THE DIGNITY OF RISK:
Balancing Rights, Self-Determination and Risk in Supported Decision-Making

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Disclaimer

This is not a presentation about the behavioral symptoms of advanced dementia, and the refusal of persons with dementia to participate in daily care.

Most of the research into Supported Decision-Making (SDM) has been done among persons with disabilities. Research into this area and its impact on persons who are aging is only just emerging. The presenters do not mean to suggest that aging is a disability, only that some of the same premises of SDM might apply to persons in both the disability and aging communities.

Basic Premises

- All people need and use help and support to make and implement decisions. It is not unique; it happens every day. We all make decisions individually and with support from others at different times in life, and to different degrees.

- Disability is a natural part of the human experience. It may come in the form of a lifelong disability, a disability acquired as one ages or as a result of some event, such as a brain injury, stroke or emotionally traumatic event.

- There is risk and consequence to every choice, every aspect of life. Some persons choose to live with more risk than do others, and are willing to accept the consequences of their choices.

The Right to Make Decisions

- The right to make decisions is not contingent upon the quality of decisions made, the process by which they are made, or the ways in which decisions are communicated.

- Some of the toughest choices are those in which the individual decides to choose freedom over safety. Appropriately negotiated risk can accomplish both.

Safety: The Elephant in the Room?

- What does it mean to be safe, and who determines this for you?
- Can we really keep people safe?
- When does trying to keep people safe become the option of greatest restriction, coercion or even abuse?
- When does the individual cost of safety (loss of autonomy, dignity, freedom) outweigh the benefits?

What is Supported Decision-Making?

- SDM has its roots in the disability community, most notably in the "Jenny Hatch" landmark case from Virginia. Its applicability to persons as they age and experience a decline in cognitive abilities is being increasingly promoted.
- The purpose of SDM is to help individuals understand the options, responsibilities, and consequences of their decisions; obtain and understand information relevant to their decisions; and communicate their decisions to the appropriate people.
- Currently, SDM is rich in theory, but lacks in documented best practices, particularly among persons who are aging.

Lack of "Best Practices"

- A review of the evidence base on SDM published in 2014 (Kohn and Blumenthal) concluded that there is little evidence to support claims that SDM empowers persons with intellectual disabilities by providing them with help in making decisions.
- Although much has been written about how SDM should work, more evidence is needed to determine how SDM functions in practice.
- A concern exists that SDM may facilitate undue influence by alleged supporters, thereby disempowering persons with intellectual disabilities.

Lack of “Best Practices” - continued

- The potential for undue influence in SDM plays out in a subtle, often undetected dynamic between two people in a relationship of trust and confidence where the will of the perpetrator is substituted for the will of the victim.
- Evidence is also lacking regarding whether or how SDM can remedy the problems associated with guardianship and other surrogate decision-making processes. Will SDM reduce the use of guardianships? What about monitoring and accountability, especially if arrangements are private and informal?

Potential Systemic Barriers to SDM

- "The American network of guardianship systems is well noted for a deep-rooted culture of paternalistic practices that rarely pursue the wants and needs of adjudicated incompetent persons." A. Frank Johns, Person-Centered Planning in Guardianship: A Little Hope for the Future, Utah Law Review, Vol. 2012, No. 3, at 1560 (2012).
- Requires a fresh look at resources, the current legal system, implementation of legislative frameworks, creation of inclusive and accommodating decision-making processes, availability of support networks, and a better identification of the role of government with regard to authority and funding.

SDM Dilemmas

- Case management looks much different today than it did in the original county-based days of COP: today, more persons live in assisted living without the benefit of formal social work services; most decisions of consequence are made via the MCO process or by corporate guardians with burgeoning caseloads.
- This is compounded by more persons living longer with a host of disabilities.
- Persons living in rural areas continue to experience few options.

Supported Decision-Making

- SDM is an alternative to guardianship which holds promise to empower many, but not all, people to use available supports to make their own choices so they can live more self-directed lives.
- Guardianship is intended as a last resort after lesser restrictive alternatives have been considered and determined not to be workable.
- Even though most states allow for limited guardianships, the number of adults under full (plenary) guardianship has risen significantly over the last two decades despite a focus on self-determination, natural supports, or actions that enhance the possibilities for people to control their lives.

Supported Decision-Making - continued

- Guardianship not only deprives a person of "legal capacity," meaning that the person no longer has the right to make decisions, but the person also is not recognized as a "legal actor," that is, a person whose decisions are entitled to legal recognition.
- SDM requires that an individual demonstrate that she or he has the capacity to make a particular decision using available support.
- Few of us are born with decision-making capacity, but learn it as we experience life. Most of us are able to learn or re-learn skills given the appropriate supports and experiences.

Supported Decision-Making - continued

- Requires that individuals be given the opportunity to learn and re-learn decision-making skills and meaningfully engage in the decision-making process. Teaching and learning opportunities related to decision-making must be available in addition to other supports, both systemic and natural.

- "Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration." Blank and Martinis, "The Right to Make Choices," The National Resource Center for Supported Decision-Making, Inclusion: March 2015, Vol. 3, No. 1, at 24-33.

Honoring Self-Determination

People with honored self-determination are typically:

- More independent
- More integrated into their communities
- Healthier
- Better able to recognize and resist abuse
- Able to make better decisions than those who are not allowed to participate in decision-making.

Khemka, Hickson, & Reynolds, 2005; Wehmeyer, Kelchner, & Reynolds, 1996; Wehmeyer & Schwartz, 1998.

When Self-Determination is Not Honored

- When persons are denied their rights to self-determination and inclusion in life's choices, they can suffer negative and lasting effects such as feelings of helplessness, hopelessness and self-criticism. Edward Deci, Intrinsic Motivation 208 (1975).

- Can result in "internalized oppression:" The result of persons being told repeatedly that they can't succeed, that they don't have skills, that something about them is substandard. As a result, the person feels reflexively oppressed and refuses the supports offered, even if they might move her toward her goal. Begins to affect the person's world view.

About Self-Determination and Risk

- Younger individuals: risk may be assessed and negotiated on the basis of current skills and potential to learn new skills, goals for future, often leading to higher degrees of acceptable risk with good wrap-around of supports. Conversations about goals usually fuller, more positive.

- Older individuals: risk may be assessed and negotiated on the basis of history and deficits, often leading to denial of request for risk, and at most extreme, imposition of guardianship in order to "protect." Conversations less about goals and more about being satisfied with status.

The Right to Make Decisions to the Maximum Extent Possible is a *Fundamental Human Right.*

- Article 12 of the Convention on the Rights of Persons with Disabilities provides that all persons have full legal capacity. It also provides that all persons have the right to make their own decisions and to act on and have those decisions legally recognized.
- Article 12 also requires states (governments) to provide the necessary support for persons with disabilities to make their own decisions, a concept called Supported Decision Making (SDM).
- Several models of SDM are emerging, employing a "human rights" approach as opposed to a social or medical model approach. There is no "one size fits all" model.

A Human Rights Model Requires:

- Recognition that individuals will have different needs and desires depending on their particular circumstances.
- Overcoming a longstanding philosophy about the need to "protect," while ensuring that SDM models do not create new or greater opportunities for abuse.
- Development of SDM models that are realistic in terms of resources currently available or able to be created in the foreseeable future.
- The avoidance of overprotection while acknowledging personal preferences, choices and the dignity of risk, while setting appropriate and person-centered safeguards.

The Words We Use

- Capacity: an understanding of the current situation and an awareness and appreciation of the potential consequences for self and/or others. NOT the same as competence.
- Natural supports.
- Person-centered and person-directed.
- "Right" choice/"wrong" choice. "Good" decision/"bad" decision. Important decisions are rarely that clear for any of us. Our own values or belief systems should not be the benchmarks used to influence the decisions of others.

Choice-Based Conversations

Depending on the choice the person wishes to make and the person's life story, conversations about the choice may need to come from a "trauma-informed" approach:

- Slow down – recognize the emotions attached to the choice as well as those attached to staff's or family's feelings of needing to protect. Control your own adrenaline first.

- Have the conversation at the time when the individual is best able to participate, not when it best fits staff's or family's schedules.

Choice-Based Conversations

- Validate the reasons for making the choice instead of trying to convince why it's a "bad" choice.
- Commend the person for the strength of her convictions, independence, perseverance. Resist the urge to say, "But…"
- Again… slow down…
- Ask: "What do you understand about your situation, health needs and risks, financial limitations, etc.?"
- Don't jump in with your own arguments when the person stops to take a breath or pauses to find the right words.

Choice-Based Conversations - Continued

- When you do jump in, make sure it's to rephrase what you think you heard the person say.

- Don't tell your own story – it's not about you. This can make the person feel like you are a superior person and they should try to be more like you.

- Avoid the temptation to be "the expert." The choice isn't being made from a clinical standpoint, but an emotional one. The person likely knows the clinical consequences of the choice, but may not have talked about the emotional consequences.

Choice-Based Conversations - Continued

- Be prepared to have the conversation more than once. The more at stake, the more thorough the discussion needs to be.
- Know how a person's values, beliefs, former lifestyle, relationships and choices play into the decision.
- Think about who is best to convey the information, who has rapport, who has answers to questions so the decision can be informed. Ask permission to bring others into the conversation, especially if they're expected to play a role of support.

Choice-Based Conversations - Continued

- Can be helpful to know the person's "style" of decision-making: quick, impulsive, seeks immediate gratification vs. deliberative, needs time, attention.

- Make transfer arrangements, appointments for assessments, consults, etc. with the person present. Not only shows transparency in process, but also promotes personal responsibility and aids in the continued thought processes about the decision being made.

When Persons Appear To:

- Shut down, close others out…
- Seem aggressive, angry…
- Seem complacent or timid…
- Lie or mislead…
- Seem manipulative…
- Seem paranoid…

- He might be feeling overwhelmed.
- She might actually be afraid of being hurt.
- She may be afraid of causing conflict.
- He may be trying to cover what he knows are deficits.
- She may be resourceful based on past necessity.
- She may be fearful.

About Respect

- Don't engage in gratuitous decision-making. Presenting a choice that isn't really a choice or that has unreasonable expectations for the person to meet in order to be successful is disrespectful.

- Don't knowingly set up a situation of failure in order to show that the person doesn't have the capacity or functional status to follow through on a decision. This, too, is disrespectful.

About Respect

- Discussions shouldn't be one-sided with others "taking sides" against the person's decisions, and using phrases like, "I'm the expert, so…," "This is how it has always worked," "It won't work if you… ."

- Find a way to say yes, if even to just part of the decision for the present time, and allow the decision to unfold incrementally, if that brings about continued dialogue and success on the decision.

Balancing Rights and Risk

- The right to speak confidentially with an advocate, or to have an advocate present at a meeting, is not dependent on a person's decision-making or cognitive status, and must be promoted without coercion or threat of retaliation of any kind.

- Rights insure the freedom of choice in care and treatment decisions, including being able to consent to or decline any proposed or ordered treatment given the best possible information.

- Rights insure personalized care based on thorough and ongoing evaluation and communication, and a dynamic care plan.

- Persons cannot be required to have a POA-HC or any other advance directive in order to move into or remain in a long term care setting.

Summary – Respect Choice, Reduce Risk

- Individualized assessments and fluid care planning.
- Ongoing assessments, monitoring and education along each step of implementing the decision.
- Practice, refine and practice again, based on possible alternatives.
- Attempt short term, incremental or modified opportunities instead of denying the whole choice.
- The activity of risk should not be disallowed simply because others disagree with taking the risk.
- Some of the toughest choices are those in which the individual decides to choose freedom over safety. Appropriately negotiated risk can accomplish both.

Summary

- How can safety, autonomy, dignity, and risk be balanced in real life and for persons of all ages?
- How can we move the discussion away from theory or hypothetical to practice?
- How can we move from systems-directed to person-directed practice?
- What are the systems changes that need to occur?
- How can we share the real life examples of people making different decisions using different decision-making methods, and what worked and did not work in different situations?

The Dignity of Risk

- What if you could never do something again because of a mistake or choice you made a long time ago?
- What if every day you just waited? For the bathroom, to smoke, to eat, for a friendly face to make eye contact and acknowledge you?
- What if your money was always kept in an envelope where you couldn't get it when you just wanted to see how much was there?
- What if people asked you to make a decision, but still did it their own way anyway and didn't tell you why?
- What if you were never ***allowed*** to make a mistake?
- What if you never got a chance? To…

The Dignity of Risk – continued

- A decision isn't the outcome or end-goal in and of itself. It is a step along the path of how a person lives his or her life or an aspect of life. Living life is a process, not a product.

- Understanding and supporting this process enables persons to more successfully make decisions incrementally, perhaps, supplementing with supports as needed instead of making the person accept more than they need or what they absolutely do not want.

- Acknowledging this ultimately insures rights that we all value and expect to endure: rights of self-determination and choice.

Resources & References

- Board on Aging and Long Term Care Ombudsman Program
  800-815-0015/http://longtermcare.wi.gov
- Disability Rights Wisconsin
  www.disabilityrightswi.org
- Guardianship Support Center
  (855) 409-9410/guardian@gwaar.org
- County Adult Protective Services Units
- Aging and Disability Resource Centers
- The Dignity of Risk. Ann M. Pooler, RN, PhD

Resources & References

- National Resource Center for Supported Decision-Making: http://supporteddecisionmaking.org; Jonathan Martinis, Legal Director, Quality Trust for Individuals with Disabilities
- Quality Trust/ Autistic Self Advocacy Network [ASAN]: Model legislation for supported medical decision-making
- Model agreements: American Civil Liberties Union/Quality Trust; Disability Rights Texas; Nonotuck Research Associates Center for Public Representation
- American Bar Association PRACTICE tool