

SUPPORTED DECISION MAKING IN LATER LIFE

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There ARE Stupid Questions

What's Your Favorite Right?

Rights=Choice

"I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose *how we are* in those circumstances."

- Jean Paul Sartre

Rights=Choice

Choice=Self-Determination

- Life control
 - People's ability and opportunity to be “causal agents . . . actors in their lives instead of being acted upon”
- Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000.

Benefits of Self-Determination

People with greater self determination are:

- Healthier
 - More independent
 - Better able to recognize and resist abuse
 - Better able to adjust to increasing care needs
- e.g., Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

Another Stupid Question

Are Your Rights Worth
ANYTHING If You're Not
Allowed to Use Them?

And Yet: 2,000 Years and Counting

- **Ancient Rome:** “Curators” appointed for older adults and people with disabilities.
- **5th Century Visigothic Code:** “people insane from infancy or in need from any age . . . cannot testify or enter into a contract”
- **Feudal Britain:** divided people with decision-making challenges into “idiots” and “lunatics” and appointed “committees” to make their decisions

Guardianship In The US

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the **vast** majority of cases- Teaster, Wood, Lawrence, & Schmidt, 2007.
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**”

- Frolik, 1998

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.

The Problem

“The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.”

- House Select Committee on Aging, H.R. Rpt. 100-641
(opening statement of Chairman Claude Pepper)

Where Do We Go From Here?

Guardianship MAY Be Needed

- In emergency situations when
 - *The person is incapacitated and cannot give consent*
 - *The person did not previously identify how decisions should be made in that situation*
 - *There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means*
- To support People:
 - *Who face critical decisions and have no interest in or ability to make decisions*
 - *Who need immediate protection from exploitation or abuse*

Guardianship Is NEVER Needed

JUST

- “Because you have ____”
- “Because you’re ____ years old”
- “Because you need help”
- “Because that’s the way its always been”
- “For your own good”

So, Where DO We Go From Here?

If we KNOW:

- That increased self-determination leads to improved quality of life;
- That decreased self-determination can result in decreased quality
- That some people need more support as they age or due to disability

Then we need a means of **INCREASING** self-determination while **STILL** providing support

A Way Forward: Supported Decision-Making

“a recognized alternative to guardianship through which people with disabilities use 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.

Think About It

How do you make decisions?

What do you do if you're not familiar with the issue?

- Taxes?
- Medical Care?
- Auto Repairs?

What Do You Do?

So, Supported Decision-Making Is A Lot
of Words For

Getting help when its needed

Just like you and me

What is SDM

- Everyone has a right to make choices
- Everyone needs support or assistance with some choices

- We all do it



SDM

- A person centered decision making model,
- Advisors offer options and explain risks and benefits to assist the Person in making choices
- Respects individual choice
- Advisors assist in implementing



Precedent

In re Peery, 727 A.2d 539 (Pa. 1999).

In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012).

Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct., 2013)

Changes in Memory and Cognition

- Early diagnosis is becoming more common
 - *Treatment*
 - *Planning*
 - *Quality of life*



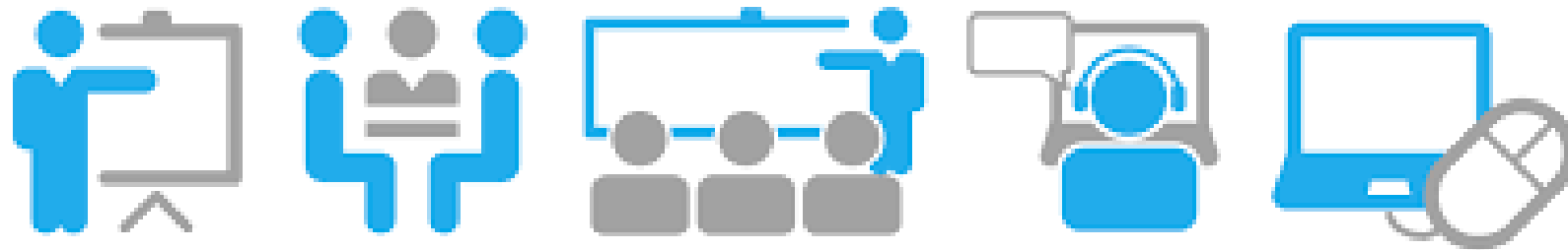
Why is SDM important?

- *Person Centered*
- *Preserving Rights*
- *Using the decision making model across the progression of the illness*



Planning for SDM

- Selecting advisors
- Training the advisors
- Legally empowering the advisors



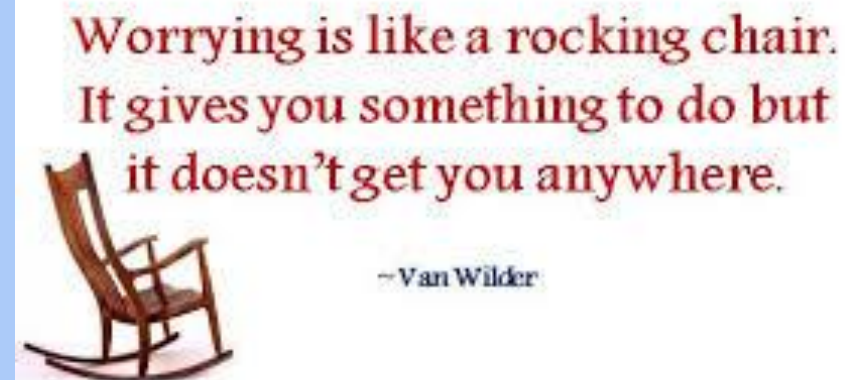
Financial Planning

- Authorized signers on accounts
- Direct deposit
- Automatic or direct payments
- Complexity of planning, varies with the complexity of the person's finances



Keep the person involved in finances

- If they don't hear about money, they assume they don't have any
- As long as possible have them sign the checks
- Talk about money in a positive way
 - *Emphasize the positive – don't induce worry*



Spending Money

■ Emily and Elmer

- *Cash or cards*
- *Affordable*
- *Not Accountable*



Durable Power of Attorney

Careful selection of the agent / advisor

Draft in oversight and limitations

Accounting to a third party

Limits on some transactions

House

Gifts

SDM Provision for POAs.



Health Care decision Making using the SDM model

- Always – always – always inform and ask for guidance on making decisions*
- An understanding of values, goals and beliefs is needed*
- Are choices consistent*
- If choices are changing, is it a tipping point?*



SDM agreements

- Guide relationship
- Set guidelines for settling disagreements between the person and the advisors

Support Opportunity: Power of Attorney with Supported Decision-Making

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. That means that I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities. **I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions.**”

Support Opportunity: Advanced Directive with Supported Decision-Making

“My agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability, with me being the final decision maker.”

Support Opportunity: Financial Authority

I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X without my agent's agreement. For example, if I want to buy or sell a car for \$20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than X, **my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree.**

Support Opportunity: Banking

I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts – including checking and savings accounts, as well as credit and debit cards – that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than \$X from any account, write a check for more than \$X, or otherwise cause more than \$X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

Support Opportunity: “Growth Clause”

“My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it **should be changed or cancelled at least every _____**.

However, unless my agent and I change the power of attorney, I cancel it, my agent resigns, or either I or my agent dies, the [] will continue.”

PRACTICAL Tool for Lawyers:



PRESUME guardianship is not needed.

- Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- Review state statute for requirements about considering such options



REASON. Clearly identify the reasons for concern.

- Money Management:
- Health Care:
- Relationships:
- Community Living:
- Personal Decision-Making:
- Employment:
- Personal Safety:



ASK if a triggering concern may be caused by temporary or reversible conditions.

- **Medical conditions:** Infections, dehydration, delirium, poor dental care, malnutrition, pain
- **Sensory deficits:** hearing or vision loss
- **Medication side effects**
- **Psychological conditions:** stress, grief, depression, disorientation
- **Stereotypes or cultural barriers**



COMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations.

- Ask “what would it take?” to enable the person to make the needed decision(s) or address the presenting concern.



TEAM. Ask the person whether he or she already has developed a team to help make decisions.

- Does the person have friends, family members, or professionals available to help?
- Has the person appointed a surrogate to help make decisions?



IDENTIFY abilities. Identify areas of strengths and limitations in decision-making

- Can the individual:
- Make decisions and explain his/her reasoning
- Maintain consistent decisions and primary values over time
- Understand the consequences of decisions



**KEEP
CALM
AND
FOCUS ON
YOUR ABILITY**

CHALLENGES. Screen for and address any potential challenges presented by the identified supports and supporters.

- Possible challenges to identified supports:
- Possible concerns about supporters:



**APPPOINT legal supporter or surrogate
consistent with person's values and
preferences.**



**LIMIT any necessary guardianship
petition and order.**



Remember to:

- Always – Always – Always keep the Person at the center of the process



Ethical Considerations

ABA Model Rule 1.14:

(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

Ethical Considerations

Comment to ABA Model Rule 1.14

“The normal client-lawyer relationship is based on the assumption that the client, **when properly advised and assisted, is capable of making decisions about important matters.** When the client is a minor or suffers from a diminished mental capacity, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, a severely incapacitated person may have no power to make legally binding decisions. **Nevertheless, a client with diminished capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being.**”

Ethical Considerations

Comment to ABA Model Rule 1.14

“The client may wish to have family members or other persons participate in discussions with the lawyer. When necessary to assist in the representation, the presence of such persons generally does not affect the applicability of the attorney-client evidentiary privilege. Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must look to the client, and not family members, to make decisions on the client's behalf.”

Ethical Considerations

Comment to ABA Model Rule 1.14

“Such measures could include: **consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decisionmaking tools such as durable powers of attorney or consulting with support groups, professional services, adult-protective agencies or other individuals or entities** that have the ability to protect the client. In taking any protective action, the lawyer should be guided by such factors as the **wishes and values of the client** to the extent known, the client's best interests and **the goals of intruding into the client's decisionmaking autonomy to the least extent feasible**, maximizing client capacities and respecting the client's family and social connections.”

Join the Conversation

National Resource Center for Supported Decision-Making:
SupportedDecisionMaking.Org

The Burton Blatt Institute: www.BBI.Syr.Edu

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thank you!