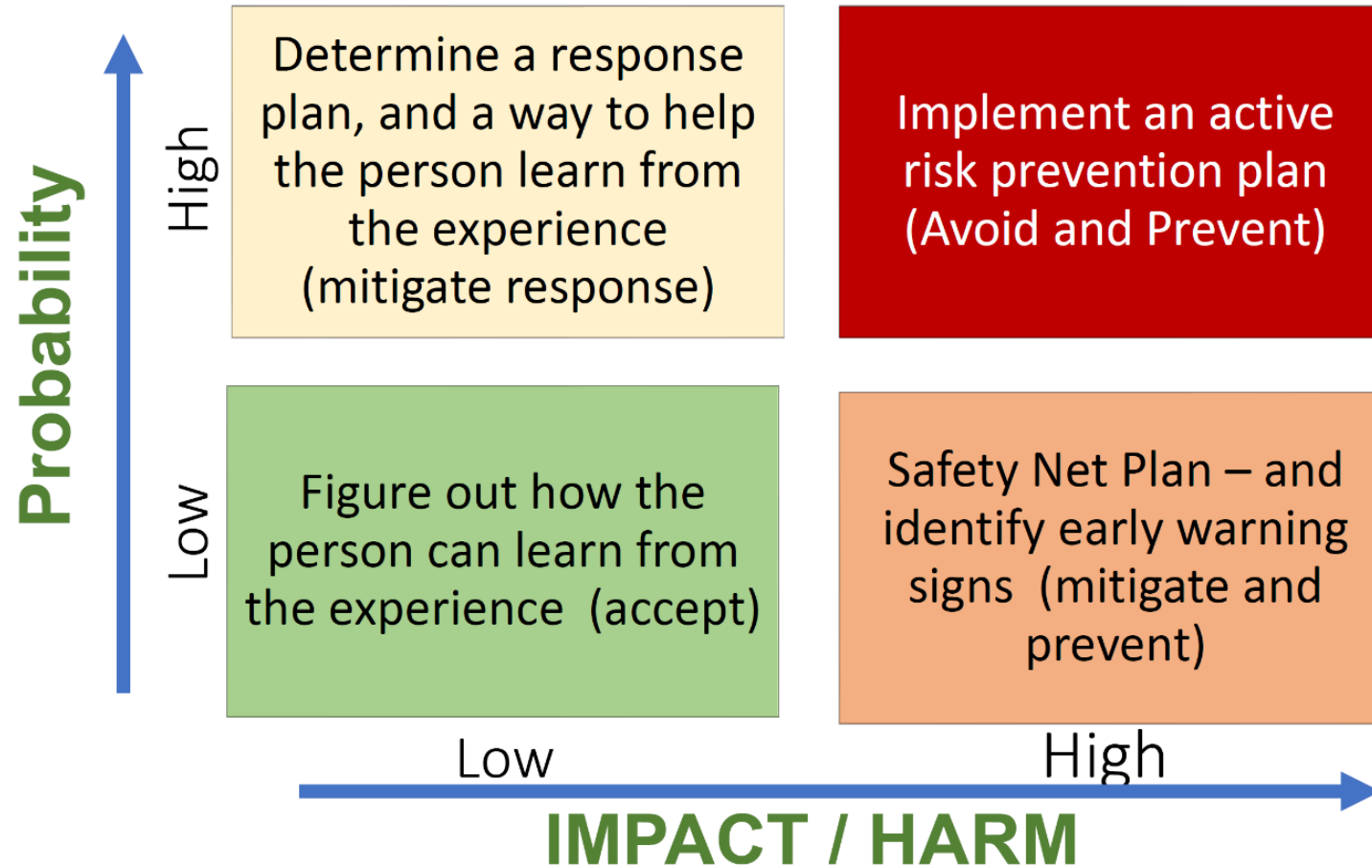
Supporting Dignity of Risk:

What's a Case Manager to do?



- Listen, listen, listen – understand the WHY for the person
- Use your person-centered planning skills
- Collaborate and use the circle of support – build consensus (reduces blaming)
- Identify and consider both potential risks and potential benefits
- Think about mitigation strategies – Technology? Environmental changes? Incremental steps?
- Take the time to help the person engage in informed decision-making, understanding risk and potential consequences
- Once a choice has been affirmed, support the decision, including learning opportunities

Thinking Through Solutions: Assessing Risk



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Collaborative Conversation: Focus on the Specific Situation and the Person

- How likely is the risk to create negative results?
 - What circumstances or factors contribute to the risk?
 - In similar situations for this person, has the risk occurred rarely, occasionally or frequently?
- How significant are the potential negative consequences?
 - 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?
- How important are the potential positive outcomes and how can we support them?
 - What does the person gain from taking this risk?
 - What risk-mitigation strategies are available?
 - What learning will occur, even with a negative outcome?

Video: Banned for Being Human



Scenario 1 - Phoebe



- Phoebe, an older adult with limited mobility and some minor cognitive limitations, wants to maintain independence and control. Despite the daily presence of a home-health aide, she has been hospitalized three times in the past year for medication errors, as she insists on continuing to manage her pills without assistance. Family members want Phoebe to receive more support at home, but she is resistant.

What else do you need to know about their story to engage collaboratively?

How might you work with the person to help them make an informed choice?

What are the learning opportunities for everyone in this situation?

Scenario 2 - Joe



- Joe, a young adult with a mental health condition and a seizure disorder, wants to learn to drive, having never held a driver's license. He is in a positive place with his recovery, maintains employment and lives in a healthy situation. His seizures are currently well-managed with medication; it has been over a year since he had any seizures. His medical providers are divided on their opinions about his driving. Joe has talked about the freedom and independence being able to drive will give him.

What else do you need to know about their story to engage collaboratively?

How might you work with the person to help them make an informed choice?

What are the learning opportunities for everyone in this situation?

Scenario 3 - Naomi



- Naomi, a 34-year-old woman with intellectual disabilities, currently lives with her parents but wants to live in an apartment. She has talked about all the reasons she wants an apartment, including her desire to have a cat, wanting privacy, and living close to her friends. Naomi's family does not support this idea and wants her to live in a provider-controlled setting.

What else do you need to know about their story to engage collaboratively?

How might you work with the person to help them make an informed choice?

What are the learning opportunities for everyone in this situation?

Risk, then, is not just part of life.
It is life. The place between
your comfort zone and your dream
is where life takes place. It's
the high-anxiety zone, but it's also
where you **discover who you are.**

– *Nick Vujicic*



Additional Resources

- Robert Perske, *The Dignity of Risk*, 1972 https://mn.gov/mnddc/ada-legacy/pdf/The_Dignity_of_Risk.pdf
- National Center on Advancing Person-Centered Practices and Systems: Person-Centered Approaches to Supporting Dignity of Risk for People with Disabilities, www.ncapps.acl.gov/docs/Webinars/2023/march/NCAPPS_Webinar_Slides_Final_230323.pdf
- *Dignity of risk in the community: a review of and reflections on the literature*, https://www.researchgate.net/publication/327713593_Dignity_of_risk_in_the_community_a_review_of_and_reflections_on_the_literature
- Council on Quality and Leadership: *Dignity of Risk* <https://www.youtube.com/watch?v=UZR6fm7pA2c>
- HCPF: Individual Rights and Rights Modifications <https://hcpf.colorado.gov/sites/hcpf/files/Individual%20Rights%20and%20Rights%20Modifications%20--%20for%20families%20and%20guardians.pdf>
- *Dignity of Risk and Living at Home Despite Severe Disability*, Lisa I. Iezzoni <https://www.hearmenowstories.org/documents/Dignity-of-Risk-and-Living-at-Home-Despite-Severe-Disability.pdf>
- *Outing The Prejudice: Making The Least Dangerous Assumption* <https://ollibean.com/outing-the-prejudice-making-the-least-dangerous-assumption/>
- *Applying dignity of risk principles to improve quality of life for vulnerable persons*, <https://pubmed.ncbi.nlm.nih.gov/31647586/>
- Please note that the following videos do include swearing, using language that some people may find offensive:
 - *A Day in the Life*: <https://www.youtube.com/watch?v=j-kDsBrHAYs>
 - *Can't Stay Up Late*: <https://www.youtube.com/watch?v=nH80ibYpyXs>

Contacts

Please contact us if you have additional questions, suggestions, or ideas.

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Thank You!

