

<h2>Supported Decision-Making: From Justice for Jenny to Justice for All!</h2>	<p>Jonathan Martinis Senior Director for Law and Policy The Burton Blatt Institute at Syracuse University Project Director, National Resource Center for Supported Decision-Making</p>
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<h3>AN IMPORTANT QUESTION</h3>
<h2>What's Your Favorite Right?</h2>
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<h3>RIGHTS=CHOICE</h3>
<p>"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 <i>how we are</i> in those circumstances." - Jean Paul Sartre</p>
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**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

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**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

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**ANOTHER IMPORTANT QUESTION**

**Are Your Rights Worth ANYTHING If You’re Not Allowed to Use Them?**

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**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

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**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

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**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).*

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### 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

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### 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)

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### 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

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**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”

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**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)

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**WE MUST’VE MEANT REALLY WELL**

Estimated number of adults under guardianship has **tripled** since 1995  
- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011

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<b>RESEARCH</b>
People under guardianship can experience a “ <b>significant negative impact</b> on their physical and mental health, longevity, ability to function, and reports of subjective well-being” - Wright, 2010
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<b>ON THE OTHER HAND</b>
People with disabilities who exercise greater self-determination have a <b>better quality of life</b> , more independence, and more community integration. - Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003
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<b>AND</b>
Women with intellectual disabilities exercising more self-determination are <b>less likely to be abused</b> - Khemka, Hickson, and Reynolds, 2005
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**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



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**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

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**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



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**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

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**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.”

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**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.”**

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**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.”

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**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.”

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**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.”

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**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

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**IN OTHER WORDS**

**JENNY IS A PERSON**

We Are All Jenny Hatch

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**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

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**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?**

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**So, SUPPORTED DECISION-MAKING IS A LOT OF WORDS FOR**

Getting help when its needed

**Just like you and me**

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**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

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**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

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**FINAL ORDER**

**EVEN DURING** the 1 year limited guardianship:

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

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**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.

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<b>WHY?</b>
<b>Jenny is Strong, Smart, Determined AND</b> She had support from: <ul style="list-style-type: none"><li>▪ Friends and professionals</li><li>▪ National Organizations and Leaders</li><li>▪ Media</li><li>▪ A Judge who was willing to Listen and Learn</li></ul>

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<b>IN OTHER WORDS</b>
<b>Jenny Got Lucky</b>

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<b>THE LESSONS JENNY TEACHES US</b>
Justice and Self-Determination should: <ul style="list-style-type: none"><li>▪ <b>NEVER</b> depend on luck or who you know.</li><li>▪ <b>ALWAYS</b> Be the Rule <b>NOT</b> the Exception</li></ul>

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**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**

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**So...**

If person can only make decisions when he or she has support, is that person incapacitated?

**ARE YOU?**

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**WHICH MEANS: ASK A QUESTION**

Before seeking or recommending Guardianship:

**What Else Have You Tried?**

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**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

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**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

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**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

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**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

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**MAKING IT HAPPEN  
STEPS IN SUPPORTED DECISION-MAKING**

- **Listen and Think:** Identify where the person wants help making decisions
- **Identify Opportunities:** Explore how the person wants to be supported and has been supported before
- **Find Supporters:** Think about and approach people, professionals, and organizations that have or could provide support
- **Coordinate Support:** Create a plan detailing when the person wants to be supported, how, from whom, and when
- **Put it in Writing:** While not mandatory, is helpful. Writings with SDM can include Supported Decision-Making Agreement (not yet recognized in FL), Powers of Attorney, Advanced Directives, Individual Services Plans, etc.

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**MAKING IT HAPPEN:  
RESOURCES**

Martinis, 2019. Making it Happen, Steps in Supported Decision-Making  
<https://publications.ici.umn.edu/impact/32-1/making-it-happen-strategies-for-supported-decision-making>

Francisco & Martinis: Supported Decision-Making Teams: Setting the Wheels in Motion:  
<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

National Resource Center for Supported Decision-Making  
EVERYONE has the Right to Make Choices

48

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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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**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>

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**FLORIDA LAW ALREADY REQUIRES IT**

“the court **must consider and find** whether there is an alternative to guardianship that will sufficiently address the problems of the incapacitated person. A guardian may not be appointed if the court finds there is an alternative to guardianship which will sufficiently address the problems of the incapacitated person.

- Fla. Stat. § 744.331(6)(b)

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National Resource Center for Supported Decision-Making  
EVERYONE has the Right to Make Choices

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**YOU'RE ALREADY USING IT:  
ETHICAL CONSIDERATIONS**

(a) Maintenance of Normal Relationship. When a client's ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability, or for some other reason, **the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.**  
Florida Rules of Professional Conduct, Rule 4-1.14(a)

National Resource Center for Supported Decision-Making  
EVERYONE has the Right to Make Choices

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**YOU SHOULD BE:  
ETHICAL CONSIDERATIONS**

**"The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. When the client is a minor or suffers from a mental disorder or disability, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, an incapacitated person may have no power to make legally binding decisions. Nevertheless, a client lacking legal competence often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being."**  
Comment to Rule 4-1.14

National Resource Center for Supported Decision-Making  
EVERYONE has the Right to Make Choices

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**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.

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**IT DOES HAPPEN**



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**IT KEEPS HAPPENING**



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**IT WILL KEEP HAPPENING**



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**IT'S STILL HAPPENING**



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**IT IS HAPPENING: LAW, POLICY, AND PRACTICE**

- Laws in 13 states and the District of Columbia recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org) \
- Supported Decision-Making in Florida: <https://disabilityrightsflorida.org/disability-topics/disability-topic-info/supported-decision-making-pilot-project>
- Projects in Florida, Georgia, Missouri, Kansas, South Carolina, North Carolina, California, Ohio, Tennessee, New York, Virginia, Kentucky, Nevada, Maine, Massachusetts, 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

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<b>AND</b>
<p><u>Opportunities for Support Are All Around Us</u></p> <ul style="list-style-type: none"><li>▪ “Informed Consent” to medical care</li><li>▪ “Person Centered Planning” in Medicare/Medicaid</li><li>▪ “Student Led” IEPs</li><li>▪ “Informed Choice” in Vocational Rehabilitation</li><li>▪ “The Conversation” and “Five Wishes” for End of Life Planning</li></ul>

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<b>JOIN THE CONVERSATION</b>
<p><b>National Resource Center for Supported Decision-Making:</b> <u><a href="http://SupportedDecisionMaking.Org">SupportedDecisionMaking.Org</a></u></p> <p><b>The Burton Blatt Institute at Syracuse University:</b> <u><a href="http://www.BBI.Syr.Edu">www.BBI.Syr.Edu</a></u></p> <p><b>Jonathan Martinis:</b> <u><a href="mailto:JGMartin@Syr.Edu">JGMartin@Syr.Edu</a></u></p>
62

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62