

# Self-Employed and Self-Determined: Guardianship is not your **ONLY** Option Webinar

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# Self-Employed and Self-Determined: Guardianship is not your ONLY Option

Featuring:

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# First Principles

# What's Your Favorite Right?

# Rights=Choice

"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=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.

# Benefits of Self-Determination (Slide 1 of 2)

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



## Benefits of Self-Determination (Slide 2 of 2)

People with disabilities who have more self determination are more likely to:

- Work
  - Make more money
  - Be more involved in managing their money
- Wehmeyer & Schwartz, 1997; Wehmeyer & Palmer, 2003

## A Critical Question

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 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

## 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).

## 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.

## Think About it...

If you were a **bank**, would you let someone who wasn't allowed to make money decisions open a checking account or loan them money?

If you were a **business**, would you enter into a contract with a company where the president wasn't allowed to sign contracts?

If you were an **employee**, would you want to work for someone who isn't allowed to sign paychecks?

# 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, National Council on Disability, 2019

# 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, more community integration, and are more likely to work.

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

## **And** (Slide 1 of 3)

Women with intellectual disabilities exercising more self-determination are **less likely to be abused**

- Khemka, Hickson, and Reynolds, 2005

## And (Slide 2 of 3)

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





## And (Slide 3 of 3)

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
- Guardianship can result in decreased quality of life and
- Increased self-determination leads to improved quality of life

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

## **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**

## So, Where DO We Go From Here? When Are Guardians Appointed?

Almost all state laws say that a person should not be ordered into guardianship unless they are “incapacitated” or “incapable” of making decisions and, even then, only if the guardianship is “necessary” or if there are no other “less restrictive alternatives” available.

# Think About It

## What Does It Mean To Be “Capable” or “Able?”

- People may be “capable” or “able” to manage their lives in some areas but not others.
  - Or be “able” or “capable” only with assistance.
  - Or be “unable” or “incapable” unless they get help.
- e.g. Salzman, 2010

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

## So Ask a Smart Question

If people can only “manage” a business or make personal or financial decisions **with assistance or support**, are they “incapacitated?”

ARE YOU?



## And Ask Another

If people can “manage” a business, or make personal and financial decisions if they get help, is a guardian “necessary?”

## Which Means

**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 be “able” and “capable”

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.

# Making It Happen

## Steps in Supported Decision-Making (Slide 1 of 2)

### 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, including work and financial decisions.

[RESOURCE: The Missouri Stoplight Tool](#)

# Stoplight Tool



# Making it Happen

## Steps in Supported Decision-Making (Slide 2 of 2)

### 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 wells, think about trying it for other life areas.
- If you're not sure what to try, brainstorm about ways to give and get support.

For example, ask a person who wants to be self-employed how they've made money and other decisions before or who has helped them. Then try that method for their business.

[RESOURCE: The "Supported Decision-Making Brainstorming Guide"](#)

# Brainstorming Guide

# Making It Happen: Steps in Supported Decision-Making (1 of 2)

## Find Supporters

- Connect with the people, professionals, agencies, and organizations that can provide the support the person wants.
- For example, if someone wants to be self-employed, consider support from programs like Special Education, Vocational Rehabilitation, and Centers for Independent Living.

# Making It Happen

## Steps in Supported Decision-Making (2 of 2)

### 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"](#)

# Setting the Wheels in Motion Guide

# Making It Happen: Steps in Supported Decision-Making

## Put it in Writing

Some state laws require that SDM be memorialized in writing, others do not

Even if its not required, a written agreement is a good idea

Create written plans saying who will give support, when, and how

Examples of agreements are at [SupportedDecisionMaking.Org](https://SupportedDecisionMaking.Org).

## Putting it in Writing II

- If the person is able to make life decisions using support, document what the support is and how it works.
- This can be as easy as creating a Supported Decision-Making Team “Roster” listing who will do what, how, and when – e.g., *In Re: Conservatorship of Marie Bergum*: Superior Court, Santa Cruz (CA), Case No: 19PR00378
- You can also include SDM in Powers of Attorney, Advanced Directives, and support plans like Individualized Education Programs (Special Education), Individualized Plans for Employment (Vocational Rehabilitation), Individualized Support Plans (Medicaid), and others.

# A Simple Sample



# 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

# The 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

[SupportedDecisionMaking.org/Node/488](https://SupportedDecisionMaking.org/Node/488)

# Opportunities are ALL Around Us

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

# The Elephant In The Room: Safety

**NOTHING:** Not Guardianship, 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).

# It Happens



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 Can HAPPEN



# It Does HAPPEN



**IT Will HAPPEN**



# It Keeps Happening

**It Will KEEP Happening**

# It IS Happening: Law, Policy, and Practice

Laws in 26 states and the District of Columbia recognizing/empowering Supported Decision-Making.

[National Resource Center for Supported Decision-Making](#)

Projects across the country focused on increasing knowledge of, access to, and recognition of Supported Decision-Making.

**But It Will ONLY HAPPEN**

If we recognize, respect, and protect

**EVERYONE'S**

Right to Make Choices.

## Remember The Challenge

**EVERY** great advance in civil rights  
fundamentally changed the way “things  
have always been”

# Remember The Obstacles

Change is **HARD**

“We were not promised ease. The purpose of life . . . is not ease. **It is to choose, and to act upon the choice.** In that task, we are not measured by outcomes. We are measured only by daring and effort and resolve.”

- Stephen R. Donaldson

## Remember the Goal

“[P]eople with disabilities will have the same opportunities for success and security as their nondisabled peers. If we change the culture, we will change the world!”

Gustin & Martinis, 2016

# Join the Conversation

The National Resource Center for Supported Decision-Making:

[SupportedDecisionMaking.Org](http://SupportedDecisionMaking.Org)

Jonathan Martinis: [JGMartinisLLC@Gmail.Com](mailto:JGMartinisLLC@Gmail.Com)



# Upcoming Events

## [Self-Employed and Self-Determined](#)

Using Supported Decision-Making In Practice

Presented by Burton Blatt Institute at Syracuse University

Wednesday, January 31, 4:00 – 5:30PM EST

## [EXIM](#) Webinar Series

Registration Links Coming Soon!

Presented by Export-Import Bank of United States

February – May 2024

# NDI Small Business Hub

- Are you an aspiring entrepreneur or existing business owner with a disability wanting help to START, BUILD and GROW your business? Visit [DisabilitySmallBusiness.org](https://DisabilitySmallBusiness.org) or email Ruth Chavez, Community Navigator at [rchavez@ndi-inc.org](mailto:rchavez@ndi-inc.org).
- Visit our Streaming TV channel for informational and motivational content for disability owned small businesses at [DisabilityOwned.com](https://DisabilityOwned.com).
- Access training, mentoring, business coaching, and \$10,000 grant opportunities through our new partnership with Verizon Small Business Digital Ready! Register here: [Small Business Training | About Verizon](#)
- Want to “Stay In The Know” about NDI’s Small Business Hub? Join our [mailing list!](#)

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