

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

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.
- **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

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, 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



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



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?

The court may appoint a guardian . . . after finding in the record based on evidence **beyond a reasonable doubt** that:

- (a) The person for whom a guardian is to be appointed is **incapacitated**; and
- (b) The guardianship is **necessary** as a means of providing continuing care, supervision, and rehabilitation of the individual, or the management of the property and financial affairs of the incapacitated person; and
- (c) There **are no available alternative resources** which are suitable with respect to the incapacitated person's welfare, safety, and rehabilitation or the prudent management of his or her property and financial affairs; and
- (d) **The guardianship is appropriate as the least restrictive form of intervention** consistent with the preservation of the civil rights and liberties of the proposed ward. - NH Statute **Section 464-A:9**

FOUR STEPS!

- (1) The person must be “incapacitated”
- (2) The guardianship must be “necessary”
- (3) There must be NO available resources that could help the person
- (4) The guardianship must be appropriate and the least restrictive form of intervention

WHAT DOES IT MEAN TO BE INCAPACITATED?

"Incapacity" means a legal, not a medical, disability and shall be **measured by functional limitations**. It shall be construed to mean or refer to any person who has suffered, is suffering or is likely to suffer substantial harm due to an **inability to provide for his personal needs for food, clothing, shelter, health care or safety or an inability to manage his or her property or financial affairs**. Inability to provide for personal needs or to manage property shall be evidenced by acts or occurrences, or statements which strongly indicate imminent acts or occurrences. **All evidence of inability must have occurred within 6 months prior to the filing of the petition and at least one incidence of such behavior must have occurred within 20 days of the filing of the petition for guardianship.**

- NH Statute 464-A:2

THINK ABOUT IT

WHAT DOES IT REALLY MEAN?

- Some people may be able to “provide” or “manage” at some times but not others
- Or may ONLY be able to “provide” or “manage” 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 provide for their needs or manage their finances when they have help, are they “incapacitated” and is a guardianship “necessary”?

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>

NEW HAMPSHIRE LAW ALREADY REQUIRES IT

- Available alternative resource" means alternatives to guardianship including, but not limited to, services such as visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers; powers of attorney, **supported decision-making agreements** such as those authorized by RSA 464-D,

WHAT ELSE HAVE YOU TRIED?

IT'S HERE!

New Hampshire Statute 464-D Recognizes Supported Decision-Making

- Sets out who may be supporters
- What supporters can and can't do
- Provides a model Supported Decision-Making Agreement

<https://casetext.com/statute/new-hampshire-revised-statutes/title-44-guardians-and-conservators/chapter-464-d-supported-decision-making>

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

- New Hampshire Law says that a Supported Decision-Making Agreement MUST “not be inconsistent” with the form in NH Stat 464D-16
<https://casetext.com/statute/new-hampshire-revised-statutes/title-44-guardians-and-conservators/chapter-464-d-supported-decision-making/section-464-d16-form-of-supported-decision-making-agreement>
- 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

- “A guardian shall act with respect to the ward in a manner which safeguards to the greatest extent possible the civil rights of the ward, and shall restrict the personal freedom of the ward only to the extent necessary.” – NH Stat 464-A:25

WHAT ARE YOU TRYING?

SDM AND MAXIMIZING SELF DETERMINATION CAN BUILD A PERSON'S "FREEDOM"

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!

- A guardian serves until . . . “the court finds removal of the guardian to be in the ward’s best interests” – NH Stat 464-A:39
- “A guardianship of the person or of the estate shall terminate upon order of the court, the death of the ward, or upon a finding by the court that the ward is no longer incapacitated.
II. (a) The ward or any person interested in the ward's welfare may, at any time, file a motion for the termination of the guardianship based upon a finding that the ward is no longer incapacitated” – NH Stat. 464-A:40

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 HAPPENS



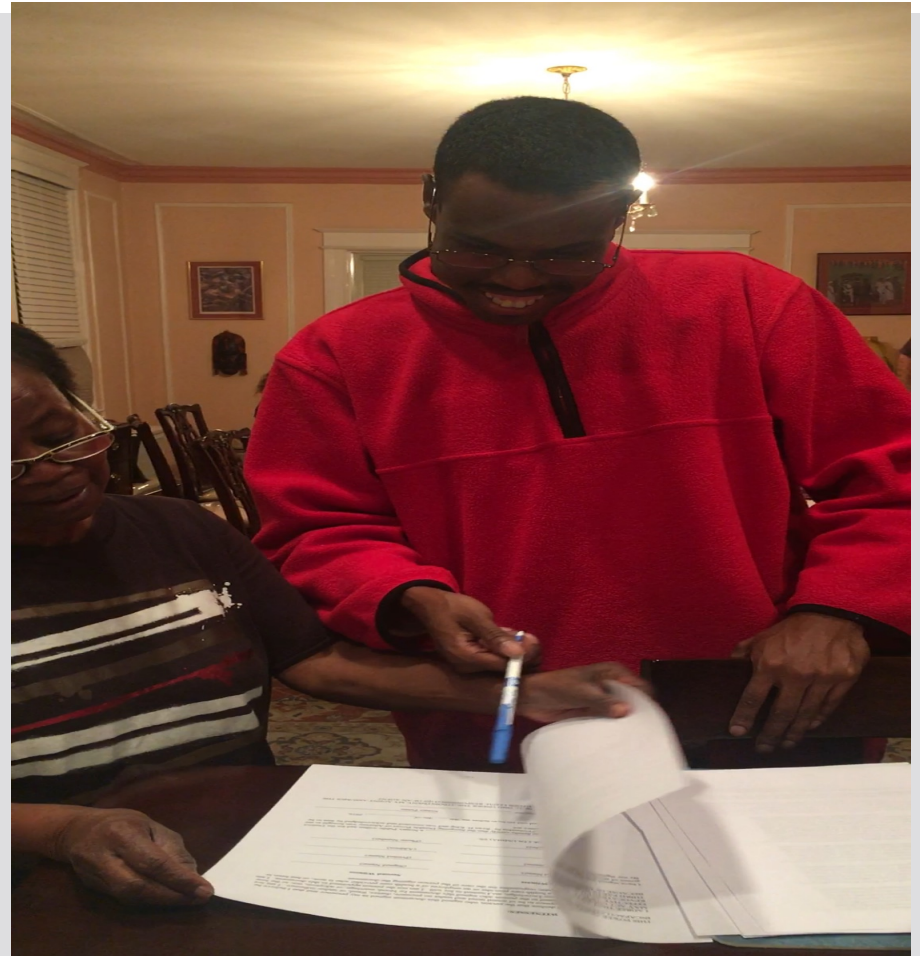
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IT IS HAPPENING



IT CAN HAPPEN



IT DOES HAPPEN



IT'S STILL HAPPENING





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IT WILL KEEP HAPPENING



IT IS HAPPENING NATIONALLY

- Laws in 14 states and the Washington DC recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- Projects in Illinois, Ohio, North Carolina, South Carolina, Tennessee, Missouri, Kansas, Vermont, New York, Kentucky, California, Nevada, Maine, Massachusetts, Florida, Georgia, Kentucky, and others 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

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

The Burton Blatt Institute at Syracuse
University: **www.bbi.syr.edu**

Jonathan Martinis: **JGMartin@Syr.Edu**

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