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
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
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?
**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
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
- “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:

- “[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)
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
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
AND

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
2017-2018
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

EVERYONE has the Right to Make Choices
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.”
IF JENNY CAN’T MAKE DECISIONS.

... How could she sign a Power of Attorney?

“[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.”
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
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
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
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 “manage” affairs some times but not others.
Or be unable to “govern” themselves unless they get help understanding the situations they face.
- E.g. Salzman, 2010
Capacity to take medicine is NOT the same as capacity to prescribe it
So...

If person can only make decisions when he or she has support, is that person 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
**Supported Decision-Making Can Address Limitations in Decision-Making**

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 capabilities;
- That people can get help exercising their Right to Make Choices without giving up that right; and
- There are as many ways to give and get help as there are people

- e.g., Dinerstein, 2012
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 life areas where he or she makes decisions now and those the person needs help to make.

RESOURCE: When Do I Want Support: https://www.aclu.org/other/when-do-i-want-support
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:”
**Making It Happen:**

**Steps in Supported Decision-Making**

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**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, and others.
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**

- Create written plans saying who will give support, when, and how
- Incorporate SDM into Person Centered Plans
- Powers of Attorney or Advanced Directives with SDM
- Incorporate SDM into support plans for programs
- If person is in guardianship, incorporate SDM into guardianship reports
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 & Martininis, 2015
**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).
Laws in 11 states and Washington DC recognizing/empowering Supported Decision-Making

National Resource Center for Supported Decision-Making –

Projects in South Carolina, Tennessee, New York, Kentucky, California, Nevada, North Carolina, Maine, Massachusetts, Florida, Georgia, and others focused on increasing access to Supported Decision-Making
Always Remember:

Supported Decision-Making ONLY works if we Recognize, Respect, and Honor EVERYONE’s Right to Make Choices

National Resource Center for Supported Decision-Making
EVERYONE has the 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

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