

Supported Decision-Making: Maximizing Self-Determination and Safety

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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
 - More well-adjusted
 - Better able to recognize and resist abuse
- 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 A RESULT

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).

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)

DINO AND LILLIAN

“To Collect Debts, Seizing Control Over Patients” New York Times, 1/25/15



DINO AND LILLIAN

- Married over 45 years
- Worked together to develop Powers of Attorney and Advanced Directives
- When Lillian developed dementia, chose a nursing home for her

DINO AND LILLIAN

After Dino asked questions about a bill and Lillian's care

- Nursing Home petitioned for a **plenary** guardianship - giving **ALL** decision-making rights to a stranger
- Nursing Home's attorney: "[G]uardianship is a legitimate means to get the nursing home paid."

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”

BUT WE MEANT WELL

“Experience should teach us to be most on our guard to protect liberty when the Government’s purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.”

Olmstead v. U.S., 277 U.S. 438 (1928)

WE MUST'VE MEANT REALLY WELL

Estimated number of adults under guardianship has **tripled** since 1995

- Reynolds, 2002; Schmidt, 1995;
Uekert & Van Duizend, 2011

RESEARCH

People under guardianship can experience a “**significant negative impact** on their physical and mental health, longevity, ability to function, and reports of subjective well-being”

- Wright, 2010

ON THE OTHER HAND

- Older adults who exercise more control over their lives have a **better quality of life**.
 - Maller, et al., 2014
- Providing support to people with dementia can lead to them being able to provide informed consent.
 - Haberstroh, et al. 2014

AND

- 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

AND

Women with intellectual disabilities exercising more self-determination are **less likely to be abused**

- Khemka, Hickson, and Reynolds, 2005

SO, WHERE DO WE GO FROM HERE?

If:

- We **KNOW** that some people need more support as they age or due to disability
- We **KNOW** that guardianship can result in decreased quality of life and
- We **KNOW** that increased self-determination leads to improved quality of life

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

MARGARET “JENNY” HATCH

Margaret “Jenny” Hatch

Twenty-Nine year old woman with Down syndrome.

- High School graduate
- Lived independently
- Employed for 5 years
- Politically active



THE SITUATION: FEBRUARY 2013

- Court Order putting Jenny in a “temporary guardianship”
- Living in a segregated group home
- No cell phone or computer, Facebook password changed
- Guardians controlled all access to her
- Working up to 5 days a week for 8 months – made less than \$1000

Court Ordered “Temporary Guardianship”

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.”

WHY?

FROM THEIR EXPERT

On Jenny's:

- Independent Living Skills: **“If she had assistance, she may be able to do that”**
- Legal Skills: **“she would need assistance to understand a legal document”**
- Money Management: **She needs “assistance with [a] bank account.”**

THEREFORE...

“She’s going to need assistance to make decisions regarding her healthcare, her living arrangements and such like that, she will need someone to guide her and give her assistance.”

PETITIONERS' SWORN STATEMENT

How could Jenny execute a Power of Attorney?

“[N]ot only did Jenny have an opportunity to review the documents, but also the attorney had the opportunity to get to know Jenny and understand her capabilities and limitations in understanding legal documents. Based on this series of observations over several visits, the attorney concluded, and we concurred, that Jenny was capable of understanding these documents.”

WHAT THAT ALL ADDS UP TO

Jenny Needs Support:

- To Understand Legal Issues
- To Understand Medical Issues
- To Understand Monetary Issues
 - In her Day to Day Life

IN OTHER WORDS

JENNY IS A PERSON

We Are All Jenny Hatch

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

AND JUST LIKE YOU AND ME:

Decisions Jenny had made with Support

- Sign Power of Attorney
 - Consent to Surgery
- Medicaid Waiver Individual Service Plan
 - Application for Paratransit
- Authorization to share medical records
- Assignment of a Representative Payee

FINAL ORDER

- First 4 pages justify guardianship.

“However”

- Guardians to be who she wants
- She lives where she wants
- Guardianship for only 1 year – Expired August, 2014
- Only over 2 things – medical and safety

FINAL ORDER

EVEN DURING the 1 year limited guardianship:

“Guardians shall assist Respondent in making and implementing decisions we have termed ‘supported decision making.’”

JENNY GOT JUSTICE



Jenny Hatch and her attorney celebrate after the court victory. (TWP)

‘I’m so happy to go home today’

Theresa Vargas

Jenny Hatch, a 29-year-old-woman with Down syndrome, can live the life she wants after a judge rules she can reside with friends.

WHY?

**Jenny is Strong, Smart, Determined
AND**

She had support from:

- Friends and professionals
- National Organizations and Leaders
- Media
- A Judge who was willing to Listen and Learn

IN OTHER WORDS

Jenny Got Lucky

THE LESSON JENNY TEACHES US

Justice and Self-Determination should:

- **NEVER** depend on luck or who you know.
- **ALWAYS** Be the Rule **NOT** the Exception

SO, WHERE DO GO FROM HERE?: WHEN IS GUARDIANSHIP NECESSARY?

EVERY STATE HAS ITS OWN GUARDIANSHIP LAWS

Example: Wis. Stat. 54.10

Guardianship is ONLY appropriate if:

"The individuals need for assistance in decision making or communication is **unable to be met effectively and less restrictively** through appropriate and reasonably available training, education, support services, health care, assistive devices, or other means that the individual will accept."

Another Example:

In Minnesota, guardians can be appointed for people who are “Incapacitated” – “an individual who . . . is impaired to the extent of **lacking sufficient understanding or capacity** to make or communicate responsible personal decisions, and who has **demonstrated** deficits in behavior which evidence an **inability** to meet personal needs”

- Minnesota Code Section 524.5-102

“the respondent's identified needs **cannot** be met by less restrictive means”

- Minnesota Code Section 524.5-310

ANOTHER EXAMPLE

A person can only be placed under guardianship if s/he is incapacitate:

Utah Code 75-1-201:

(22) “Incapacitated” means “a judicial determination after **proof by clear and convincing evidence** that an adult’s ability to do the following is impaired to the extent that the individual **lacks the ability**, even with technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self care:

- (a) Receive and evaluate information
- (b) Make and communicate decisions
- (c) Provide for necessities such as food , shelter, clothing, health care, or safety”

YET ANOTHER

In Missouri a person cannot be placed under guardianship unless s/he is incapacitated:

Missouri Law Chapter 475.010.1,
“incapacitated” means:

“is **unable** by reason of any physical or mental condition to receive and evaluate information or to communicate decisions **to such an extent that he or she lacks capacity to meet essential requirements** for food, clothing, shelter, safety or other care such that serious physical injury, illness, or disease is likely to occur.”

THINK ABOUT “CAPACITY” AND “ABILITY”

- People may have “capacity” to make some decisions but not others.
 - Or be able to make decisions some times but not others.
 - Or be unable to make decisions unless they get help understanding the decision to be made.
- Salzman, 2010

So...

If a person only has the
“capacity” or “ability” to make
decisions **with assistance or
support**, is s/he incapacitated?

ARE YOU?

WHICH MEANS: ASK A QUESTION

Before seeking or
recommending Guardianship:

**What Else Have You
Tried?**

OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS

“Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”

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

SUPPORTED DECISION-MAKING CAN ADDRESS LIMITATIONS IN DECISION-MAKING

Supported Decision-Making can help people:

- Understand information, issues, and choices;
 - Focus attention in decision-making;
 - Weigh options;
 - Ensure that decisions are based on their own preferences
 - Interpret and/or communicate decisions to other parties.
- Salzman, 2011

IT'S A PARADIGM, NOT A PROCESS

There is no “one size fits all” method of Supported Decision-Making.

Can include, as appropriate

- Informal support
 - Written agreements, like Powers of Attorney, identifying the support needed and who will give it
 - Formal Micro-Boards and Circles of Support
- Martinis, Blanck, and Gonzalez, 2015

IN COMMON

ALL Forms of Supported Decision-Making recognize:

- That EVERYONE has The Right to Make Choices to the maximum of their capabilities;
 - That people can get help exercising their Right to Make Choices without giving up that right; and
 - There are as many ways to give and get help as there are people
- e.g., Dinerstein, 2012

SUPPORTED DECISION-MAKING AND SELF DETERMINATION

“Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration”

- Blanck & Martinis, 2015

MANY STATE LAWS ALREADY REQUIRE IT!

Wis. Stat. 54.10 - Guardianship is **ONLY** appropriate if:

"The individuals need for assistance in decision making or communication is **unable to be met effectively and less restrictively** through appropriate and reasonably available training, education, support services, health care, assistive devices, or other means that the individual will accept."

WHAT ELSE HAVE YOU TRIED?

OPPORTUNITIES FOR SDM ARE ALL AROUND US

- “Informed consent”
- “Informed choice”
- “Person Centered Planning”

Are ALL forms of SDM!

SDM OPPORTUNITY: PERSON CENTERED PLANNING

It's REQUIRED in Medicaid HCBS Waiver programs -**Final Rules CMS 2249-F and CMS 2296-F**

Medicaid Waiver Services **MUST** address “health and long-term services and support needs in a manner that reflects individual preferences and goals” and

- Be Driven by the person
- Include people chosen by the person
- Give primary consideration to and Include things important to the person

“LIFE PLANNING”

“It is my and my agent’s intent that we will work together to implement this [Power of Attorney/Advanced Directive/Agreement/Plan]. 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.”

SDM OPPORTUNITY

MEDICAL DECISION-MAKING

“[M]y 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.”

SDM 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.**

THE PRACTICAL METHOD

BY AMERICAN BAR ASSOCIATION

PRESUME that guardianship is not needed.

REASONS for concern – “What’s the problem?”

ASK if the problem is temporary or easily addressable- “What’s the root cause?”

COMMUNITY Connect with resources – “What would it take to solve the problem?” and “Who can provide that?”

TEAM Has the person already identified people s/he wants to work with?

IDENTIFY If the person does not have a team, examine abilities, limitations, wants, needs, and contacts to see if a team can be made or supports provided

CHALLENGES Are there potential problems with team members or resources?

APPOINT If the person wants to give someone else the power to support or make decisions, help the person do it consistent with his or her wishes

LIMIT As a last resort, seek a guardianship limited to **ONLY** those areas the person **cannot** make decisions with or without support

ALWAYS REMEMBER

- **EVEN** IF the person is "Incapacitated" or is being abused or neglected, it does **NOT NECESSARILY** mean the person **NEEDS A GUARDIAN**.
- It could just be the person needs new or better supports.

**REASSESS AND REAPPLY PRACTICAL:
WHAT ELSE HAVE YOU TRIED?**

EVEN IF GUARDIANSHIP IS NEEDED THE NATIONAL GUARDIANSHIP ASSOC

EVEN IF a guardianship is necessary

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

WHAT ELSE ARE YOU TRYING?

WHEN WHAT YOU'VE TRIED WORKS

Wisconsin Statute 54.64

“ A ward . . . any person acting on the ward's behalf, or the ward's guardian may petition for a review of incompetency, to have the guardian discharged and a new guardian appointed, or to have the guardianship limited and specific rights restored”

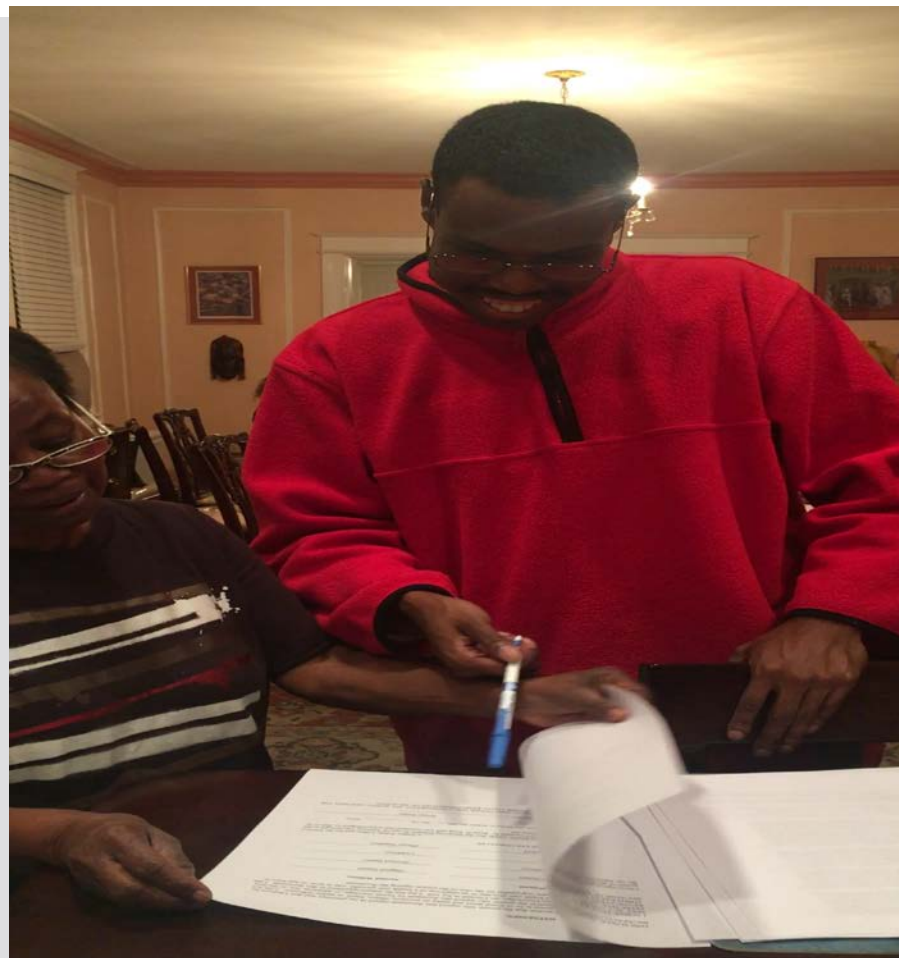
DOESN'T THAT MEAN...

A Guardian's job is to work with the person:

- To help the person learn to make his or her own decisions, with support
- To build self-determination
- To help the person learn to meet his or her "needs" through "less restrictive" means
- And then ask the Court to terminate the guardianship?

Guardianship as a Way-Station, Not a Final Destination

IT CAN HAPPEN



THE ELEPHANT IN THE ROOM: SAFETY

NOTHING: Not Guardianship, Not Supported Decision-Making is 100% "Safe."

HOWEVER: Supported Decision-Making Increases Self-Determination (Blanck & Martinis, 2015), which is correlated with increased Safety (Khemka, Hickson, & Reynolds, 2005).

SIGNS AND SIGNALS –ABUSE AND NEGLECT

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal
- Basic needs not being met
- Overdependence on another
- Bills not being paid
- Living below means
- Things are missing

BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions

**NEVER FORGET:
DINO, LILLIAN, AND JENNY**

Supported Decision-Making
ONLY works if we recognize,
respect, and protect
EVERYONE'S
Right to Make Choices.

REMEMBER THE CHALLENGE

EVERY great advance in civil rights fundamentally changed the way “things have always been”

REMEMBER THE OBSTACLES

Change is **HARD**

“We were not promised ease. The purpose of life . . . is not ease. **It is to choose, and to act upon the choice.** In that task, we are not measured by outcomes. We are measured only by daring and effort and resolve.”

- Stephen R. Donaldson

REMEMBER THE GOAL

Older adults and People with Disabilities having “the same opportunities for success and security as their nondisabled peers. . . . If we change the culture, we will change the world!”

Gustin & Martinis, 2016

JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making:

SupportedDecisionMaking.Org

The Burton Blatt Institute at Syracuse University: BBI.Syr.Edu

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