Supported Decision-Making: Protecting Rights, Ensuring Choices

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PART I: INTRODUCTION TO SUPPORTED DECISION-MAKING
THERE ARE STUPID QUESTIONS

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
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, p. 440).
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?
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 (Teaster, Wood, Lawrence, & Schmidt, 2007).
- “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.

When denied self-determination, people:
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).
“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

- 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.”
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”
“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 **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, p. 354)
On The Other Hand

- Older adults with more self-determination have improved psychological health including better adjustment to increased care needs. (O’Connor & Vallerand, 1994)
- 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)
People with Intellectual and Developmental Disabilities who do NOT have a guardian are more likely to:

- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the Religion of their choice

2013-2014
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
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.”
“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.”
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 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).
“[A]n individual with cognitive challenges is the ultimate decision maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual’s words and behavior to determine his or her goals and preferences.”

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

AND JUST LIKE YOU AND ME:
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 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
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.

Lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity.

(Salzman, 2010)
So...

If a person can 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
524.5-310 FINDINGS; ORDER OF APPOINTMENT.
(a) The court may appoint a limited or unlimited guardian for a respondent only if it finds by clear and convincing evidence that:
(1) the respondent is an incapacitated person; and
(2) the respondent's identified needs cannot be met by less restrictive means . . . .

WHAT ELSE HAVE YOU TRIED?
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
ALL Forms of Supported Decision-Making recognize:

- The person’s Right to Make Choices on an equal basis with others;
- That a person can receive support in decision-making without giving up his or her Right to Make Choices; and
- People often need assistance in making or communicating their choices and there are many ways to provide that assistance (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)
Opportunities are ALL Around Us

- “Informed Consent” to medical care
- “Person Centered Planning” in Medicare/Medicaid
- “The Conversation” and “Five Wishes” for End of Life Planning
- “Student Led” IEPs
- “Informed Choice” in Vocational Rehabilitation
PART II: FROM THEORY TO PRACTICE
SPECIAL EDUCATION

Purpose of the IDEA:

“to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.”

Self determination is the ultimate goal of education (Halloran, 1993)

Schools should focus on improving students’ ability to set goals, solve problems, make decisions and advocate for themselves and, just as importantly, to give students the opportunity to exercise these skills. (Wehmeyer & Gragoudas, 2004).
Guardianship is the default option for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).

School personnel are the most frequent source of recommendations that parents seek guardianship (Jameson, et al, 2015).
THE STUDENT actually engages in self-determination

THE STUDENT can practice different decision-making methods in a “safe environment”

THE STUDENT leads meeting

THE STUDENT Identifies goals and objectives with assistance from professionals and people THE STUDENT invites
Doesn’t That Sound Like

Supported Decision-Making?
Transition Services include:

“instruction, related services, community experiences, the development . . . post-school adult living objectives, and, when appropriate, acquisition of daily living skills”

20 USC 1401(34)
Transition Planning Starts: “Beginning not later” than the year the student turns 16
(20 U.S.C. § 1414(d))

And Continues: At least until student is 21
(34 CFR §300.101)
If there are concerns the student can’t make decisions, or may need guardianship

**Transition Services should provide:**

“Instruction [and] related services” to help with the “acquisition of daily living skills”

**NECESSARILY including decision-making skills** like Supported Decision-Making
VR program provides services and supports to help people with disabilities:

“prepare for, secure, retain, advance in, or regain employment”

Rehabilitation Act, 2006, § 722 (a)(1)
The skills you need to work are the **SAME** ones you need to build self-determination and avoid guardianship?

- Self-care
- Organization
- Communication
- Interpersonal Skills
Would **YOU** hire or retain someone who has difficulty:

- Following directions or staying on task?
- Communicating with you or your customers?
- Getting along with co-workers?
If these “life skills” limitations are related to a person’s disability and make it harder for him or her to prepare for, get, or keep work:

**VR MUST PROVIDE SERVICES AND SUPPORTS TO HELP OVERCOME THEM**
A person is eligible for VR if s/he

- Has a disability
- Wants to Work
AND
- VR services will help him or her work.

People who receive SSI/SSDI are presumed eligible!

34 CFR 361.42
The Individualized Plan for Employment (IPE)

Lays out the **PERSON’S** employment goal – the job the **PERSON** wants to get – and he services the **PERSON** chooses to get there.

34 CFR 361.46
VR Counselor must work WITH the person and give the person information to help THE PERSON identify AND CHOOSE his or her employment goal and the services and supports needed to get there.

e.g., 34 C.F.R. 361.52
Doesn’t That...

Sound like Supported Decision-Making?
It’s REQUIRED in Medicaid HCBS Waiver programs - Final Rules CMS 2249-F and CMS 2296-F

Medicaid Waiver Services MUST:

- Be Driven by the person
- Include people chosen by the person
- Give primary consideration to and Include things important to the person
Rule 1.14 of the Minnesota Rules of Professional Conduct

When a client's capacity to make adequately considered decisions in connection with a representation is diminished . . . Lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.
Comment (1) to 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. . . .

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.
Comment to (3) Rule 1.14
The client may wish to have family members or other persons participate in discussions with the lawyer. . . . 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.
**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
“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.”
“My agent will only have “full power” to make health care decisions for me if I am unable to make decisions, either because the doctor in charge of my care (attending physician) decides that I lost this ability temporarily or my attending physician and a consulting doctor agree that I have lost this ability permanently.

Otherwise, 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.”
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.
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.
“The Conversation” and “Five Wishes”

A facilitated process where the Person makes decisions about the types of hospice, palliative care, and services s/he wants.
“GROWTH CLAUSE”

“My agent and I will review this [Power of Attorney/Plan/Advanced Directive/Agreement] to see if it should be changed or cancelled at least every two years. However, unless my agent and I change the [], I cancel it, my agent resigns, or either I or my agent dies, the power of attorney will continue.”
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
SIGNS AND SIGNALS — EXPLOITATION AND CAREGIVER NEGLECT

- Basic needs not being met
- Overdependence on another
- Bills not being paid
- Living below means
- Things are missing
- Unexplained ATM or Credit Card
- Unexplained cash withdrawals
- Unexplained changes in lifestyle
- Retitling assets
- Changes in power of attorney
People, corporations, and other organizations that are licensed by the Commissioner of Human Services MAY NOT be appointed guardians:

- (1) under section 524.5-309 of the Uniform Probate Code, any individual or agency that provides residence, custodial care, medical care, employment training, or other care or services for which the individual or agency receives a fee may not be appointed as guardian unless related to the respondent by blood, marriage, or adoption; and

- (2) under section 245A.03, subdivision 2, paragraph (a), clause (1), a related individual as defined under section 245A.02, subdivision 13, is excluded from licensure. Services provided by a license holder to a person under the license holder's guardianship are not licensed services.

- (d) Upon the transfer or death of a person, any funds or other property of the person must be surrendered to the person or the person's legal representative, or given to the executor or administrator of the estate in exchange for an itemized receipt.

- MN Code Section 245D.06
BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions
Incapacitated person. "Incapacitated person" means an individual who, for reasons other than being a minor, 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 for medical care, nutrition, clothing, shelter, or safety, even with appropriate technological assistance."
BUT . . . 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.
- **524.5-310:** "The court may appoint a limited or unlimited guardian for a respondent **only** if . . . the respondent's identified needs **cannot be met by less restrictive means** . . . ."
- **REASSESS AND REAPPLY PRACTICAL**
EVEN IF GUARDIANSHIP IS NEEDED
THE POINT OF THE PROCESS

- 524.5-310 "The court shall grant to a guardian only those powers necessitated by the ward's limitations and demonstrated needs and, whenever feasible, make appointive and other orders that will encourage the development of the ward's maximum self-reliance and independence.

- 524.5-313(6) "[Guardian has] the duty and power to exercise supervisory authority over the ward in a manner which limits civil rights and restricts personal freedom only to the extent necessary to provide needed care and services."

- 524.5-316 [Guardian's reports must include] "a recommendation as to the need for continued guardianship and any recommended changes in the scope of the guardianship"
People Under Guardianship STILL Have the Right to Make Choices:

People under guardianship:
- Must be treated with dignity and respect and receive consideration of their wishes
- “Exercise control of all aspects of life not delegated specifically by court order”
- Can talk to or visit with people they choose unless there is proof it would “harm” them
- Ask the court to change the guardianship or change where they live
- Vote
- Minnesota Code 524.5-120
GUARDIANSHIP AS A WAY-STATION, NOT A FINAL DESTINATION

- The Court and Guardian's Job is to MAXIMIZE self-determination and independence
- The Guardian should work to increase self-determination through Supported Decision-Making or other means
- Then ask the Court to remove or limit guardianship
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
**REMEMBER THE GOAL**

EVERY person the “causal agent” in his or her life.

- We all need help making decisions
- Older adults and People with Disabilities may need more or different help but have the SAME rights
JOIN THE CONVERSATION


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