Supported Decision-Making:
From Justice for Jenny to Justice for All!

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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
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?

REALLY Think About Your Life
**And Yet: 1,500 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
“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
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.

Study after Study shows:

- “[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)
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 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 **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

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
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
People with Intellectual and Developmental Disabilities who **DO NOT** have a guardian are **MORE** likely to:

- Live in their own homes or apartments instead of a group home
- Be involved in making choices about their lives
- Be included in their community
- Have their rights respected
- Have community jobs
- Be able to go on dates or get married

2017-2018
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
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.”
“I believe what would be beneficial to Jenny is that she is afforded the opportunity to have individuals around her who support and love her, who give her the assistance she needs.”
“[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 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 it's 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
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.
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
The Lesson Jenny Teaches Us

Justice and Self-Determination should:

- **NEVER** depend on luck or who you know.
- **ALWAYS** Be the Rule **NOT** the Exception
When Does a Person “Need” A Guardian?

In Rhode Island, a court may appoint a guardian if it finds by clear and convincing evidence that the person:

- needs a limited guardian to provide assistance with decision making in the areas of financial, health care, residential and/or relationship matters; or
- needs a full guardian to provide assistance with decision making in all areas;
People may need help making some decisions but not others.
Or may ONLY be able to make decisions if they have help.
Or need different types of help depending on how they are feeling.

- e.g. Salzman, 2010

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

If people can ONLY make decisions in the areas of financial, health care, residential, relationship or ANY other life areas if they have help, do they “need” a guardian?

DO YOU?
Which Means: Ask a Question

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 Ability;
- That you can get help exercising your Right to Make Choices without giving it up; and
- That there are as many ways to give and get help as there are people

- 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
In a study, young adults who used Supported Decision-Making showed:

- Increased independence, confidence, and decision-making abilities
- Made better decisions
- Had enhanced quality of life

- Martinis & Beadnell, 2021

http://supporteddecisionmaking.org/node/488
Rhode Island Law Already Requires It

- “The court shall not appoint a guardian or limited guardian if the court finds that the needs of the proposed ward are being met or can be met by a less restrictive alternative or alternatives.” RI Gen L Sec 33-15-4

- Supported Decision Making is recognized as “as an alternative to guardianship.” – RI Gen L. Sec. 42-66.13-2

What else have you tried?
Listen and Think

- Supported Decision-Making should always be based on the person’s strengths, needs, and interests.
- Start by encouraging the person to think about decisions he or she makes now and those the person needs help to make.
Identify Opportunities and Challenges

- Explore the types of support the person wants to use.
- Talk about the support he or she uses now. If one way of supporting the person works well, think about trying it for other life areas.
- If you’re not sure what to try, brainstorm about ways to give and get support.
- RESOURCE: The “Supported Decision-Making Brainstorming Guide:”
Find Supporters

- Connect with the people, professionals, agencies, and organizations that can provide the support the person wants.

- Consider support from programs like Special Education, Vocational Rehabilitation, Medicaid Waiver, Centers for Independent Living.
Coordinate Support

- Work with the person, supporters, professionals, and agencies to develop a Supported Decision-Making plan laying out who will support the person and how the person will use that support.

MAKING IT HAPPEN:
STEPS IN SUPPORTED DECISION-MAKING

Put it in Writing

- Rhode Island Law says that Supported Decision-Making Agreement MUST “not be inconsistent” with the form in RI Gen L. Section 42-66.13-10
- You can ALSO create written plans saying who will give support, when, and how
- Incorporate SDM into IEPs, IPEs, ISPs, and other support plans for programs
EVEN AFTER GUARDIANSHIP

- The guardian must make decisions “in the best interests” of the person under guardianship. - RI Gen L. Section 33-15-29

- Guardianship system must help people “develop[] or regain[] their abilities to the maximum extent possible” – RI Gen L Section 33-15-1

WHAT ARE YOU TRYING?
SDM and Maximizing Self Determination Is In A Person’s “Best Interests”

Remember:

People with greater self determination are:

- Healthier
- More independent
- More likely to be employed
- More well-adjusted
- Better able to recognize and resist abuse

- Khemka, Hickson, & Reynolds, 2005; O’Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

KEEP TRYING!
“If, because of a change in the partially incapacitated individual's level of decision making ability, the scope and duties of the limited guardianship order no longer meet the needs of the individual and/or fail to afford the individual as much autonomy as possible, modification of the limited guardianship order is required.” – RI Gen L Sec. 33-15-4

“The court shall remove any limited guardian or guardian or conservator upon finding that the ward, based on a decision making assessment tool, has the capacity to make decisions regarding his or her health care, finances, residence, and/or relationships.” RI Gen L. Sec 33-15-18.
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 “take care of” their person and property
- And then ask the Court to terminate the guardianship?

**Guardianship as a Way-Station, Not a Final Destination**
It CAN Happen

Jenny Hatch and her attorney celebrate after the court victory. (TWP)

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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.
IT DOES HAPPEN
IT KEEPS HAPPENING
IT WILL KEEP HAPPENING
It’s STILL HAPPENING
Laws in 13 states and the Washington DC recognizing/empowering Supported Decision-Making


Projects across the country focused on increasing access to Supported Decision-Making
Supported Decision-Making ONLY works if we Recognize, Respect, and Honor EVERYONE’s Right to Make Choices
Opportunities for Support 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
JOIN THE CONVERSATION


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

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