

Dignity of Risk in a Risk Averse Industry

Recognizing Residents' Rights to Make Choices

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Meet our Panel

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How long have you worked/surveyed in a long-term care setting?

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Objectives

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- Recognize the impact of self-determination and autonomy on quality of life
- Understand the concept of surplus safety, and how to avoid it
- Identify federal regulations that support resident rights
- Debunk capacity myths
- Recognize “low” risk/”high” risk resident choices
- Identify actions that can be taken to promote choice and mitigate risk and resident harm associated with choices

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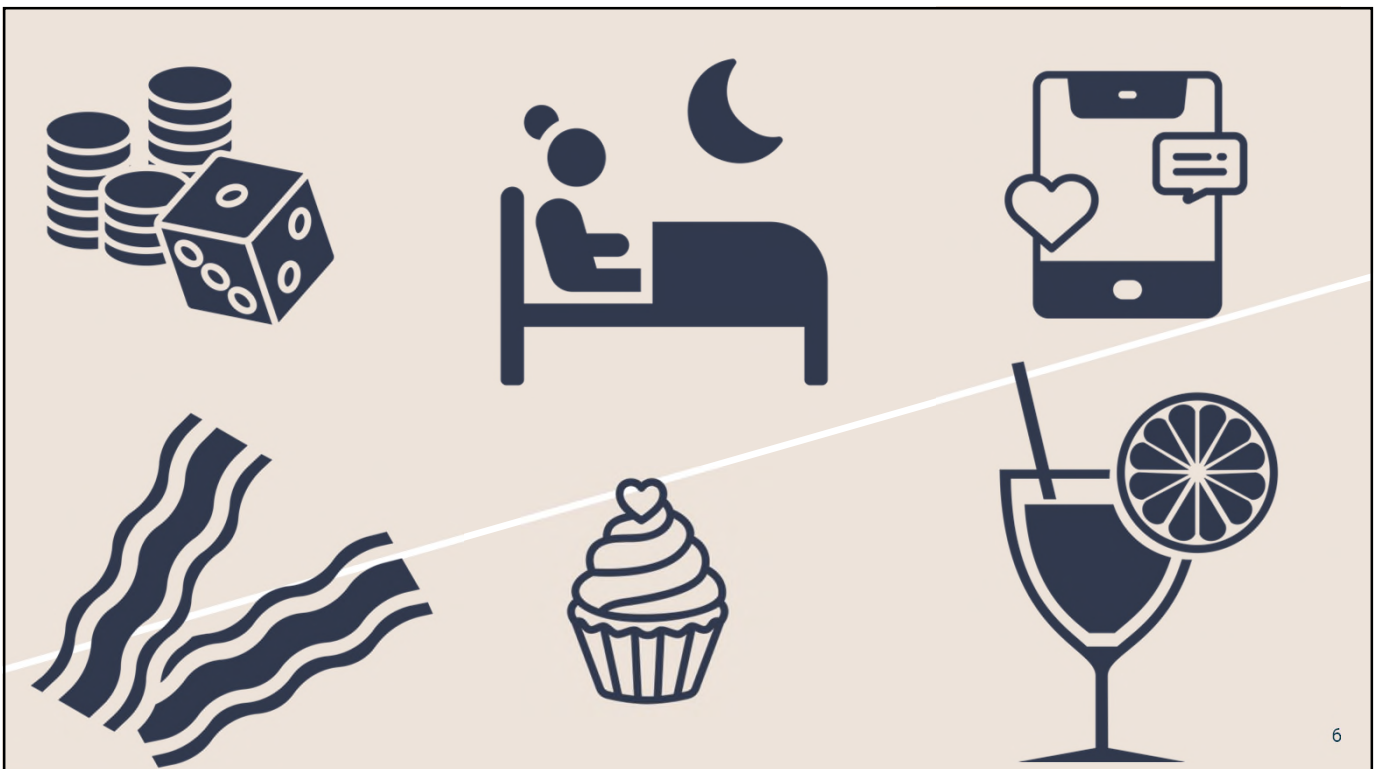


Are there things you enjoy or occasionally do, even though you know its not "good for you"?

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What is Surplus Safety?

Surplus safety is excessive safety measures intended to prevent harm, and is prevalent in nearly every aspect of life in a nursing home including bathing, sleeping, eating, recreational activities, etc.



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Why is Choice Important?

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- Making choices for oneself is a cherished and basic right and the essence of what it means to be an adult.
- It's the law! Federal law grants nursing home residents the right to self-determination.
- Research demonstrates that people with greater self-determination are healthier, more independent, and more able to recognize and resist abuse.



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Dignity of Risk

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Dignity is the state or quality of being worthy of honor and respect and is a basic human right, regardless of age. “Dignity of risk” is the belief that elders and people with disabilities are entitled to self-determination and the right to make their own choices.

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Rooted in Regulation

Resident's have the right to autonomy, self-determination and quality of life.

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F550- §483.10(a) Resident Rights.

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The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility, including those specified in this section. §483.10(a)(1) A facility must treat each resident with respect and dignity and care for each resident in a manner and in an environment that promotes maintenance or enhancement of his or her quality of life, recognizing each resident's individuality. The facility must protect and promote the rights of the resident.

§483.10(a)(2) The facility must provide equal access to quality care regardless of diagnosis, severity of condition, or payment source. A facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services under the State plan for all residents regardless of payment source. §483.10(b) Exercise of Rights. The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States. §483.10(b)(1) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility. §483.10(b)(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights and to be supported by the facility in the exercise of his or her rights as required under this subpart.

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The Ombudsman Approach

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Older Americans Act requires the LTC ombudsman program to provide ombudsman services at the direction of the resident and only with resident consent

So.... we start with the resident regardless of the reported resident's capacity and we assume the resident has ability to provide consent until we determine differently

We visit with the resident to determine if the resident can consistently express their wishes and concerns and give direction to the ombudsman for investigation and resolution

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When the Resident Can't Consent

- Older Americans Act requires the long-term care ombudsman to work with a legal representative to address the concerns brought before the program
- So.... we ask the nursing home staff for details about the legal representative including access to review the authorizing document
- If there is no legal representative for the resident or the representative has not been granted authority related to the concern, the local ombudsman can seek consent from the State Ombudsman to advocate on behalf of the resident

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Capacity for What?

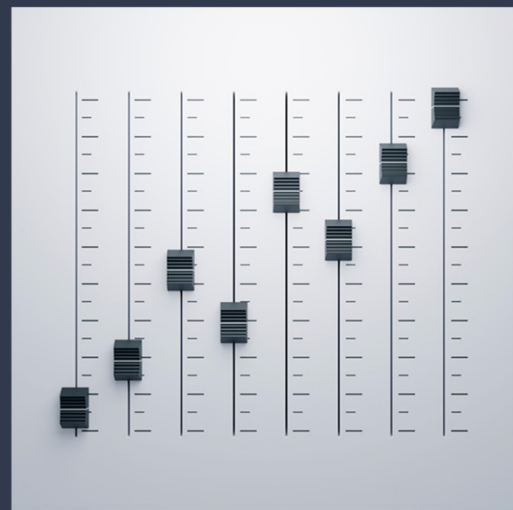
Assessing capacity through a practical and specific lens to maximize autonomy & choice

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Capacity is not...

- A diagnosis
- Static
- All or nothing
- Something that can be reliably determined through a cursory evaluation



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Adults...

- Are presumed to have capacity
- Are their own legal decision-makers. The right to make decisions in some /all domains can be limited only if a POA has been activated, a guardianship has been assigned (not just petitioned), or a rep payee has been appointed.
- Are allowed to make decisions with which providers/caretakers disagree.
- Can ask or arrange for help without those requests being considered evidence of incapacity.

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Myth

Capacity is static



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Fact

Capacity can vary even in a single day and change—for better or worse—over time

Factors that can impact capacity include:

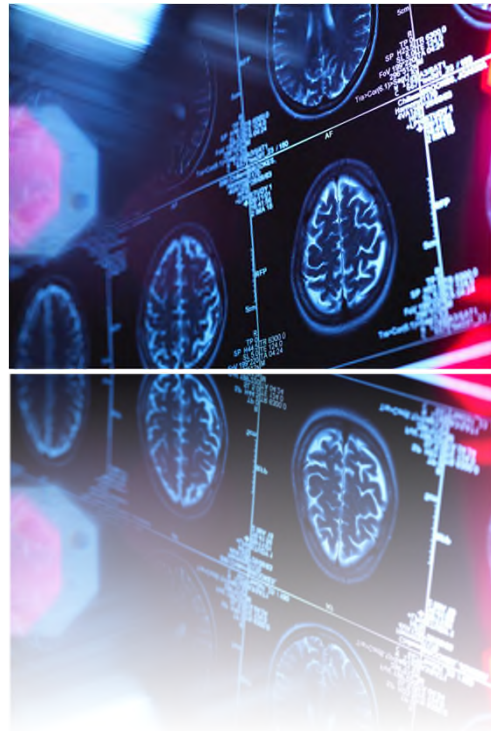
- Medications
- Dehydration
- Acute illness/infection
- Delirium
- Psychiatric illness
- Sleep deprivation
- Grief
- Anxiety
- And more....

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Myth

Incapacity is a diagnosis



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Fact

Capacity is separate
from a diagnosis

Dementia \neq Incapacity

Developmental
Disability \neq Incapacity

Mental Illness \neq
Incapacity

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Myth

“Bad” decisions
demonstrate
incapacity



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Fact

A person has the right to make a “bad” decision. What matters for capacity is the *process* the person used to arrive at the decision.



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Practical tips for nursing home staff

Don't...

- Assume a capacity determination from a hospital stay or during a time of acute illness necessarily reflects the the person's current capacity
- Rely only on a numerical score from a brief screening tool
- Generalize that incapacity in one area means incapacity in all areas
- Require surrogate decision-makers if not necessary



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Practical tips for nursing home staff

Do...

- Assess capacity under best circumstances for resident to succeed
- Reassess capacity frequently
- Be specific: capacity for what?
- Help residents maximize and, if possible, regain autonomy
- Honor choices to the greatest extent possible even if the person has cognitive deficits or a decision-maker



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A word to the wise...
we're not all
speaking the same
language when we
talk about capacity

- **Doctors** tend to focus on medical decision-making and may use terminology and tools others have difficulty interpreting
- **Lawyers** focus on legal capacity to make decisions or take certain actions
- **Occupational therapists, social workers, and caseworkers** may focus on *functional* capacity to perform practical tasks
- **Family members** and others may use words like "incompetent," "incapacitated," "guardian" and "power of attorney" without understanding what they mean or the consequences of those labels.

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Assessing Decision-Capacity

- Understanding
- Appreciation
- Reasoning
- Expressing a Choice

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Assessing Decision-Capacity: Understanding

- What diagnosis do you have?
 - (dementia, dysphagia, risk of falls)
- What is it you are attempting to do?
 - (leave AMA, eat solid foods, go for a walk)

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Assessing Decision-Capacity: Appreciation

- Do you believe you have the listed problem(s) or diagnoses?

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Assessing Decision-Capacity: Reasoning

- What are the risks or potential consequences?
- How can you minimize them?
- What are the potential benefits?
- What are your expectations?

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Assessing Decision-Capacity: Expressing a Choice

- Does the choice make sense, based on the conversation we've just had?
- Is the choice truly your own, or are you making it because someone else is forcing you?

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Assessing Decision-Capacity

- Provide relevant information
- Repeat as often as necessary
- Address sensory deficits
- Address language barriers
- Use language appropriate for patient literacy

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How well can you gauge risk?



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Showering/bathing independently

Low Risk
Medium Risk
High Risk

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Dressing independently

Low Risk
Medium Risk
High Risk



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Spending time with loved ones

Low Risk
Medium Risk
High Risk



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Sleeping/waking when preferred

Low Risk
Medium Risk
High Risk

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Spending time outdoors

Low Risk
Medium Risk
High Risk




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What is the greatest barrier to honoring resident choice in nursing homes?

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What's next? How to Mitigate Risk and Honor Resident Choice

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Care Planning: Creating a Foundation That Honors Resident Choice

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Care Plan “Musts” §483.21(b)

- Must include the resident and resident representative (when applicable) when developing
- Must describe the resident's medical, nursing, physical, mental and psychosocial needs and preferences and how the facility will assist in meeting these needs and preferences.
- Must be person-centered and reflect the resident's goals for admission and desired outcomes. Person-centered care means the facility focuses on the resident as the center of control, and supports each resident in making his or her own choices.
- Must reflect the resident's goals and expectations for the care and services he or she wishes to receive and include measurable steps to achieve those goals.
- Must reflect interventions to enable each resident to meet his/her objectives
- Must be developed by interdisciplinary care team within 7 days of completion of comprehensive assessment
- Must be reviewed at a minimum quarterly

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Mitigating Risk Through Assessment and Documentation

- When appropriate or requested, engage resident's family in preference assessment discussion

Document a preference assessment in resident's own words

- Conduct and document risk assessment for each of resident's preferences
- Explain/communicate preference risks to resident/resident's family

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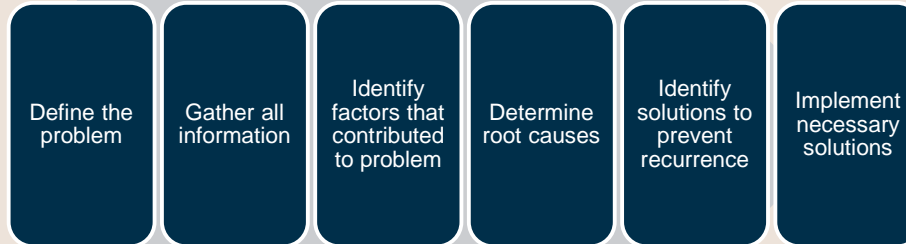
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Monitoring Preferences: QAPI- Assessing Injury, and Adverse Outcomes

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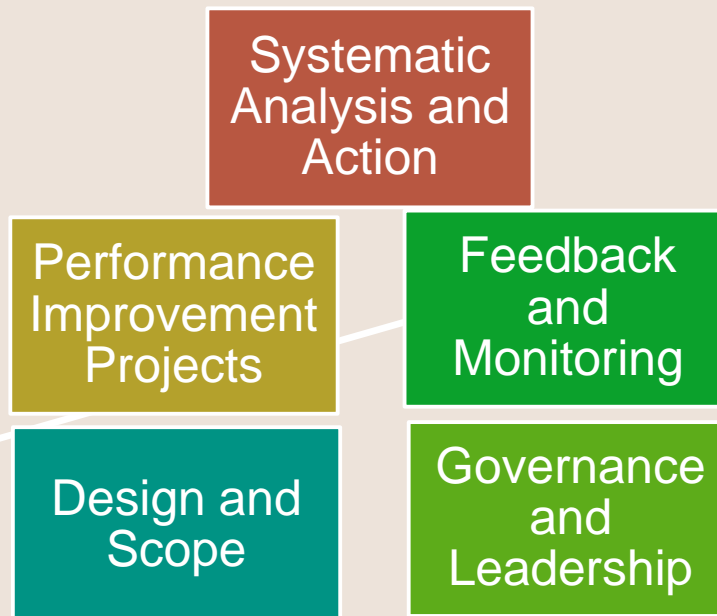
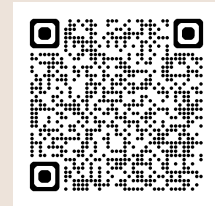
Conducting a Root Cause Analysis



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QAPI Elements



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Practical Application

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Case One

Mr. Thomas is an 82 yo male with Parkinson's Disease. He lives in a SNF. His tremor and gait are worsening and he has started losing weight. His daughter begins bringing in THC gummies and provides him one nightly. She thinks it is helping with his tremor and appetite.

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Case One

How would you approach this with Mr. Thomas and his daughter?

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Case Two

Ms. Smith is a 75 yo female who resides in a SNF. She has osteoporosis and falls frequently. Most recently, she fractured her left wrist after a fall, which was her first serious injury. However, she is unwilling to give up her daily 20 minute walk around the facility garden and says the exercise is important for her health.



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Case Two

How would you approach Ms. Smith's care?



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Case Three



Mr. Huang resides in a SNF but is no longer keeping up with payments. He now owes the facility over \$5,000 in unpaid bills. He has an activated power of attorney for healthcare and the facility administration is contemplating petitioning for guardianship to allow the POA to take over his financial affairs.

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Case Three



How would you approach Mr. Huang's care?

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Case Four



Mr. Brown resides in a SNF and receives hemodialysis three times weekly. However, he has found attending dialysis more onerous and uncomfortable and has started expressing a desire to stop. His daughter, who is his legal (full) guardian wants him to continue. He is now combative with staff when transportation arrives.

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Case Four

How would you approach Mr. Brown's care?

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Q&A

Ask the panel...

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