



CESDM

CENTER FOR EXCELLENCE
IN SUPPORTED DECISION MAKING



Guardianship: A False Sense of Safety in Avoiding Maltreatment?

31st Annual NAPSA Conference

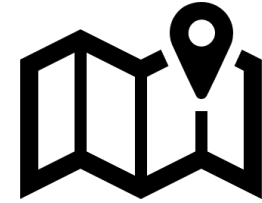
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Objectives

1. Understand why guardianship may be overly burdensome and overly protective
2. Explain how the person-centered approach of SDM protects individual rights while still protecting those who are vulnerable to maltreatment
3. Describe the tension between family and professionals' safety concerns and quality of life and desires of the person served

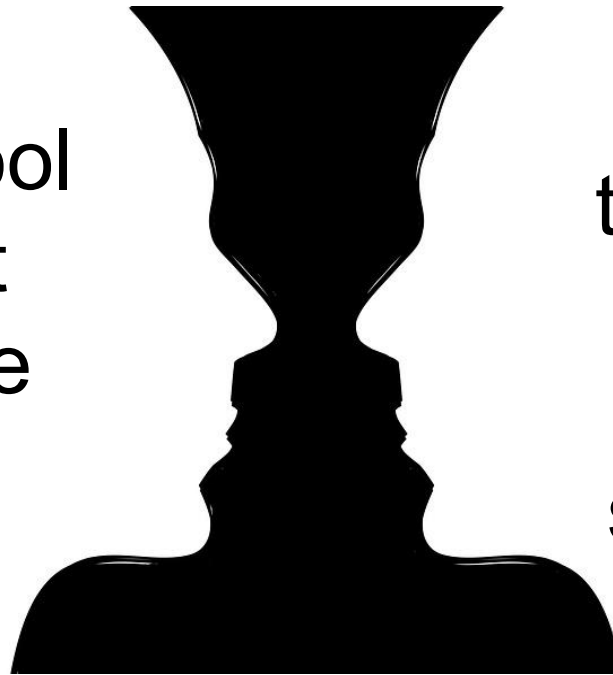
Roadmap



- Guardianship: safety, protection, and unintended consequences for person being protected
- Supported Decision Making: introduction and basics
- Navigating vulnerability and risk

Guardianship

Valuable tool
to protect
Vulnerable
Adult?



Heavy-handed
tool which strips
constitutional
right to
self-determinati
on?

Is Guardianship the Best Solution?

- An ethical issue: removing constitutional right to self-determination / autonomy:
Human Rights
- Expensive: to incapacitated person, family, society
- The problem of scarce resources

Is Guardianship the Best Solution? (cont'd)

- Not useful to “solve” many problems:
 - Behaviors
 - Family issues
 - Lack of appropriate care provider or setting
- Potentially emotionally devastating to person and family
- Negative impacts on the person...

Can Guardianship Make Things Worse?

Medical Orders
vs.
Quality of Life



Can Guardianship Make Things Worse?

Dignity of Risk

vs.

Safety



Can Guardianship Make Things Worse?

Loss of sense of power and self-determination = potential for

- increased resistance
- reduced cooperation
- decreased sense of self-worth

Can Guardianship Make Things Worse?

Risk of Guardian Overreach

- Well-intended, worried guardian
- Fears of liability
- Power and control
- Providers (and person) turn to guardian for *all* decisions
- Little opportunity for growth/skill development

Reasons for Guardianship

- To prevent or respond to maltreatment
- To address poor choices
- To address lack of ability to make informed choices
- To protect vulnerable adults

Guardianship to Stop/Prevent Maltreatment

“George” is 77, living with dementia in long-term care, has guardian because son was using undue influence and coercion to access funds. His family approaches his guardian about moving to the lovely residential care home closer to them. This eventually leads to revelation that his guardian stole his entire estate; the funds are essentially unrecoverable.

Guardianship to Address Poor Choices

“Steve”, age 27, was appointed a guardian due to his intellectual disability. He continued to live with his mother/guardian but they were constantly fighting, and he made “bad” choices regarding drug and alcohol use, friend and dating choices, such that his mother kicked him out of the home. He is now homeless.

Guardianship to Address Poor Choices

“Tracee”, age 25, has a history of drug use and shoplifting around the time the guardianship was established at age 18.

- Her guardian and group home staff will not let her carry a purse, or only clear plastic purse.
- Sober since age 19, she wants to move to more independent living, but her guardian says no, because she may start using again.

Guardianship to Protect Vulnerable Adults

“Violet” is 53, has schizophrenia and an intellectual disability; she grew up in foster care and was appointed a guardian at age 18. She has been complaining of stomachache for months; providers just discovered a painful STD.

Guardianship

- The ultimate protection?
- Promotes false sense of security?
- Increases risk of maltreatment for some?

GUARDIANSHIP IS:

- an excellent tool....when it's necessary
- sometimes the only way to protect a person experiencing vulnerabilities
- sometimes the only way to meet the person's own goals
- to be utilized only in extreme circumstances when there is no other way to protect person/meet goals: last resort

Changing Perspectives: Recognizing That:

- guardianship has historically been overused
- guardianship often sought to solve problems that guardianship can't solve
- protections of guardianship also bring significant risks to the person
- guardianship may promote false sense of security, hiding risks to the person

Supported Decision Making

- Changing perspectives of guardianship and supporting people with disabilities
- Understanding benefits of self-determination
- Supported Decision Making: how we all make decisions

SUPPORTED DECISION MAKING

The protective power of
self-determination

Research: Benefits of Self-Determination

People with disabilities who exercise greater self-determination have a **better quality of life**, more independence, and more community integration.

Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

Research: Self-Determination & Maltreatment

- “Women with intellectual disabilities exercising more self-determination are less likely to be abused.” Khemka, Hickson, and Reynolds, 2005
- “Older adults with more self-determination have improved psychological health including better adjustment to increased care needs” O’Conner & Vallerand, Canadian Journal on Aging, 1994

Research: Benefits of Self-Determination

- Older adults who exercise more control over their lives have a **better quality of life.**
- Providing support to people with dementia can lead to them being able to provide informed consent.

Mallers, et al., 2014

Haberstroh, et al. 2014

SUPPORTED DECISION MAKING

An Alternative to Guardianship for
many people

Supported Decision Making: Definition

“a recognized alternative to guardianship where people with disabilities use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the 'need' for a guardian”

(Blanck & Martinis, 2015)

Supported Decision Making: Paradigm Shift

- Understand we all have the right to make choices
- Needing help \neq needing guardianship
- Confront own/others' assumptions about:
 - Capacity & Diagnosis
 - Need for *legal* decision maker
 - Ability of family (however imperfect) to play significant and positive role
- Confront own and other professionals' lack of comfort with ambiguity

May Require New Approaches from Us

- Confront your own risk tolerance
- Build trust/joining
- Advocate for decisions person can make
- Accommodate for disabilities
- Give information about rights
- Help person understand “needs” as well as “wants”
- Facilitate realistic goal setting (Insight Proxy)
- Identify and link to formal and informal resources and supporters

AS WE'VE KNOWN FOR FORTY YEARS

When denied self-determination, people:

- “[F]eel helpless, hopeless, and self-critical” - Deci, 1975.
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function - Winick, 1995

Supported Decision-Making (SDM)

Quality Trust for Individuals with Disabilities

1 What is SDM?

A process in which people who need assistance with decision-making receive the help they need and want to make life decisions for themselves

A way to preserve rights and build an existing capacity with real life experience and learning

An essential element for achieving self-determination and meaningful inclusion in community

An empowering, skill building and transformative approach to assisting people

2 What can you do?



Acknowledge decision-making as a basic human right and natural part of the human experience

Expect that all children with disabilities will develop as decision-makers and ensure involvement in decision-making throughout the lifespan

Help people develop relationships and support systems necessary for accessing support in decision-making when needed (e.g. Friends, family, trusted professionals and generic service providers, etc.)

Learn to evaluate the need for intervention by weighing the risk of harm or failure with the risk of loss of dignity, self-direction and overall quality of life.

Educate people and families on the options available.

3 What happens now?

Little to no emphasis on "teaching" decision-making skills

Low expectations for children or adults with disabilities to be involved in decision-making in meaningful ways

Superficial use of "preferences" in structured programming

Bias toward use of substituted decision making methods (e.g., guardianship) as a primary support



4 Rethinking Support

How do all people become good decision-makers?

What role and responsibility do professional "helpers" have to support individual decision-making?

What about the role of families?

What could support look like? (one size will not work for all)



5 Providing Support

Take direction from the person and his or her will and preferences

Customize actions to and with the person

Find new tools for your toolbox:

Communication
Peer Support
Practical Experiences
Life Coaching

Be flexible and try multiple ways



Reference

Quality Trust for Individuals with Disabilities, The Council on Quality Leadership, and Burton Blatt Institute. "Supported Decision Making: An Agenda for Action" February 2014

 **Quality Trust**

www.dccqualitytrust.org

www.supporttoddecisionmaking.org

of America®
WISCONSIN

Navigating

Self-Determination
(Dignity of Risk)
Vs.
Protection (Safety)

Self-Determination vs. Protection

Decision: Client:	Low Risk Outcome	High Risk Outcome
Capacitated/ Informed Decision-making	right to risk	right to risk
Questionable Capacity	right to risk	higher value placed on protection/right to be safe
Incapacitated	right to risk	safety/protection is goal

Navigating Choice vs. Safety

- Is person able to understand the associated risk? (have we supported them to do so?)
- Likelihood it will cause serious harm?
- Can that “serious harm” be reduced/addressed?

Capacity & Likelihood of Harm Considerations

Varying perspectives

- person's current and previous values, goals, preferences
- poverty, cultural differences
- person's goal vs. provider goals
- Is this really a safety issue, or is it power & control, or well-intended but misguided overemphasis on safety

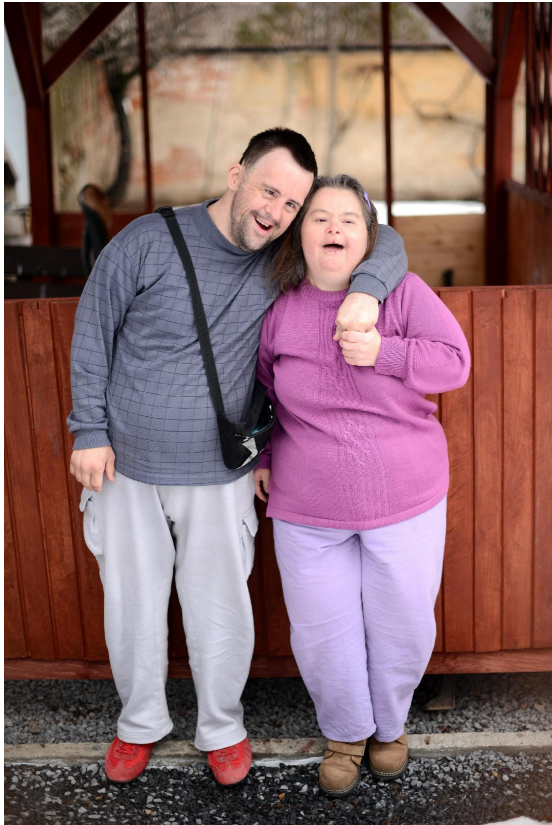
Building Protections & Minimizing Risk

- Community education
 - See something, say something
 - Supporting our neighbors
 - Maltreatment warning signs
- Communication: trusting relationships, reducing social isolation
 - Why are some people reluctant to report problems?

Building Protections & Minimizing Risk

- Skill building, recognizing scams
- Supported Decision Making
Agreements & Teams
 - Supporters
 - Monitors
 - Broadly defined team members
- Informal supporters

Navigating Choice vs. Safety



Restricting Activities vs. Addressing Risk

- Safety in the community
- Personal expressions: hair, clothing, tattoos
- Relationships
- Safety on the internet/smart phones

Navigating Choice vs. Safety

What are person's likely responses if try to force non-smoking, healthy diets, exercise, etc.?

- Quality of life/life satisfaction
- Conflict / power struggles
- Trying to do it / not do it anyway

Navigating Choice vs. Safety

- Help person understand how it will impact desired outcomes and life goals
- Have we asked the person about their ideas: why they like/don't like, don't want to/want to do the thing?

Navigating Choice vs. Safety

- Is there a creative way to meet both choice and safety?
- Trials, skill building, coaching

Safety & Protection: Proceed with Caution

Weigh “benefit” of protection with harm it may cause:

- Does the need for safety (avoiding likely serious harm) outweigh potential losses to quality of life / life satisfaction / autonomy?
- Will the protection plan actually even protect the person?



NAPSA Code of Ethics

Adult Protective Services...promote safety, independence, & quality-of-life for older persons & persons with disabilities...being mistreated or in danger of being mistreated, and who are unable to protect themselves.

Guiding Value: Every [APS] action...must balance duty to protect the safety of the VA with the adult's right to self-determination.

Secondary Value: Older persons and persons with disabilities who are victims of mistreatment should be treated with honesty, caring, and respect.



Principles

- Adults have the right to be safe.
- Adults retain all their civil and constitutional rights i.e., the right to live their lives as they wish, manage their own finances, enter into contracts, marry, etc. unless a court adjudicates otherwise.
- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others.
- Adults have the right to accept or refuse services.



Practice Guidelines: APS Responsibilities

- Recognize that the interests of the adult are first concern of any intervention.
- Avoid imposing personal values on others
- ...
- Recognize *individual differences* such as cultural, historical and personal values.
- Honor right of adults to *receive information* about choices & options in *form or manner that they can understand*.
- To the best of one's ability, involve the adult as much as possible in developing the service plan.
- Focus on case planning that *maximizes the vulnerable adult's independence and choice* to the extent possible based on the adult's capacity.



Practice Guidelines: APS Responsibilities

- Use the *least restrictive services* first whenever possible—community-based services rather than institutionally-based services.
- Use *family and informal support systems first* as long as this is in the best interest of the adult.
- Maintain clear and appropriate professional boundaries.
- In the absence of an adult's expressed wishes, support casework actions that are in the adult's *best interest*.
- Use substituted judgement in case planning when historical knowledge of VA's values is available
- Do no harm. Inadequate or inappropriate intervention may be worse than no intervention.

*To deny the right to
make choices in an
effort to protect the
person with disabilities
from risk is to diminish
their human dignity.*

~ Robert Perske

Safety and Choice

“...our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life ... we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”

— [Atul Gawande, *Being Mortal: Medicine and What Matters in the End*](#)

Resources

- *When the Guardian is An Abuser*
National Center on Law & Elder Rights, June 2019
<https://ncler.acl.gov/getattachment/Legal-Training/When-the-Guardian-is-an-Abuser-Ch-Summary.pdf.aspx?lang=en-US>
- *Mandated Reporting of Abuse of Older Adults and Adults with Disabilities*
https://ncea.acl.gov/NCEA/media/Publication/NCEA_NAPSA_MandatedReportBrief.pdf

Resources

- NAPSA Code of Ethics
<https://www.napsa-now.org/about-napsa/code-of-ethics/>
- CESDM Guide to SDM in MN: A Resource for Families and Other Professionals
[www.voamnwi.org/pdf
files/cesdm-guide-to-supported-decision-making](http://www.voamnwi.org/pdf/files/cesdm-guide-to-supported-decision-making)

Resources

- National Resource Center on Supported Decision Making
www.supporteddecisionmaking.org
- *American Bar Association: The PRACTICAL*
[www.americanbar.org/groups/law_aging/res](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)
[ources/guardianship_law_practice/practical](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)
[tool.html](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)

Resources

- *Supported Decision-Making Theory, Research, and Practice to Enhance Self-Determination and Quality of Life*
www.cambridge.org/us/academic/subjects/law/human-rights/supported-decision-making-theory-research-and-practice-enhance-self-determination-and-quality-life?format=HB



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