Overreach by Fiduciaries: Is Supported Decision-Making Part of the Answer?

David Godfrey – ABA Commission on Law and Aging

Morgan K. Whitlatch - Quality Trust for Individuals with Disabilities, National Resource Center for Supported Decision-Making
LIFE IS LIKE A BOX OF CHOCOLATES
YOU NEVER KNOW WHAT YOU'RE GOING TO GET
What is your favorite Right?
What is a Fiduciary?

• It exists where one person places complete confidence in another in regard to a particular transaction or one's general affairs or business.
• The relationship is not necessarily formally or legally established but can be.
• It can involve moral or personal responsibility, due to the potential for superior knowledge and training of the fiduciary as compared to the one whose affairs the fiduciary is handling.
Money

- Authorized on Bank Accounts
- Representative Payee
- Agent on a Power of Attorney
- Entrusted with money
  - Here is $10
  - Here is $10, use it to meet my needs, I’ll let you know when I need it
Health Care

- Agent for Health Care – surrogate – proxy – agent on a power of attorney that includes health care – default by law
  - Has the ability to make Health Care Decisions only when the Person lacks the ability as defined by state law
  - The Person retains the ability to make decisions unless the doctors certify as required by state law that they lack the ability to do so (or court order)
  - In most states, the Person can revoke the appointment or directions in an advance directive by simply saying they wish to
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
What is Overreach?

Beyond the scope of authority
Disregarding the wishes of the Person
Person Driven Planning
Supported Decision Making

• All Adults have a fundamental right to make choices
• Adults with severe limitations can express preferences to guide decisions
• The Person should be empowered to make decisions, and be supported by advisors
“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**:
  • 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” (Whemeyer, 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
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

Skills/Capacity

- Expectations
- Life Experiences
- Risk
- Environment
- Available Support
- Preferences and Interests
- Other Variables (individual and situational)
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

<table>
<thead>
<tr>
<th>“Poor” decisions often:</th>
<th>“Better” decisions often:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on limited aspects of a problem or situation</td>
<td>Reflect an understanding of different perspectives</td>
</tr>
<tr>
<td>Consider only immediate benefits</td>
<td>Focus on both short and long range goals</td>
</tr>
<tr>
<td>Oversimplify issues, <em>i.e.</em>, good/bad, right/wrong</td>
<td>Look at multiple potential outcomes</td>
</tr>
<tr>
<td>Are influenced by emotional factors</td>
<td>Include a process for analysis and thinking</td>
</tr>
<tr>
<td>Are reactive</td>
<td>Use tools and resources for making decisions</td>
</tr>
</tbody>
</table>
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](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**
What are the limits on a POA?

- Can not override grantor
- Beyond that, read the document and know the state laws
- Only powers granted
Example: Role for SDM in POA

- **Example – DC Durable POA for Health Care with Special Provisions for SDM**

- This **State-Specific Example** includes a list of **“SPECIAL PROVISIONS”**

1) **Effective immediately after I sign this Power of Attorney, I authorize all health care providers to release, and I give consent to the use and disclosure of, health information about me to my attorney-in-fact(s) for treatment and advocacy purposes**, pursuant to [LIST LOCAL AND FEDERAL PRIVACY LAWS], and other local and federal privacy laws and regulations. I specifically authorize my attorney-in-fact to request, receive, and review any information regarding my physical and/or mental health, including my medical records from physicians, hospitals, or outpatient clinics, and/or any records relating to the services and/or care provided by or through the [LIST LOCAL GOVERNMENT AGENCIES] and any successor agencies.

2) **Except as described in Section 1 above, my attorney-in-fact will have the authority to act for me with respect to health care only in the event I am certified to be incapacitated to make my own decisions, even with support, either temporarily or permanently.** Such mental incapacity must be certified, in writing, in accordance with D.C. Code § 21-2204, by both a physician and either a qualified psychologist or psychiatrist, who also are required to state the cause and nature of the mental incapacity and its extent and probably duration.
• “SPECIAL PROVISIONS AND LIMITATIONS” (continued):

3) Until such time as the certifications in Section 2 are made, my attorney-in-fact will give me the support I need and want to make my own decisions. This means my attorney-in-fact will help me understand the situations I face and the decisions I have to make. Therefore, at times when my attorney-in-fact does not have full power to make any decision(s) for me, s/he will provide support to make sure I am able to make decisions to the maximum of my ability, with me being the final decision-maker.

4) In the event the certifications in B.2 are made, my attorney-in-fact will follow my expressed or known wishes regarding health care services, service providers, and activities that I want or need. I am able to communicate what I like and dislike about the activities and service providers that work with me. [LIST ANY OTHER LIMITATIONS]
POA – “Growth Clause”

“My agent and I will review this Power of Attorney to see if it should be changed or canceled 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 Power of Attorney will continue.
Health Care Disputes

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

“I’d like a second opinion.”
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

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
Adult Children

• A handful of states have an old statute that says that adult children are responsible for the needs of their parents
  • Almost never enforced
• Children generally have no RIGHT to inherit* or control
• Are not entitled to anything

• * Except in Louisiana
Guardians and Conservators

- **Court-appointed** fiduciaries
- Owe **duty to the Person**
- Are **accountable to the Court**
- Guardian has authority to make decisions as described in the appointment – and as limited by state and federal law
- **Does this mean we should shut the Person out?**
  - **No**, according to the National Guardianship Association.
SDM – Before & Within Guardianship

• “Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”

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.”

Guardianship – The Last Resort

• The Person clearly lacks capacity to make or communicate choices, even with support
  • AND

• All alternatives have been exhausted
  • AND

• A critical decision that requires legal authority must be made to protect the Person from imminent harm
  • OR

• The Person clearly lacks capacity and Guardianship is the only way to stop abuse or exploitation
  • Then only to the extent necessary
Exhaust the Options

http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
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
Starting points

• Know the law in your state
• Read the documents
• Limits are what is not granted
• Stand up and simply say “No!”

• Complication – one size does not fit all
Remember to:

- Always – Always – Always keep the Person at the center of the process
Ask Questions Now or Later

David Godfrey, Senior Attorney
ABA Commission on Law and Aging
202-662-8694
David.Godfrey@AmericanBar.Org

Morgan Whitlatch, Legal Director
Quality Trust for Individuals with Disabilities
202-449-4004
MWhitlatch@DCQualityTrust.Org

National Resource Center for Supported Decision-Making
SupportedDecisionMaking.Org
202-448-1448
JHJP@DCQualityTrust.Org
About this Project

This project is supported, in part, by grant number HHS-2014-ACL-AIDD-DM-0084, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.