

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

Jonathan  
Martinis  
Jonathan Gerald  
Martinis, LLC

**THINK ABOUT YOUR LIFE**

What's Your Favorite  
Right?

# RIGHTS=CHOICES

“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

# 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

**REALLY THINK ABOUT YOUR LIFE**

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.
- **5<sup>th</sup> 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

## 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).*

# WHEN PEOPLE ARE DENIED LIFE CONTROL

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 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, Rifenburg, & 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



NATIONAL  
CORE  
INDICATORS™

# AND

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



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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

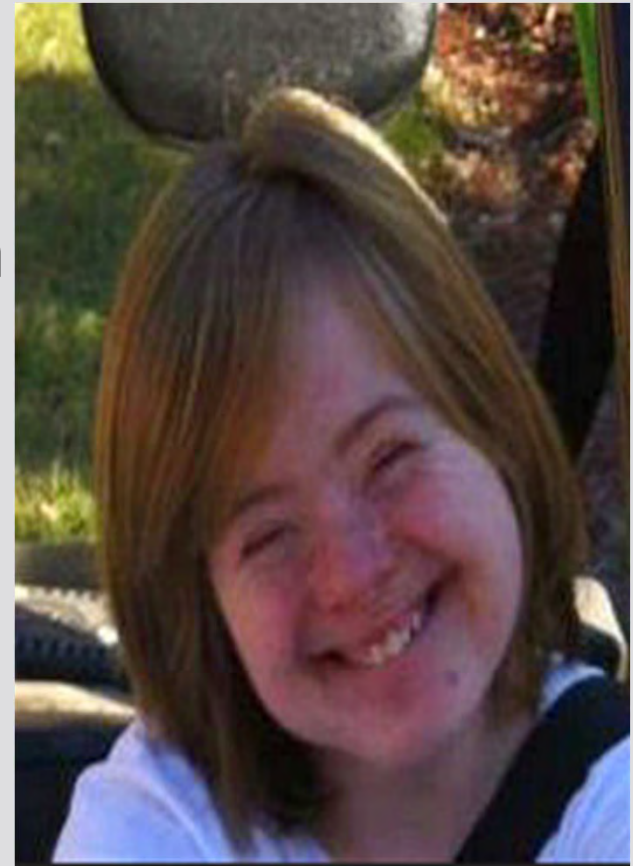
Then we need a means of **INCREASING** self-determination while **STILL** providing support

# 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.”

# HOW COULD JENNY 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 LESSON JENNY TEACHES US

Justice and Self-Determination should:

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

# SO, WHERE DO GO FROM HERE?

## 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;

# THINK ABOUT IT

## WHAT DOES IT MEAN TO “NEED”?

- 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?**

## 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 HELP PEOPLE “TAKE CARE OF” THEMSELVES AND THEIR PROPERTY

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 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 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

# RESEARCH

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?**

# 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 decisions he or she makes now and those the person needs help to make.
- RESOURCE: The Missouri Stoplight Tool:  
<https://www.moddcouncil.org/uploaded/Guardianship%20Manual%20Appendix%201.pdf>

# 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 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:"  
<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.

# 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>

# 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!

# WHEN WHAT YOU TRIED WORKS!

- “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.

## DOESN'T THAT MEAN...

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)

## **‘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.

# IT DOES HAPPEN



# IT KEEPS HAPPENING



# IT WILL KEEP HAPPENING



# IT'S STILL HAPPENING



# IT IS HAPPENING ACROSS THE US

- Laws in 13 states and the Washington DC recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org)
- Projects across the country focused on increasing access to Supported Decision-Making

**BUT IT WILL ONLY HAPPEN  
IF WE REMEMBER THAT**

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](http://SupportedDecisionMaking.Org)

**The Burton Blatt Institute at Syracuse  
University:** [BBI.Syr.Edu](http://BBI.Syr.Edu)

**Jonathan Martinis,**  
[JGMartinisLLC@Gmail.com](mailto:JGMartinisLLC@Gmail.com)