

Representing a Person with a Guardian: Strategies for Incorporating Supported Decision-Making

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**LIFE IS LIKE A BOX OF
CHOCOLATES**

FOR NEVER AGAIN ONLY FOUR MORE DAYS



What is your favorite Right?



Guardianship

- Is a fiduciary relationship where the guardian is given the power to make some or all decisions for the person – Va. Code Ann. 64.2-2019
- The vast majority of guardianships – over 90% - are “plenary” and give the guardian the power to make all decisions for the person - Teaster, Wood, Lawrence, & Schmidt, 2007

The relationship between guardian and ward

Guardians have “substantial and often complete authority over the lives of vulnerable [people].”

4 NAELA J. 1, 7 (2008).

This includes power to make the most basic health, personal, and financial decisions.

AARP, Guardianship Monitoring: A National Survey of Court Practices 1-2 (2006).

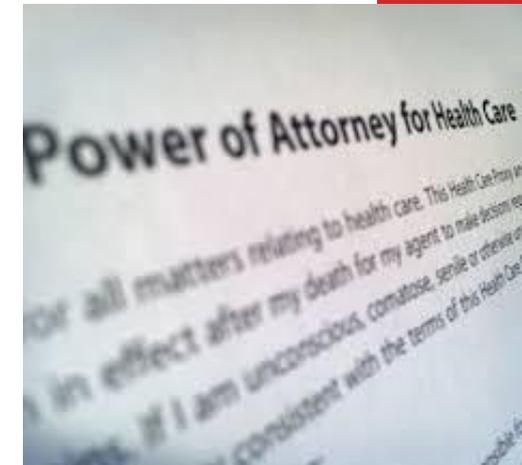
Guardian's Power over Money

- Decides how to save, spend, invest ward's money
- Decides whether or where the person works
- Manages benefits like SSI/SSDI



Guardian's Power over Health Care

- Decides what kind, or whether, the person receives health care
- Decides what doctors the person sees and for what
- Can consent or withhold consent to treatment, including life saving treatment



Guardian's Power over Personal Decisions

- Where is the person going to live
- Social Activities
- Relationships
- How is the person to be cared for
- What options are available for clothing
- Entertainment



Guardian's Power over Just about Everything

A Virginia guardianship order – *Ross and Ross v. Hatch*, Va. Cir. (Newport News), Case No. CWF-120000-426

Guardians had the power:

“[T]o make decisions regarding visitation of individuals with Respondent, Respondent's support, care, health, safety, habilitation, education, therapeutic treatment and, if not inconsistent with an order of commitment, residence.”

But....

Just being in guardianship should not take away a person's right to be involved in making decisions



Virginia law

A guardian shall, to the extent feasible, encourage the incapacitated person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs. A guardian, in making decisions, shall consider the expressed desires and personal values of the incapacitated person to the extent known and shall otherwise act in the incapacitated person's best interest and exercise reasonable care, diligence, and prudence. A guardian shall not unreasonably restrict an incapacitated person's ability to communicate with, visit, or interact with other persons with whom the incapacitated person has an established relationship.

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Va Code Ann. 64.2-2019(E)

Doesn't that sound like

Supported Decision-Making

People working with “friends, family members and professionals to help them understand the situations and choices they face, so they may make their own decisions”

- Blanck & Martinis, 2015

Therefore

- “To the maximum extent feasible” Supported Decision-Making should be incorporated into the guardianship plan for the person to make sure s/he has the maximum opportunity to make his or her own decisions and/or gain or regain the capacity to make decisions
- E.g. Va Code Ann. 64.2-2019

National Guardianship Association on Supported Decision-Making in Guardianship

“[T]he supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary”

- National Guardianship Association Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, 2015

Which means

As the attorney for a person in guardianship, you should be advocating for the person to make as many decisions as possible

e.g. Rule of Professional Conduct 1.14, comment 1:

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. . . . [A] client with diminished capacities often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. For example . . . some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

“Supported Decision-Making”: What?

- **Supports and/or services** that help people with disabilities (including, e.g., older people with age-related dementia) make their **own decisions**, by using friends, family members, professionals, and other **people they trust trust**:
 - To help **understand** the issues and choices;
 - Ask **questions**;
 - Receive **explanations** in language they understands; and
 - **Communicate** their own decisions to others.

(e.g, Blanck & Martinis 2014, Dinerstein 2012, Salzman 2011)

- Think about it:
 - How do you make decisions?
 - **Don't we all use Supported Decision-Making?**

“Supported Decision-Making”: What?

- There is **no “one size fits all”** method of Supported Decision-Making.
- It is a **paradigm**, not a process or program
 - It means working with the person to identify where help is needed and finding ways to provide that help.
 - The key question is: **“What will it take?”**
- Supported Decision-Making **“solutions also are different for each person.** Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best . . . With supported decision-making the **possibilities are endless.”**
(Administration for Community Living, “Preserving the Right to Self-Determination: Supported Decision-Making”)

Common Considerations in SDM

- **All forms of SDM recognize:**
 - The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others.
 - That a person can **take part in a decision-making process** that does not remove his or her decision-making rights; and
 - **People will often need assistance** in decision-making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.
- **Human Dignity**
 - Everyone has a right to make choices
 - Everyone needs support or assistance with some choices

Supported Decision-Making: Why?

- 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).
- 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; Wehmeyer & Schwartz 1998; O’Connor & Vallerand)

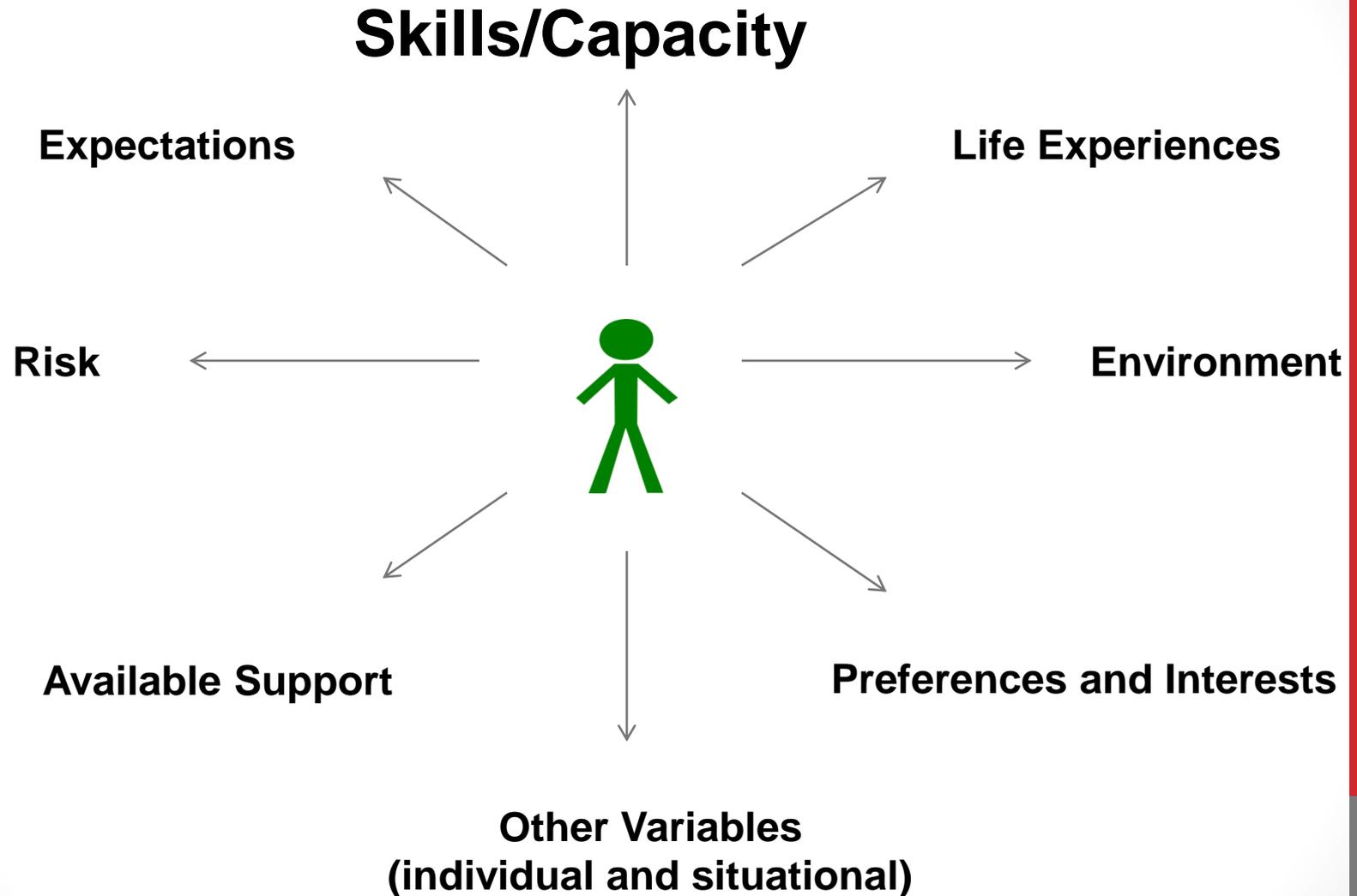
Supported Decision-Making: How?

- **Issue #1**: Human Decision-Making
- **Issue #2**: Assessment
- **Issue #3**: SDM versus Substitute Decision-Making
- **Issue #4**: Rethinking Support of Decision-Making
- **Issue #5**: SDM Tools

Issue #1: Human Decision Making

- **Many decisions are made every day**
 - Some big, some small.
- Capacity is **not “black and white”**
 - It is not based solely on IQ or diagnosis
 - People may be able to make some decisions, and not others. Or at some times, and not others.
- **No standard process or measure of “goodness”**
 - “Good” decision-making seems part science and part art?
 - Who decides if our decisions are “good”?
- **Elements of “capacity”**-The person:
 - Understands his or her situation
 - Understands the risks
 - Communicates a decision based on that understanding

Issue #2: Assessment



Issue #3: Supported vs. Substitute Decision-Making

- Ask: **Who** is making the final decision?
 - “Make with” vs. “Make for”
- If it is the **person** → **Supported** Decision-Making
- If it is **someone else** → **Substitute** Decision-Making
 - There is an **important role** a Substitute Decision-Maker should play in **effectuating the person’s wishes** and **supporting the person’s involvement in decision-making**.

Issue #4: Rethinking Support of Decision-Making

- **How do people build and/or maintain decision-making skills?**
 - With opportunities
 - With practice.
- **What role and responsibility do you have to support decision-making?**
 - Promote meaningful choice and person-centered planning.
- **What can this kind of support look like?**
 - Consider each person, situation, and decision.

Supporting Decision-Making

- **Respect** the person you support as the decision-maker.
 - **Always consult the person**, including those considered “vulnerable”
 - **Avoid “undue influence”** when discussing “important to” versus “important for.”
 - **Strike a balance** – advice and assistance to inform the person’s choices
 - Ultimately, the **choice belongs to the person**
- **Help develop and raise the person’s decision-making voice.**
 - How? Practice opportunities! Access to options!
 - Use the SDM decision-making model across the progression of an illness
- **Recruit other support**, as needed.
- **Leave room for mistakes.**

Supporting Decision-Making

“Poor” decisions often:

- Focus on limited aspects of a problem or situation
- Consider only immediate benefits
- Oversimplify issues, *i.e.*, good/bad, right/wrong
- Are influenced by emotional factors
- Are reactive

“Better” decisions often:

- Reflect an understanding of different perspectives
- Focus on both short and long range goals
- Look at multiple potential outcomes
- Include a process for analysis and thinking
- Use tools and resources for making decisions

Issue #5: SDM Tools

- Effective Communication
- Informal or Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation
- Supported Decision-Making Guide
 - <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>



Remember: SDM is a tool, not an outcome.

SDM Tools (continued)

- **Written Documents**
 - Release of Information forms – “HIPAA” or “FERPA”
 - Other Written Plans
- **Written Agreements**
 - Statutory Forms in TX and DE
 - Model Forms
 - <http://supporteddecisionmaking.org/node/390>
- **U.S. Americans with Disabilities Act**
 - Provides civil rights protections for people with disabilities, including requiring “reasonable modifications to policies, practices, and procedure” to avoid discrimination.
 - Decision-making support can be a reasonable accommodation!

Who has Authority – a few quick bright lines

- An Adult = has the right and authority to make any choice
 - Legal or illegal
 - Best interest or not best interest
 - Yes or no
 - Good or bad
- Agent under a Power of Attorney
 - Has the authority granted in the document or by law
 - Has an obligation to put the best interest of the grantor first
 - If they take advantage – it may be a crime
 - Is not obligated to act
 - **Grantor retains all authority**



SDM can minimize Health Care Disputes

- Living Will says no life prolonging care
 - Guardian authorizes care
- Living Will says prolong life
 - Guardian authorizes withholding or withdrawing care
- No Living will
 - Life Prolonging Care Issues

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"I'd like a second opinion."

SDM can keep the person involved in finances

- If they don't hear about money, they assume they don't have any and may withdraw from all financial issues, even giving gifts – Salzman, 2011
- For as long as possible, the person should sign/cosign checks and stay involved in money decisions
- Talk about money in a positive way

Worrying is like a rocking chair.
It gives you something to do but
it doesn't get you anywhere.



— Van Wilder

Spending Money

- Emily and Elmer
 - Cash or cards
 - Affordable
 - Not Accountable



Joint Accounts

- Typical and standard
 - Owned in proportion to contribution
 - Any owner is presumed to have a right to spend or withdraw
 - One owner can not block the other
- Two signature accounts
 - Require two signatures for withdrawal
 - Can have trigger values
- For the benefit of – Totten Trust accounts
 - Named account holder for the benefit of another person
 - Not my money



Trusts

- Have to read the terms of the trust
- Enforceable in courts
- Trustees subject to strong limitations



Spouse

- Must provide for “Necessaries of Spouse”*
- Obligation to provide and protect
- Out of date concepts
 - Wife as property of the husband
 - Merger or Unity of person
 - Mrs. George Godfrey



- * some limitations apply, varies by state

SDM Within Guardianship

- **“Under all circumstances**, efforts should be made to encourage every person under guardianship:
 - to **exercise his/her individual rights** retained and
 - participate, to the maximum extent of the person's abilities, in all decisions that affect him or her,
 - to **act on his or her own behalf** in all matters in which the person is able to do so, and
 - to **develop or regain his or her own capacity** to the maximum extent possible.”

National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making” (2015)

SDM as proactive planning

- Better planning
- Selection and training of advisors
- Training and commitment to SDM principles of putting the Person at the Center



Good Decision Making Requires

- Understanding of the Person's
 - Culture
 - Values
 - Goals
 - Tipping Points



Training Decision-Makers

- Buy in from family and friends
 - As Adults, we are allowed to make choices
 - Sometimes bad choices
 - We don't always do:
 - What is in our "best interest"
 - Or what is "good for us"
 - Or what others think we "should do"
 - Or what others would "do if it were me"



Put the Person First

- It is not always easy.
- It means you are not in control – you are supporting the person to be in control.
- It means watching a loved one not always having or doing what you think is “the best.”

How to balance the risk of abuse and exploitation

- Draft in **accountability and accountings** in all planning documents
- Plan for **multiple advisors** (fiduciaries)
- **When you see abuse, get help.**
 - Abuse is not about the Person.
 - Abuse is about someone who wants to take advantage of or hurt the Person
 - **Abuse happens in all settings and all relationships**
 - **We abuse people by over-protecting them.**

Supported Decision-Making: Why?

- **When denied self-determination**, people can:
 - “[F]eel **helpless, hopeless, and self-critical**” (Deci, 1975, p. 208).
 - Experience “**low self-esteem**, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).
- **Decreased Life Outcomes**
 - Overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354)

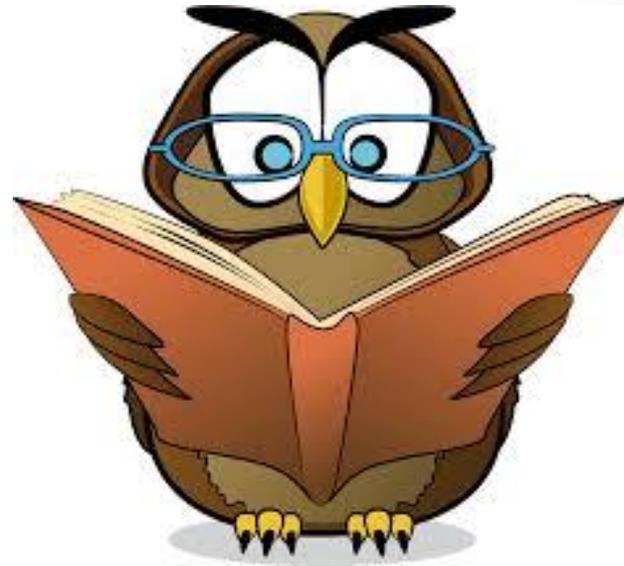
Call in the Lawyers

- Interrupting documents
- Understanding the law
- Arguing for honoring the wishes of the Person
- Defending against guardianship
- Modifying or terminating a guardianship -
- Va Code Ann. 64.2-2012



Starting points

- Know the law
 - Read the documents
 - Limits are what is not granted
 - Stand up and simply say “No!”
-
- Complication – one size does not fit all – Blanck & Maritnis, 2015



Remember to:

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



Ask Questions Now or Later

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