

Introduction to Supported Decision-Making

The Supported Decision-Making Webinar Series

Presented by
Quality Trust for Individuals with Disabilities
Burton Blatt Institute
Autistic Self Advocacy Network

April 30, 2014



Today's Webinar

- ***Introduction*** – Tina Campanella, Chief Executive Officer, Quality Trust for Individuals with Disabilities
- ***Panel2***
 - Margaret "Jenny" Hatch, leader, advocate and inspiration to people across the country
 - Jonathan Martinis, Legal Director for Quality Trust for Individuals with Disabilities
 - Kelly Morris, advocate and parent
- ***Reactor*** – Ari Ne'eman, President and co-founder of the Autistic Self Advocacy Network
- ***Questions and Answers***

Justice for Jenny . . . And for Everyone



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.

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

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.”**

Their Expert

What would help Jenny?

“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.”

Their Sworn Statement

How could Jenny execute 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.”

Records from Service Provider

Case Manager worked with Jenny so she could understand, complete and sign:

- **Medicaid Waiver Individual Service Plan**
- **Application for Paratransit**
- **Authorization to share medical records**
- **Assignment of a Representative Payee**
- **Application for an ID Card**

Thanks!



So...

Jenny is a person who 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

Obstacles

“Guardianship for your Own Good”

- Wright, J (2010)

“I have a first cousin who has the same intellectual disability as Ms. Hatch. I’d want somebody to take care of her.”

- Judge Pugh: 2/10/13

Road Map

Supported Decision-Making:

- **We all do it, every day.**
- **Jenny does it already**
- **It will increase Jenny's independence**
- **It will make her LESS likely to be abused or neglected**
- **Education, training, supports and services available through Medicaid**

Evolution of a Judge

To our Psychologist:

“Would it be fair to say that incrementally she could begin at a group home . . .”

“I’m not talking about independence now. I’m talking about gradual . . . Then maybe some independence of herself....”

Evolution of a Judge

To our Expert on Independence

“If a decision is made to give . . . individuals with intellectual disabilities more freedom, will there be true examination”

“I would always be there for the guardianship. . . [W]e can make it a limited guardianship, we can have the guardian working in conjunction with the people from the . . . Medicaid waivers.”

Evolution of a Judge

To our Medicaid Expert

“My grandmother said there’s a lot of things that you want in life that make it the best. . . In a perfect world, everything you say that could take place probably could take place. . . But you and I know that this is not a perfect world.”

“You have a different expertise that lends itself to telling us . . . What can be accomplished, not what will be.”

Final Order

First 4 pages justify guardianship.

“However”

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

Full Evolution of a Judge

EVEN DURING the 1 year limited guardianship:

“Guardians shall assist Respondent in making and implementing decisions we have termed ‘supported decision making.’”

“As stated by an expert witness, Robert Dinerstein, ‘[A] guardian’s job . . . is to make the judgment that the individual would make if he or she was able to express that judgment rather than say . . . what the guardian thinks would be right.’”

Jenny Got Justice!



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.

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

Really, Why?

Jenny Got Lucky

The Defining Civil Rights Issue for People with Disabilities

Justice and Self-Determination should:

- **NEVER depend on luck or who you know.**
- **Be the Rule not the Exception**

Obstacles

- Number of adults under guardianship has **TRIPLED** since 1995 (Schmidt, 1995; Reynolds, 2002; Uekert & Van Duizend, 2011).
- Typical advice when a person with disabilities turns 18 is STILL:
 - (1) Get Guardianship
 - (2) Get SSI

Why?

- A continuing public perception that People with Disabilities need “protection, not rights.”
Dinerstein, R. (2012).
- “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)

Opportunities

- Cases challenging guardianships and promoting Supported Decision-Making as an alternative
- State laws recognizing Supported Decision-Making as a valid legal arrangement and alternative to guardianship
- Federal, State and Local policies recognizing and encouraging Supported Decision-Making

Not Just Justice for Jenny

Justice for You

Justice for Me

Justice for Everyone

www.JennyHatchJusticeProject.Org