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

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There ARE Stupid Questions

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 = 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)
When denied self-determination, people:

- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).

We’ve Known for Forty Years
“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))
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, p. 354)
On the Other Hand

- Older adults 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, 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
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)
Really, We Meant Well

Estimated number of adults under guardianship has tripled since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).
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”
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

- Thirty 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.”
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
Preach

“I don’t need a guardian. I just need a little help.”

– Jenny Hatch

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

ARE YOU?
“Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”

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.

(Salzeman, 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
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 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)
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 EVERY decision in his or her life.

- We all need help making decisions
- People with Disabilities may need more or different help but have the SAME rights
Not Just Justice for Jenny

Justice for You
Justice for Me

Justice for Everyone
Contact Us

Quality Trust

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