Supported Decision-Making: Maximizing Self-Determination and Safety
What’s Your Favorite Right?
"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
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
Are Your Rights Worth ANYTHING If You’re Not Allowed to Use Them?
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
“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- Used in the vast majority of cases
  - “As long as the law permits plenary guardianship, courts will prefer to use it.”
  - Frolik, 1998
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.
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 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
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

EVERYONE has the Right to Make Choices
GUARDIANSHIP IS NEVER NEEDED

JUST

- “Because you have ____”
- “Because you’re ____ years old”
- “Because you need help”
- “Because that’s the way it’s always been”
- “For your own good”
“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)
Estimated number of adults under guardianship has \textit{tripled} since 1995

- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011
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**.
  - Mallers, et al., 2014

- Providing support to people with dementia can lead to them being able to provide informed consent.
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
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

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.”
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.”
“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.”
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.”
Jenny Needs Support:

- To Understand Legal Issues
- To Understand Medical Issues
- To Understand Monetary Issues
- In her Day to Day Life
JENNY IS A PERSON

We Are All Jenny Hatch
“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 it's needed.

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
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
EVEN DURING the 1 year limited guardianship:

“Guardians shall assist Respondent in making and implementing decisions we have termed ‘supported decision making.’”
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
Jenny Got Lucky
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
A person can only be placed under guardianship if s/he is incapacitated:

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”
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.”
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.
- Salzeman, 2010
If a person only has the “capacity” or “ability” to make decisions with assistance or support, is s/he incapacitated?

ARE YOU?
Before seeking or recommending Guardianship:

What Else Have You Tried?
“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 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
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
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 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
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.”
“[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.”
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 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”
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
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).
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.
EVERY great advance in civil rights fundamentally changed the way “things have always been”
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
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
National Resource Center for Supported Decision-Making: 
SupportedDecisionMaking.Org

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

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