Supported Decision-Making: What, Why, & How

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Part I

Supported Decision-Making: What & Why

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

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EVERYONE has the Right to Make Choices

RIGHTS = CHOICES

"Ryan is a whole person. We want him to be whole. **The decision process is part of being whole** . . . If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him."**

– Herbert King

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, 1997 & 1998; Powers et al., 2012; Shogren et al., 2014; Wehmeyer & Palmer, 2003)

).

Are Your Rights Worth ANYTHING If You're Not Allowed to Use Them?

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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)

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).

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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

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 have ___ diagnosis"
- "Because you need help"
- "Because that's the way its always been"
- "For your own good"

That is not enough!

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 overbroad or undue 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

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Justice for Jenny

Margaret "Jenny" Hatch

- 31 years old
- 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."

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).

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

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Final Court Order for Jenny

- 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

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.

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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

Where Do We Go From Here? Think About It

If a person can make decisions **with assistance or support**, is s/he "incapacitated"?

ARE YOU?

Or, As Maryland Law Says…

Md. Estates & Trusts Code Ann. § 13-705(b)

Guardianship of the person is only appropriate if:

"a person lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person, including provisions for health care, food, clothing, or shelter, because of any mental disability, disease, habitual drunkenness, or addiction to drugs, **and that no less restrictive form of intervention is available** which is consistent with the person's welfare and safety."

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)

So, Ask Yourself:

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)

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).

Common Considerations

- All forms of SDM recognize:
  - The person's **autonomy, presumption of capacity, and right to make decisions** on an equal basis with others;
  - That a **person can take part** in a decision-making process that does not remove his or her decision-making rights; and
  - People will **often needs assistance** in decision-making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(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)

To Reach the SDM Goal:

Every person should be part of every decision about his or her life.

- We all need help making decisions.
- People with disabilities may need more or different help, but should be supported to exercise their **Right to Make Choices** in their own lives.

Arc of Maryland 2016 Theme

Part II

Supported Decision-Making: How?

Supported Decision Making in

Special Education & Transition Services

Studies Show:

Students who have self-determination skills are more likely to successfully make **the transition to adulthood**, including improved education, employment and independent living outcomes.

(Wehmeyer & Schwartz, 1997)

Getting There: The IDEA

"Under IDEA, schools must ensure that students in special education receive services reasonably calculated to enable the child to receive **educational benefits**."

Board of Education v. Rowley , 458 U.S. 176 (1982)

What Are "Educational Benefits?"

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)

Promoting self-determination is a special educational **"best practice"** (Wehmeyer & Hughes, 1998).

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)

Close Down The On Ramp

Make Self-Determination the "Default Option"

Start Early

- Self-Determination and Decision-Making should be written into IEPs **AS SOON AS POSSIBLE**.
- DC Public Schools has begun including it in pre-K!

Make It A Goal

- **Include IEP Goals and Objectives** related to self-determination.
- For every goal, there should be an **application of self-determination** to get there.
- **"I statements"** in IEP Goals and Objectives to ensure student involvement and accountability

Example: Writing Goals

Instead of "Use proper grammar," try:

"I will identify a subject I want to write about and use proper grammar and punctuation in my stories 3 out of every four times."

Creating and Reaching Goals: 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

Sounds Great, How Do I Do It?

Implement it Early

- What is the school district's policy on developing self-determination and decision-making skills?
- Encourage and develop model self-determination goals
- Student Involved in IEP Process from Day 1

Evaluations

We already know that FAPE includes "special education and related services designed. . . **prepare them for . . . independent living."** (20 U.S.C. § 1400(d)(1)(A))

So, evaluate self-determination and independent living skills

"Dear School" Letter

Parents have a right to request evaluations for **ANYTHING.**
(20 USC 1415(b)(1))

"I believe **STUDENT** has limitations in self-determination and decision-making that are keeping **STUDENT** from making educational progress, including preparing **STUDENT** for independent living. Pursuant to 20 USC 1415(b)(1) and I ask that you conduct an evaluation of **STUDENT** to determine if this is so and what services will help **STUDENT** overcome the limitations."

"Dear School" Part 2

"I disagree with the results of your self-determination, decision-making skills evaluation. I still believe that **STUDENT** has limitations in those areas that are preventing **STUDENT** from making educational progress. Therefore, pursuant to 34 C.F.R. 300.502, I request an Independent Educational Evaluation at public expense"

Use "Transition Services"

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)

In Maryland, 14, or younger if appropriate!

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

Transition Activities

- Taking part in home, school and community activities that relate to their interests
- Identifying and networking with people and agencies that can provide services and supports
- Identifying short and long term goals and providers of information, services and training to help reach them

(Waters, D., Zanghi, M., Ansell, D., Armstrong, E., & Sutter, K., 2010).

You Have at Least 7 Years

If there are concerns the student can't 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 &
Life Planning

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"
  - Under the ADA, a doctor must reasonably accommodate the person's disability when obtaining informed consent.
- **Ability to make decisions is a continuum**. A person may be able to make some but not others, and at certain times and not others.
  - Capacity to take medication is not the same as capacity to prescribe medication!
  - Capacity to consent to a flu shot is not the same as capacity to consent to open heart surgery.

Therefore

There is a need to empower and enable Informed Consent in ways that are

- Flexible
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

Doesn't That Sound Like Supported Decision-Making?

Supported Decision-Making "is not a program. Rather, it is a **process of working with the person to identify where help is needed and devising an approach for providing that help**."

"**The solutions also are different for each person**. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless."

Administration for Community Living, "Preserving the Right to Self-determination: Supported Decision-Making"

How?

Think about a HIPAA release

What does it do?

Or Be More Formal…

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

"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

What Is Person Centered Planning?

Person Centered Plan MUST:

- Address "health and long-term services and support needs in a manner that **reflects individual preferences and goals**."
- Result "in a **person-centered plan with individually identified goals and preferences**, including those related community participation, employment, income and savings, health care and wellness, education and others."

www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf

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

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 usel

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."

Or Use Model Forms

Models are available at:

http://supporteddecisionmaking.org/sites/default/files/sample-supported-decision-making-model-agreements.pdf

SDM – Before & Within Guardianship

- "**Supported decision making** should be considered for the person **before guardianship**, and the supported decision-making process should **be incorporated as a part of the guardianship** if guardianship is necessary."

National Guardianship Association, "Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making" (2015)

SDM Principles Within Guardianship

- "**Under all circumstances**, efforts should be made to encourage every person under guardianship:
  - to **exercise** his/her individual **rights** retained and
  - **participate**, to the maximum extent of the person's abilities, **in all decisions** that affect him or her,
  - to **act on his or her own behalf** in all matters in which the person is able to do so, and
  - to **develop or regain** his or her own **capacity** to the maximum extent possible."

National Guardianship Association, "Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making" (2015)

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:
www.DCQualityTrust.Org

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