

Supported Decision- Making: Protecting Rights, Ensuring Choices, Empowering Independence

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THERE ARE STUPID QUESTIONS

What's Your Favorite
Right?

RIGHTS=CHOICES

“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=CHOICES

CHOICES=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 U.S.

“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)

IN DELWARE

Guardians have the powers:

“necessary to protect, manage and care for the disabled person.”

“The guardian of the person may exercise the same powers, rights and duties respecting the care, maintenance and treatment of the disabled person that a parent has respecting the parent's own unemancipated minor child”

DEL CODE § 3922

DELAWARE GUARDIAN POWERS CAN INCLUDE

“A guardian shall have either the care of the disabled person's person or the possession and management of all the disabled person's real and personal property or both the care of the person and the possession and management of the property, except to the extent the Court of Chancery may otherwise direct”

- Control money and property
- Right to say where the person lives
- Consent to or Direct medical care
- Consent to marriage

DEL CODE § 3922

THAT MEANS

- **UNLESS** the Court limits the powers of the Guardian, the Guardian has **ALL** power over the person and his or her money.
- If the Court **DOES** limit the power, then the person has all power the Court **DOESN'T** give the Guardian

Up to 90% of Guardianships are FULL

WHEN PEOPLE ARE DENIED LIFE CONTROL

Study after Study shows:

- “[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).

ON THE OTHER HAND

- People with more self-determination have improved psychological health including better adjustment to increased care needs.

(O'Connor & Vallerand, 1994)

- People 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

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



NATIONAL
CORE
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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 an IQ of ____”
- “Because you’re sick”
- “Because you need help”
- “Because that’s the way its always been”
- “For your own good”

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

JUSTICE FOR JENNY

Margaret “Jenny” Hatch

- Twenty Nine year old woman with Down syndrome.
- High School graduate
- Lived and worked independently
- Volunteered in many political campaigns



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

JENNY'S RIGHTS: IN ONE SENTENCE

Guardians Have 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?

“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).

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 DEFINING ISSUE FOR PEOPLE WITH DISABILITIES

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 IT

If a person can **ONLY** make decisions **with assistance or support**, does s/he need a guardian?

DO YOU?

OR, AS DELWARE LAW SAYS...

Delaware Code Section 3901

Guardian is only appointed IF:

The person is **UNABLE** “properly to manage or care for their own person or property”

**SO, BEFORE THINKING ABOUT
GUARDIANSHIP, ASK....**

**WHAT ELSE HAVE YOU
TRIED?**

SUPPORTED DECISION-MAKING CAN HELP PEOPLE BE “ABLE”

- 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)

SUPPORTED DECISION-MAKING IS 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).

SUPPORTED DECISION-MAKING: THREE CORE PRINCIPLES

- EVERYONE Has the Right to Make Choices
- You can get help making choices without giving up your Right to Make Choices
- There are as many ways to get help as there are ways to make choices

OPPORTUNITIES ARE ALL AROUND US

- “Informed Consent” to medical care
- “Person Centered Planning” in Medicare/Medicaid
- “Student Led” IEPs
- “Informed Choice” in Vocational Rehabilitation
- “The Conversation” and “Five Wishes” for End of Life Planning

Supported Decision- Making and Special Education Transition Services

THE WHOLE PURPOSE OF SPECIAL EDUCATION

“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).

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)

Shut Down the On Ramp

- Effective Special Education Advocacy MUST focus on Self-Determination.
- If Self-Determination is the “Default Option” Guardianship isn’t even a consideration!

Why Are People Put In Guardianship?

Guardianship happens when people can't "take care of themselves in a manner that society believes is appropriate."

(Kapp, 1999).

Learning to “Take Care” Through Special Education?

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))

Continues: At least until student is 21
(34 CFR §300.101)

TRANSITION WHO'S WHO

- The state Vocational Rehabilitation (VR) agency - help with supports and services designed to help people with disabilities gain and maintain employment.
- State or local agencies providing services to people with developmental disabilities. These include the Protection and Advocacy System, University Center for Excellence, and DD Council
- Independent Living Centers (ILCs). Education, advocacy training, plans for self-sufficiency, counseling, service coordination and other services designed to help people with disabilities live as independently as possible.
- Representatives from the Social Security Administration who can provide information, supports and services to help people with disabilities become employed or maintain employment.

deFur (2010)

TRANSITION IS IT'S OWN PLAN!

Should include:

- “interagency agreements that clearly articulate roles, responsibilities, communication strategies and other collaborative actions that enhance . . . program development and service delivery.” (Kohler, P., & Field, S., 2003).
- Detailed plans overcome the “fragmented system of services within high schools and adult services . . . contributing to the failure of special education to prepare youths for the future.” (Katsiyannis, A., deFur, S., & Conderman, G., 1998).

YOU HAVE YEARS!

If there are concerns the student can't "take care of him/herself," 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

Supported Decision-Making in Health Care and Life Planning

THE SITUATION OUT THERE

- In DC....
 - 70% of people served by Department on Disability Services have a guardian or substitute decision-maker.

- Nationally....
 - According to the CQL database, only one-half or fewer of the over 8,100 people reviewed were exercising choices about home, work, goals or services in a way that was meaningful to them.

MAYBE THAT'S BECAUSE...

In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

(Jameson, et al 2015)

KEY CONCEPT: “INFORMED CONSENT”

Like “Capacity” is to guardianship, it is the lynchpin of self-determination in medical care

Three Key Parts:

- Information to the person
- Understanding by the person
- Choice by the person

AS WITH EVERY DECISION

- Assistance can be provided to help individual make medical decisions:

“Explain that to me in English”

- Ability to make decisions is a continuum. A person may be able to make some but not others

Capacity to take medication is not the same as capacity to prescribe medication!

JUST ONE EXAMPLE

Think about a HIPAA release

What does it do?

How Can You Make it Into a
Supported Decision-Making
Agreement?

POWER OF ATTORNEY LANGUAGE

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. 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.**”

MEDICAL ADVANCED DIRECTIVE LANGUAGE

“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.”

“PERSON CENTERED PLANNING” IN MEDICAID WAIVERS

REQUIRED in Medicaid HCBS Waiver programs -
Final Rules CMS 2249-F and CMS 2296-F

Services MUST:

- Be Driven by the person
- Include people chosen by the person
- Occur at times/locations convenient to the person

DOESN'T THAT SOUND LIKE...

Supported Decision-
Making?

YOU CAN USE SUPPORTED DECISION MAKING

- To help the person understand all components of the plan
- To help the person prioritize what is important to him/her
- To help the person build a network of supporters for the plan and beyond
- To help the person communicate and implement his or her choices

PLANNING THROUGHOUT THE LIFE COURSE

Supported Decision-Making can work in a number of contexts – if it requires a decisions, Supported Decision-Making can help the person exercise the Right to Make Choices

IT TAKES A NETWORK

A Supported Decision-Making Team can include:

- The Person
- The Person's chosen Friends, Family, Professionals
- Case Manager
- Providers
- Advocates
- Anyone Else who Can Contribute!

THINK BROADLY!

TEAMWORK

- Review! Go through each area of the individual's life.
 - Example: Financial, Medical, Social, Employment
- Brainstorm! Does the person need support in these areas?
 - If so, talk about what support could help, who could provide it, and how
- Write! As you develop support solutions, create a written plan or “road map” for the person and team to use!

<http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

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.**

“GROWTH CLAUSE”

“My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it **should be changed or cancelled 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 [] will continue.”

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

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal

SIGNS AND SIGNALS - EXPLOITATION

- Basic needs not being met
- 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

SIGNS AND SIGNALS – CAREGIVER NEGLECT

- Dependence on another, isolation
- Basic needs not being met
- Inappropriate living environment
- Caregiver not seeking resources or help
- Caregiver not assisting with needs
- Caregiver dismissive of wants and needs
- Changes in dress, hygiene, or housekeeping
- Diet – weight gain or loss
- Desire to see doctor not met
- Medications not available

SIGNS AND SIGNALS- SELF NEGLECT

- Failure to meet basic needs despite ability
- Poor hygiene
- Lack of needed health care
- Unsafe living conditions

BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions

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 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

Quality Trust for Individuals with Disabilities: DCQualityTrust.Org

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

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