

THE DIGNITY OF RISK:
Balancing Rights, Self-Determination & Risk
in Care Transitions

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The Words We Use

- Person-centered **AND** person-directed
- Self-determination
- Supported decision-making – an alternative to guardianship
- Limited guardianship
- Dignity of risk
- Unconditional respect: having a relationship with the persons we interact with
- 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

The Words We Use

- The resident chooses or declines instead of refuses or is noncompliant.
- “Right” choice/”wrong” choice. “Good” decision/”bad” decision. Important decisions rarely that clear. Our own values or belief systems should not be the benchmarks used to influence the decisions of others.
- Manage or Mitigate: The same or different?

Things to Consider

- Thinking only of yourself, what right is most important to you?
- When do rights cease? Why, and who makes these decisions?
- Do you ever make decisions that cause conflict with others, that might place immediate gratification over health or safety, that you wish others would understand?
- When others important to you voice opposition to your decision, what happens? How does that feel?

Resident Transitions

- From the hospital for rehab, going back home
- From the hospital or other LTC setting, assumed to be "long term"
- From own home
- To and from hospital repeatedly
- To own home or home of someone else

Any of us can be vulnerable when in the midst of any type of transition. Supports have to be timely and not rushed, planful and "real" not just a standardized prescription or plan.

When your resident appears to:

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| • Shut down, close others out... | • He might be feeling overwhelmed. |
| • Seem aggressive, angry... | • She might actually be afraid of being hurt. |
| • Seem complacent or timid... | • She may be afraid of causing conflict. |
| • Lie or mislead... | • He may be trying to cover what he knows are deficits. |
| • Seem manipulative... | • She may be resourceful based on past necessity. |
| • Seem paranoid... | • She may be fearful. |

Affirmation

- Relationships and “hospitality” are the keys to most favorable resolutions.
- Hospitality = inclusiveness, promotes transparency, equalizes power and control, embraces diversity of ideas and accessibility.
- The strength of relationships and hospitality can directly impact how persons perceive safety and autonomy, and ultimately how they make choices.

Affirmation’s Cause & Effect

- Cause = more power, more control (self-control?).
- Effect = Oftentimes better informed choices, fuller participation, less risk.
- Impact = Perceived highest quality of life.

Choice-Based Conversations

Depending on the choice the resident wishes to make, conversations about the choice may need to come from a “trauma-informed” approach:

- Slow down – recognize the emotions attached to the resident’s 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 resident is best able to participate, not when it best fits staff’s or family’s schedules.

Choice-Based Conversations

- Validate the resident's reasons for making the choice instead of trying to convince about why it's a "bad" choice.
- Commend the resident for the strength of her convictions, independence, perseverance. Resist the urge to say, "But..."
- Again... slow down...
- Ask the resident: "What do you understand about your situation?" "What's your body telling you?"
- Don't jump in with your own arguments when the resident 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 resident say.
- Don't tell your own story - it's not about you. This can make the resident 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 resident likely knows the clinical consequences of the choice.

Choice-Based Conversations - Continued

- Be prepared to have the conversation more than once. The more at stake, the more thorough the discussion.
- 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 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 resident's "style" of decision-making: quick, impulsive, seeks immediate gratification vs. deliberative, needs time, attention.
- Make transfer arrangements, appointments for assessments, consults, etc. with your resident present. Not only transparent but also promotes resident responsibility.

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 resident to meet in order to be successful is disrespectful.
- Don't set up a situation of failure in order to show resident that she or he doesn't have the capacity or functional status to follow through on a decision.

About Respect

- Discussions shouldn't be one-sided with person(s) "taking sides" against the resident'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, and allow the decision to unfold incrementally, if that brings about continued dialogue on the decision.

Balancing Rights & 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, with best possible information, any proposed or ordered treatment.
- Rights insure personalized care based on thorough and ongoing evaluation, communication and a dynamic care plan.
- Residents cannot be required to have a POA-HC or any other advance directive in order to move into a long term care setting.

Provider Rights

- Accurate pre-assessment information, from all appropriate parties, in order to commit to caring for a new or returning resident.
- Ability to develop a skilled and person-centered care team in order to facilitate necessary discussion and continuous care planning. The resident leads this team, regardless of decision-making or cognitive capacity.
- Access to necessary and appropriate medical providers and services to meet any unique needs or desires of the resident, including those with expertise in specific areas such as dementia, mental health, chronic conditions.
- To be compensated as per an admission agreement, for services provided, and to enact remedies, as may be necessary, under the guidance of the appropriate administrative code.

Substitute Decision-Maker Rights

- The right to speak confidentially with an advocate on behalf of a resident without coercion or threat of retaliation of any kind.
- The right to expect that directives made by or on behalf of a resident, via a POA-HC document or an order of guardianship, will be respected by all involved in that resident's care and treatment.
- The right to participate, at the request or on behalf of a resident, in a skilled and person-centered care team in order to facilitate necessary discussion and continuous care planning. The resident leads this team, regardless of decision-making or cognitive capacity.

Limitations of Substitute Decision-Makers

- *“Nothing about me without me.”*
- A resident’s wishes must, by statute, always be considered in decisions made on their behalf, regardless of having been deemed incapacitated or incompetent.
- MCO’s and/or county case managers are not surrogate decision-makers in the legal sense, but are essential brokers for services and supports. Surrogate decision-makers may not defer decisions to an MCO or other case manager.

Limitations of Substitute Decision-Makers

- *“Nothing about me without me.”*
- Providers must understand the boundaries of substitute decision-makers:
 - ✓ POA’s for health care make health care decisions only, and then as the resident would choose to make the decisions, if able. Only the resident can change agent(s).
 - ✓ Guardians make decisions in the best interest of the resident, but always taking into consideration the resident’s preference, if known or able to be expressed.

About Self-Determination

- 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.

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
- Make better decisions than those who are not allowed to participate in decision-making.

Source: 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, they can suffer negative and lasting effects such as feelings of helplessness, hopelessness and self-criticism.

Source: 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.

Supported Decision-Making

"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."

Source: Peter Blanck and Jonathan G. Martinis (2015) "The Right to Make Choices": The National Resource Center for Supported Decision-Making, Inclusion: March 2015, Vol. 3, No. 1, pp. 24-33.

Summary - Reducing Risk

- Individualized assessments and fluid care planning
- Ongoing assessments, monitoring & 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 would decide to choose freedom over safety. Appropriately negotiated risk could accomplish both.

Summary

- Residents/Tenants/Members have rights.

- Decision-makers, care providers and MCO's have responsibilities.

- All must respect, promote and protect residents' exercise of rights.

- "Nothing about me without me:" the resident always has a voice that can and must be heard.

Summary

- When your resident wants to make a choice that conflicts with orders, rights of others, seems unsafe:
- *Discern whether there are reasons for concern vs. reasons for denial.*
 - *What aspects of the choice are concerning?*
 - *What might it take to minimize or extinguish the concern?*
 - *Who can make mitigating the risk happen?*
 - *Are there alternatives or compromises?*

The Dignity of Risk

- What if you could never do something again because of a mistake or choices 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 never got to make a mistake?
- What if you never got a chance? To...

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 a life or an aspect of life. Living life is a process not a product.

Understanding and supporting this 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

- 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

Resources

- National Resource Center for Supported Decision-Making:
<http://supporteddecisionmaking.org>; Jonathan Martinis, Legal Director, Quality Trust for Individuals with Disabilities
- From The Consumer Voice: <http://theconsumervoiceweb.org>
 - Consumer to Consumer: Tips for a Successful Nursing Home Transition
 - Quality Care, No Matter Where: Successful Nursing Home Transitions
- The Dignity of Risk. Ann M. Pooler, RN, PhD
- Mitigating Risk Checklist; Karen Schoeneman
