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

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THERE ARE STUPID QUESTIONS

What's Your Favorite Right?

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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

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: 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

- 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.
- Experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," decreasing their ability to function - Winick, 1995

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)

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

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

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
2017-2018

NATIONAL CORE INDICATORS™

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

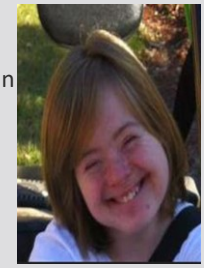
Then we need a means of **INCREASING** self-determination while **STILL** providing support

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



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 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."

WHY? FROM THEIR EXPERT

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."**

THEREFORE…

"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."

AND…

"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

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"

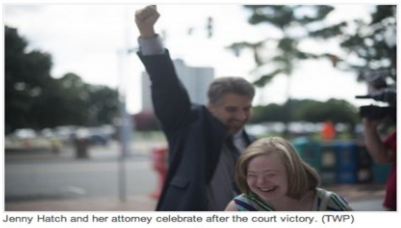
- Guardians to be who she wants
- She lives where she wants
- Guardianship for only 1 year – Expired August, 2014
- Only over 2 things – medical and safety

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 Lessons Jenny Teaches 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 "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?

Which Means: Ask a Question

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 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

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:

- 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

Making It Happen
Steps in Supported Decision-Making

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

Making it Happen
Steps in Supported Decision-Making

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 wells, 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:" http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf

Making It Happen: Steps in Supported Decision-Making

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

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Making It Happen Steps in Supported Decision-Making

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.
- RESOURCE: "Setting the Wheels in Motion": http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf

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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

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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

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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).

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It IS Happening

- Laws in 11 states and Washington DC recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- 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

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Always Remember:

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

And

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

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

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