

Supported Decision- Making: Protecting Rights, Ensuring Choices

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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, p. 440).

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, p. 208).
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).

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

(credit: “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, 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, Rifenburg, & 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)

AND

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

Margaret “Jenny” Hatch

Twenty-Nine year old woman with Down syndrome.

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



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.”

ALL BECAUSE

“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.”

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).

NATIONAL GUARDIANSHIP ASSOCIATION

“[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 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 DINO, LILLIAN, AND JENNY TEACH US

Justice and Self-Determination should:

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

WHERE DO WE GO FROM HERE? THINK ABOUT “CAPACITY”

- 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?

WHICH MEANS

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 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:

- 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 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)

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

EXAMPLE: 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.**”

20 U.S.C. § 1400(d)(1)(A) (emphasis added).

THEREFORE

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).

AND YET....

- 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)

CLOSING THE ON RAMP TO GUARDIANSHIP: : THE STUDENT LED IEP

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?

CLOSING THE ON RAMP TO GUARDIANSHIP: TRANSITION PLANNING

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)

YOU HAVE (AT LEAST) 5 YEARS

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)

TO CLOSE THE ON RAMP

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

EXAMPLE: VOCATIONAL REHABILITATION

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)

WHAT IF...

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

EMPLOYMENT BASED 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?

THEREFORE

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

ELIGIBILITY

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

MAKE A PLAN

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

KEY CONCEPT: “INFORMED CHOICE”

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?

EXAMPLE: PERSON CENTERED PLANNING

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

EXAMPLE: “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.”

EXAMPLE: MEDICAL DECISION-MAKING

“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.”

EXAMPLE: 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.**

EXAMPLE: BANKING

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.**

EXAMPLE: END OF LIFE PLANNING

“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.

EXAMPLE: “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.”

**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

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

- We all need help making decisions
- Older adults may need more or different help but have the SAME rights

JOIN THE CONVERSATION

**National Resource Center for
Supported Decision-Making:**
SupportedDecisionMaking.Org

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