

SHARED DECISION-MAKING AND DIGNITY OF RISK

Susan Fisher

Wisconsin Guardianship Support Center – Managing Attorney
Greater Wisconsin Agency on Aging Resources, Inc.

&

Kim Marheine

Ombudsman Services Supervisor
State of Wisconsin Board on Aging and Long Term Care

Something to Consider...

In the long run, we shape our lives, and we shape ourselves. The process never ends until we die. And the choices we make are ultimately our own responsibility.

- Eleanor Roosevelt

Overview of Presentation

- Important Terms
- Core Concepts and Presumptions
- Surrogate Decision-Making
- Types of: POA Agent, Representative Payee, Conservator, and Guardian
- Frequent Problems
- Planning and Preparation
- Negotiating Risk
- Foreseeable Harm
- Options & Points to Consider
- Elders and Self-Direction
- Questions and Discussion

SHARED DECISION-MAKING:

Concepts and Types

Important Terms

- **Self-Determination:** Right individual possesses to make own decisions
 - Also known as autonomy or “respect for persons”
 - Preeminent consideration where all decision-making should start from
- **Surrogate Decision-Making:** Act of making significant decisions on another’s behalf
 - Surrogate Decision-Maker: Person making the decision
 - Common Examples: Guardian or agent acting under Power of Attorney
 - Surrogate Decision-Making or Surrogate Decision-Maker (SDM)

Core Concepts & Presumptions

- All people have fundamental rights and inherent freedoms.
 - Right to self-direction and personal choice.
 - Right to Individuality and Expression: Unique beliefs, religious practices, preferences, styles, personalities, etc.

Core Concepts & Presumptions , cont'd

- Upon turning 18, an adult is legally competent and able to self-direct his or her life.
 - Presumption remains unless person is adjudicated incompetent in a guardianship action.
- Right to choose/make own decisions and right to participate in decision making by individual
 - Even if have a SDM. SDM should be conscious of the rights involved and parameters of role.
 - SDM should understand the need to participate as
 - (a) respecting individual's uniqueness and right to self-determination, and
 - (b) providing certain benefits, like by participation, individual can maintain/develop decision making skills.

Core Concepts and Presumptions, cont'd

- At times, an individual may not be able to make his or her own decisions and there is a need for a SDM to provide consent.
- Examples: An emergency situation, progressive illness, or scheduled surgery

Core Concepts and Presumptions, cont'd

- **Need formal legal mechanism to transfer SDM authority.**
 - Significant liberty interests involved.
 - Note: WI is not a “family consent” state. Family members cannot provide consent for other family members. Need a specific and designated SDM to make decision

Core Concepts and Presumptions, cont'd

- **How SDM Can Be Obtained:** By individual's designation or by the court
 - Examples:
 - By the individual's designation: powers of attorney
 - By court: guardianships
- **Least Restrictive Alternative**
 - Choices made should be the least restrictive alternative available
 - As well as appointment of /activation of mechanism allowing for SDM

Surrogate Decision-Makers

- **SDM's Highest Goal:** The preservation of autonomy to the greatest extent possible
- **How to achieve this goal:**
 - Consider functional decision-making.
 - Functional decision-making is both a skill and an ability.
 - When: For each situation and decision
 - When looking at an individual's functional decision-making, consider the individual's
 - Ability to understand and communicate;
 - Life experience and practice can help develop it; and
 - Assistance by and effect of others.

Surrogate Decision-Makers, cont'd

- **Functional decision-making is variable:**
 - **Variable upon the person:** The existence of a SDM should not lead to the assumption that the individual cannot make any decision. Without and with assistance, an individual may be able to make a choice.
 - **Range of individual's decision making ability**
 - No decision-making ability (e.g., comatose)
 - Can provide opinion or preferences
 - Can make decision with assistance
 - Can make decision

Surrogate Decision-Makers, cont'd

- **Variable by the moment and the matter:**
The individual might be able to make decisions during specific periods or about specific topics
 - Example:
 - The individual might be more able to make decisions midmorning than other periods of the day.
 - The individual might understand a specific subject very well but others not as well.

Types of Surrogate Decision-Makers

- **Examples of SDM (lowest to highest in gravity)**
 - Agent (self-chosen)
 - Rep payee (SSA but can be self-chosen)
 - Conservator (court process but self-chosen)
 - Guardian (court process - possibly self-chosen but still subject to court approval)

Surrogate Decision-Makers: POA Agent

- **Agent Acting Under a Powers of Attorney**
 - A **Power of Attorney (POA)** is a legal document expressing the wishes of the individual (principal) and the delegation of specific SDM powers to a chosen agent

Surrogate Decision-Makers: POA Agent, cont'd

- Benefits and Considerations
 - Execution of a POA is a primary way to self-direct post incapacitation.
 - Allows the agent to carry out the individual's expressed wishes
 - Selection of agent
 - Selection of powers conferred
 - Limitations of powers (not to confer)
 - Clarity on significant decisions (e.g., end of life wishes)
 - A well-drafted POA may avoid the need for guardianship should one become incapacitated.
 - If a guardian is needed, legal preference is given to the appointment of the POA agent.

Surrogate Decision-Makers: POA Agent, cont'd

- **Agent's duties and role:** Follow expressed wishes of the individual
 - contemporary as well as per document
- **Health Care POA:** Per Wis. Stat. § 155.20(5), the health care agent shall act in good faith consistently with the desires of the principal as expressed in the power of attorney for health care instrument or as otherwise specifically directed by the principal to the health care agent at any time
- **Durable POA/ POA for Finances:** Per Wis. Stat. § 244.14(1)(1), Notwithstanding any provisions to the contrary in the power of attorney, an agent who has accepted appointment shall do all of the following: (a) Act in accordance with the principal's reasonable expectations to the extent actually known by the agent and, if those expectations are not known, in the principal's best interest. (b) Act in good faith. (c) Act only within the scope of authority granted in the power of attorney.

Surrogate Decision-Makers: POA Agent, cont'd

- **Limitations:**
 - Limited by type of POA and by law
 - What does the principal (the individual) want?
 - What does the POA actually say?
 - Type:
 - HCPOA agent – to make health care decisions only
 - POAF- Financial decisions
 - Revocation at any time, including after incapacity
 - Possibly controls when it is effective (e.g., upon incapacity or specific duration)

Surrogate Decision-Makers: Representative Payee

- **Representative Payee**
 - **What a representative payee does:** Person who receives the social security benefit on behalf of another and administers the distribution of the social security benefit for the support of the individual
 - Regarding Social Security benefits
 - Frequently called “**rep payee**”

Surrogate Decision-Makers: Representative Payee, cont'd

- **Benefits:** No court action and no finding of competency or poor management needed (but SSA may make the decision if one is needed)
- **Limitations:** Only that benefit within control and not other money or property, no SDM authority over other areas if needed like contracts or other benefits, SSA is federal and not state

Surrogate Decision-Makers: Conservator

- **Conservator:** Person chosen by individual who is subject to court oversight that will manage a person's income and estate
 - Same duties and possible powers as a guardian of estate (i.e., only financial and property related)
 - But self-chosen (by individual)
 - No finding of incompetency

Surrogate Decision-Makers: Guardian

- **Guardianship** is a court process that may result in a guardian being appointed to manage another's finances and/or oversee that person's well-being if that person is determined to be incompetent by the court.

Surrogate Decision-Makers: Guardian, cont'd

- As a mechanism, guardianship
 - **Should be person-specific.**
 - **Should consider whether any advance planning was done.**
 - Existence, sufficiency, and then the appointment of an agent as the guardian
 - **Should consider rights/powers retained and rights/powers that may be removed.**
 - Limited to ward's current state and abilities
 - Significant consideration should be given to what rights/powers must be removed and what rights/power can be maintained by ward
 - Can the ward exercise the right/power and make choice with assistance? (i.e., can it be limited but exercised with consult of guardian)
 - Individual retains all rights/powers unless specifically removed by the court, including the retention of constitutional rights.
 - Individual always retains other rights like right to counsel, to talk to ombudsmen, access to the court, etc.

Surrogate Decision-Makers: Guardian, cont'd

- WI has adopted the “**best interest**” standard and not the “**substitute judgment**” standard for SDM.
- The guardian is to make decisions that will be in the **best interest** of the individual.
- In other states, the “**substitute judgment**” standard allows for the guardian to make decisions based upon previously expressed wishes or what the individual would have chosen if competent.

Surrogate Decision-Makers: Guardian, cont'd

- Although a WI guardian uses the “best interest” standard for SDM, the WI guardian must still consider the individual's personal preferences by law.

Surrogate Decision-Makers: Specific to Guardian of the Person

- **Guardian of the Person:** Per Wis. Stat. § 54.25(2)(d)3, when exercising the applicable powers and duties, the guardian of the person must:
 - Place the least possible restriction on the individual's personal liberty and exercise of constitutional and statutory rights.
 - Promote the greatest possible integration of the individual into his or her community.
 - Make diligent efforts to identify and honor the individual's preferences with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation.

Surrogate Decision-Makers: Specific to Guardian of the Person, cont'd

- **Note:** If making an opinion contrary to the ward's expressed wishes, the guardian must consider the ward's understanding of the nature of the decision, the consequences of the decision, level of risk involved, value in developing ward's decision-making skills (and exercise of those skills), and need for wider experience. See Wis. Stat. § 54.25(2)(d)3.

Surrogate Decision-Makers: Specific to Guardian of Estate

- **Guardian of the Estate:** Per Wis. Stat. § 54.20 (1), in exercising the powers of the guardian of the estate, the person shall consider “consistent with the functional limitations of the ward,” all of the following:
 - The ward's understanding of the harm that he or she is likely to suffer as the result of his or her inability to manage property and financial affairs.
 - The ward's personal preferences and desires with regard to managing his or her activities of daily living.
 - The least restrictive form of intervention for the ward.

Frequent Problems

- SDM based on SDM's preferences and not person's preferences
- Failure to consider functional decision-making
- Family influence
- Lack of knowledge about parameters of role

Prevention & Planning

- **For individual:**
 - Perform (carefully) advance planning
 - Have multiple conversations with intended SDM
 - Become aware of resources in community (e.g., ADRC, options counseling, alternatives to residential care specific to your county, etc.)
 - Educate self about SDM and parameters of role.

Prevention & Planning, cont'd

- **As a surrogate decision-maker,**
 - Educate self about role as SDM.
 - Participate in conversations with the individual multiple times.
 - Respect, inquire, consider, then act – but never assume. Review each decision with the person. The individual may have a varying functional capacity depending on time of day, health, how engaged, etc.
 - Engage with choices.
 - Example: “Would you like to do activities A or B tomorrow?” vs. “What would you like to do tomorrow?”

DIGNITY OF RISK

A Long Term Care Ombudsman's Perspective

Recap

- Self-determination and surrogate decision-making should not be either/or, but should work in collaboration to preserve and respect the individual's autonomy.
- All persons have fundamental rights.
- Surrogate decision-makers must be aware of and respect the rights and preferences of the individual and must know the parameters of their roles.

More recap

- Health Care POA's make health care decisions only and agree to serve according to the desires of the principal (individual).
- Guardians make decisions in the best interest of the ward (individual), but they must still also consider the ward's personal preferences and desires.
- A guardian must promote the greatest possible integration of the individual into her or his community.

Negotiating Risk

- Premise that consumers have a right to choose and decline services, to take risks, and to live in accordance with other values besides optimal health and safety.

Negotiating Risk

Ask:

- Has everything possible been considered?
- Have reasonable steps been taken to prevent foreseeable harm?
- Applicable standards of practice include comprehensive assessment and noting conditions that could lead to risk, as well as things that motivate toward better choices.
- Emphasis on consumer choice increases the responsibility to notice risk factors and to take reasonable steps to prevent foreseeable harm, but does not mean denying the request simply because risk exists.

Foreseeable Harm

Reasonable steps to prevent foreseeable harm can be determined only with consideration of all these factors:

- Decisional capacity—the ability to make decisions in accordance with her or his own values
- The nature of the harm that might result
- The likelihood that the harm will occur
- The person's acceptance of the suggested steps to mitigate harm

Options to Consider

- Brainstorm ways of eliminating the risk or minimizing the harm related to risk.
- Consider not only the “hard” costs, but also the costs to the individual in terms of choices and rights, values, ability to learn (the rights of the individual have precedence over the values or comfort levels of decision-makers).
- Create options that balance both safety and individual rights.
- Negotiate short term opportunities as opposed to denying the entire choice.
- Always consider the principle of “least restrictive.”

Final Thoughts on Negotiating Risk

- Don't give up on a person or a person's expressed preference because the individual chooses to decline a process, service, treatment, etc.
- Start small, move slow, if that's all that can be done in the moment.
- Look for ways to motivate all parties involved toward understanding and collaborative change.
- Ask whether the risk exists because of the choices of the individual, or because the appropriate and empowering supports and services are not created.
- Re-visit, re-try, re-negotiate

Points to Consider

- MCO's are not surrogate decision-makers in the legal sense, but are essential brokers for services and supports that enable negotiated 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.

More Points to Consider

- **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
- **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”

Older Adults and Self-Direction

- Older adults in institutional care seem to defer most decisions, and sometimes even expressions of self-determination relative to quality of life and end-of-life care, to an adult child, trusted friend, facility staff.
- Some that do attempt to actively self-direct are oftentimes labeled as “challenging,” “unrealistic,” or “lacking insight,” particularly in facilities or within MCO/health care structures that have a paternalistic view of their roles.

“HOME”

- *This* is my home.
- This *is* my home.
- This is *my* home.
- This is my *home*.

For Discussion

- Older adults with mental health challenges seem to find fewer community supports available to them, thus may live in institutional care even if medical need is not great.
- Perceptions of increased safety and 24-hour availability of oversight are noted as the most frequent reasons for families to choose institutional care for an older adult.

Summary

- Clients have rights
- Decision-makers, care providers and MCO's have responsibilities
- All must respect and protect clients' rights
- “Nothing about me without me:” the client always has a voice that must be heard

Credits

Credit information about Negotiated Risk to:

- Ann M. Pooler, RN, PhD
- Roy Froemming WI DHFS discussion paper on "Liability Issues in Self-Directed Supports," December 1999.
- Barbara Bowers Quality in WI Partnership Program, 1996, p .21

Resources Available

- BOALTC Ombudsmen
- WI Guardianship Support Center
- WI DHS publication, “Guardianship of Adults,” found on the DHS website at <http://www.dhs.wisconsin.gov/publications/P2/p20460.pdf>
- WI Bar Association (Elder Law Section) & National Academy of Elder Law Attorneys (NAELA)

STATE OF WISCONSIN BOARD ON AGING AND LONG TERM CARE

Long Term Care Ombudsman Program/Helpline
1-800-815-0015

Medigap Helpline
1-800-242-1060

Medicare Part D Helpline
1-855-677-2783

Guardianship Support Center

- **How to reach the GSC?**
- By phone: (855) 409-9410
- By email: guardian@gwaar.org
- By fax: (866) 561-2652
- Address: Elder Law and Advocacy Center
- 1414 MacArthur Road
- Suite #306
- Madison, WI 53714

QUESTIONS?

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