

**Supported Decision-
Making:
Protecting Rights,
Ensuring Choices**

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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

Older adults and people with disabilities 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 AND CONSERVATORSHIP IN THE U.S.

“Plenary” or “Full” Guardianship and Conservatorship

- Gives the guardian/conservator power to make ALL decisions for the person.
 - Used in the **VAST** Majority of cases
 - “As long as the law permits plenary [guardianship/conservatorship], **courts will prefer to use it.**”
- Frolik, 1998

AS A RESULT

Guardians and conservators 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)

DINO AND LILLIAN

“To Collect Debts, Seizing Control Over Patients” New York Times, 1/25/15



DINO AND LILLIAN

- Married over 45 years
- Worked together to develop Powers of Attorney and Advanced Directives
- When Lillian developed dementia, chose a nursing home for her

DINO AND LILLIAN

After Dino asked questions about a bill and Lillian's care

- Nursing Home petitioned for a **plenary** guardianship - giving **ALL** decision-making rights to a stranger
- Nursing Home's attorney: "[G]uardianship is a legitimate means to get the nursing home paid."

WHERE DO WE GO FROM HERE?

Guardianship and Conservatorship **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/CONSERVATORSHIP 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/conservatorship has **tripled** since 1995

- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011.

RESEARCH

People under guardianship and conservatorship 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

- Older adults with more self-determination have improved psychological health including better adjustment to increased care needs.
 - O'Connor & Vallerand, 1994
- Older adults who exercise more control over their lives have a **better quality of life**.
 - Mallers, et al., 2014
- Providing support to people with dementia can lead to them being able to provide informed consent.
 - Haberstroh, et al. 2014

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 or conservator 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



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 and conservatorship 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

Her 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 AND LILLIAN TEACH US

Justice and Self-Determination should:

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

So, Where DO We Go From Here?

Conservatorship for Older Adults and Others WITHOUT Intellectual and Developmental Disabilities

(1) If the court finds by **clear and convincing evidence** that the respondent is **incapable of managing the respondent's affairs**, that the respondent's affairs cannot be managed adequately without the appointment of a conservator and that the appointment of a conservator is the least restrictive means of intervention available to assist the respondent in managing the respondent's affairs, the court may appoint a conservator of his or her estate after considering the factors set forth in subsection (g) of this section.

(2) If the court finds by **clear and convincing evidence** that the respondent is **incapable of caring for himself or herself**, that the respondent cannot be cared for adequately without the appointment of a conservator and that the appointment of a conservator is the least restrictive means of intervention available to assist the respondent in caring for himself or herself, the court may appoint a conservator of his or her person after considering the factors set forth in subsection (g) of this section.

- CT Gen. Stat. 45a-650

WHEN IS A PERSON “INCAPABLE”?

- (c) “Incapable of caring for one's self” or “incapable of caring for himself or herself” means that a person has a mental, emotional or physical condition that results in such person being **unable** to receive and evaluate information or make or communicate decisions to such an extent that the person is unable, even with appropriate assistance, to meet essential requirements for personal needs.
 - (d) “Incapable of managing his or her affairs” means that a person has a mental, emotional or physical condition that results in such person being unable to receive and evaluate information or make or communicate decisions to such an extent that the person is **unable**, even with appropriate assistance, to perform the functions inherent in managing his or her affairs . . .
- CT Gen Stat. 45a-644

So, Where DO We Go From Here?

Guardianship for People WITH Intellectual and Developmental Disabilities

(a) If the court finds, by **clear and convincing evidence**, that the respondent is, by reason of the severity of the respondent's intellectual disability, **totally unable** to meet essential requirements for the respondent's physical health or safety and **totally unable to make informed decisions about matters related to the respondent's care**, the court shall appoint a **plenary guardian or plenary coguardians** who shall have all those powers and duties provided for in section 45a-677.

(b) If the court finds **by clear and convincing evidence** that the respondent is **able to do some, but not all, of the tasks necessary to meet essential requirements** for the respondent's physical health or safety or that the respondent is able to make some, but not all, informed decisions about matters related to the respondent's care, **the court shall appoint a limited guardian or limited coguardians.**

CT Gen. Stat. 45a-676

WHAT DOES IT MEAN TO BE “UNABLE”

“Unable to meet essential requirements for his or her physical health or safety” means the **inability** through one's own efforts and through acceptance of assistance from family, friends and other available private and public sources, to meet one's needs for medical care, nutrition, clothing, shelter, hygiene or safety so that, in the absence of a guardian, serious physical injury, illness or disease is likely to occur.

“Unable to make informed decisions about matters related to his or her care” means the **inability** of a person with intellectual disability to achieve a rudimentary understanding, after conscientious efforts at explanation, of information necessary to make decisions about his or her need for physical or mental health care, food, clothing, shelter, hygiene, protection from physical abuse or harm, or other care.

“Unable to manage his or her finances” means the **inability** of a person with intellectual disability to receive and evaluate information or make or communicate decisions to such an extent that the person is unable, even with appropriate assistance, to perform the functions inherent in managing his or her finances.

CT Gen Stat. 45a-669

THINK ABOUT IT

WHAT DOES IT MEAN TO BE “UNABLE”?

- People may be able to make 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

Capability to take medication is not the same as capacity to prescribe it!

So...

If people are ONLY “able” to make decisions and manage their lives if they have help, is guardianship/conservatorship needed?

DO YOU NEED ONE?

WHICH MEANS: ASK A QUESTION

BEFORE seeking or recommending
guardianship or conservatorship

**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 BE “CAPABLE” OF TAKING 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>

SDM FITS IN CONNECTICUT LAW FOR PEOPLE WITHOUT INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

People without intellectual and developmental disabilities cannot be put in conservatorship unless conservatorship is the **“least restrictive means of intervention”**

- CT Gen. Stat. 45a-650

WHAT ELSE HAVE YOU TRIED?

SDM FITS IN CONNECTICUT LAW FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

“Unable to meet essential requirements for his or her physical health or safety” means the inability through one's own efforts and **through acceptance of assistance from family, friends and other available private and public sources**, to meet one's needs for medical care, nutrition, clothing, shelter, hygiene or safety so that, in the absence of a guardian, serious physical injury, illness or disease is likely to occur.

“Unable to make informed decisions about matters related to his or her care” means the inability of a person with intellectual disability to achieve a rudimentary understanding, **after conscientious efforts at explanation, of information necessary to make decisions** about his or her need for physical or mental health care, food, clothing, shelter, hygiene, protection from physical abuse or harm, or other care.

“Unable to manage his or her finances” means the inability of a person with intellectual disability to receive and evaluate **information or make or communicate decisions to such an extent that the person is unable, even with appropriate assistance**, to perform the functions inherent in managing his or her finances.

- CT Gen Stat. 45a-669

WHAT ELSE HAVE YOU TRIED?

THE ELEPHANT IN THE ROOM: SAFETY

NOTHING: Not Guardianship, Not Conservatorship, Not Supported Decision-Making is 100% "Safe."

HOWEVER: Supported Decision-Making Increases Self-Determination (Blanck & Martinis, 2015), which is correlated with increased Safety (Khemka, Hickson, & Reynolds, 2005).

SDM HAPPENS



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.

IT IS HAPPENING



IT CAN HAPPEN



IT DOES HAPPEN



IT'S STILL HAPPENING





IMG_8642.heic

IT WILL KEEP HAPPENING



IT IS HAPPENING: ALL AROUND THE US

- In the last 10 years, since Jenny's case, 25 states and the District of Columbia have changed their laws to formally recognize SDM
- The National Resource Center for Supported Decision Making (www.supporteddecisionmaking.org) provides information and resources on SDM
- Projects around the country to increase knowledge, access to, and use of SDM!
- In Connecticut, email **SDMinfo@gmail.com** or visit <https://ctsilc.org/supported-decision-making> for more information

**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
- “The Conversation” and “Five Wishes” for End of Life Planning
- “Person Centered Planning” in Medicare/Medicaid
- “Student Led” IEPs
- “Informed Choice” in Vocational Rehabilitation

JOIN THE CONVERSATION

The Connecticut Supported Decision-Making Coalition: www.CTsilc.org/supported-decision-making/

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

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