

Introduction to Supported Decision- Making

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FIRST PRINCIPLES

What's Your Favorite
Right?

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

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

BUT WE ALSO KNOW

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.

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

A MILLION PEOPLE

Estimated number of adults under guardianship has **tripled** since 1995

- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011, National Council on Disability, 2019

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”

RESEARCH

People in overbroad or undue 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

- Older adults with more self-determination have improved psychological health including better adjustment to increased care needs.
 - O'Connor & Vallerand, 1994
- People with disabilities who exercise greater self-determination have a **better quality of life**, more independence, and more community integration and better able to recognize and resist abuse
 - Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003; Khemka, Hickson, and Reynolds, 2005

RESEARCH

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



NATIONAL
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

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

SUPPORTED DECISION-MAKING CAN HELP PEOPLE BE “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.

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>

IT HAPPENS



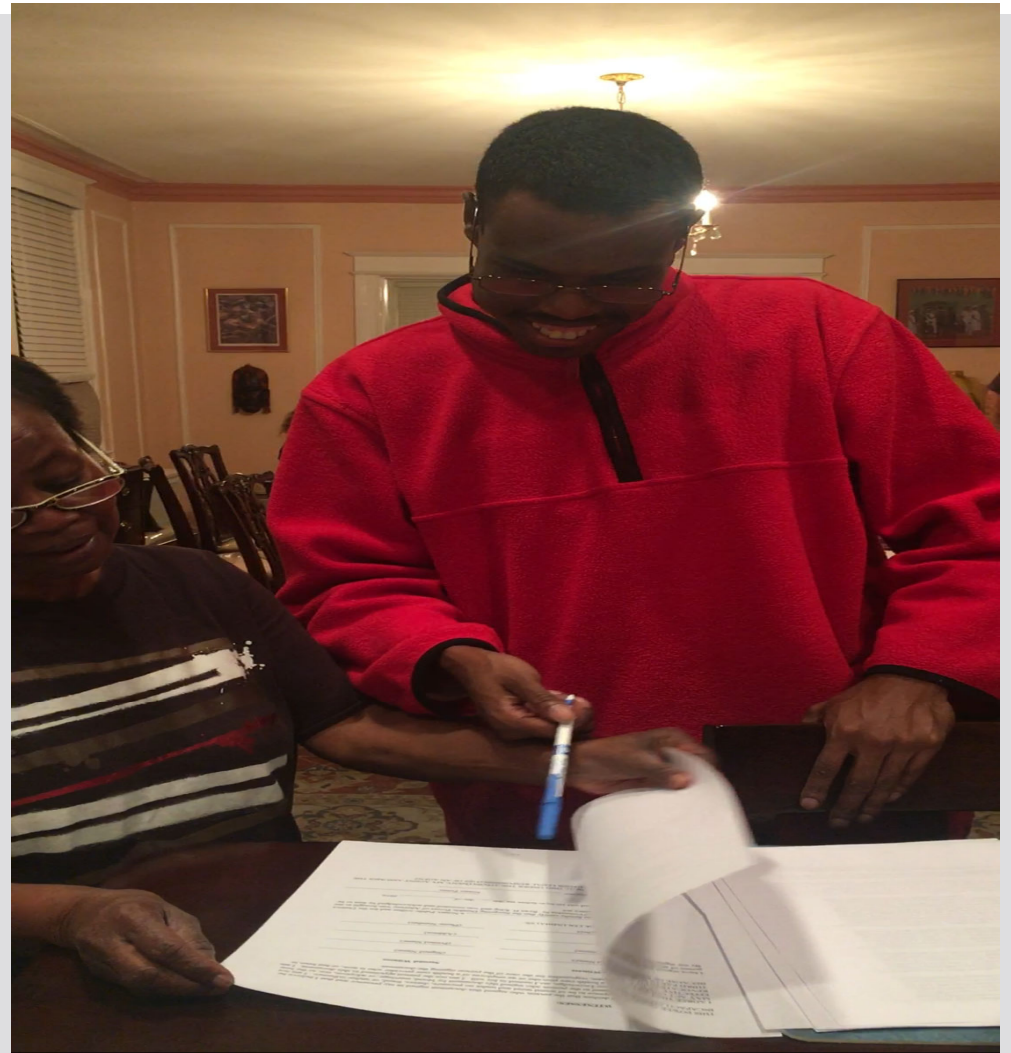
Jenny Hatch and her attorney celebrate after the court victory. (TWP)

‘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 IS HAPPENING



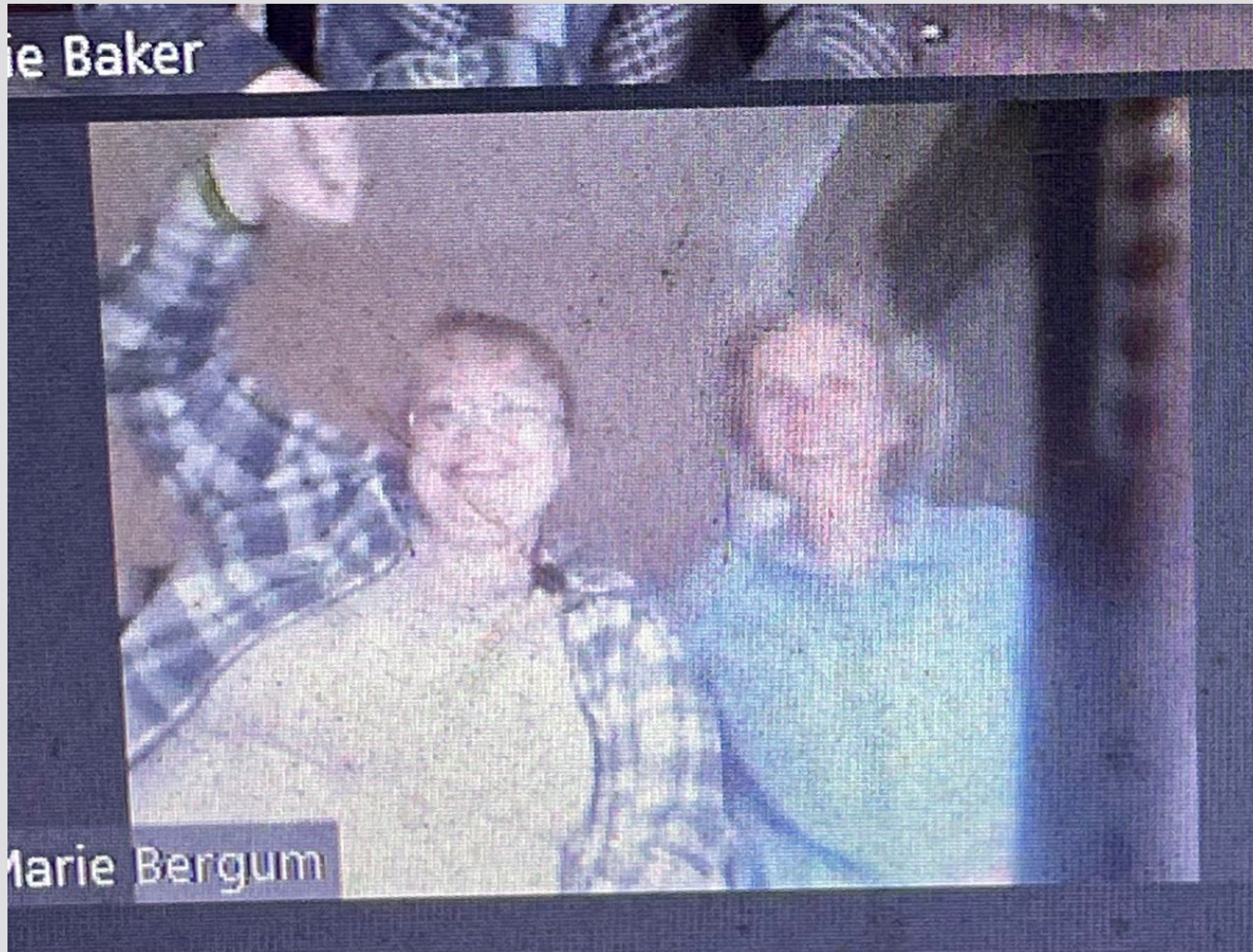
IT CAN HAPPEN



IT DOES HAPPEN



IT'S STILL HAPPENING





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IT WILL KEEP HAPPENING



IT IS HAPPENING: LAW, POLICY, AND PRACTICE

- Laws in 23 states and the District of Columbia recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- Projects in Missouri, South Carolina, North Carolina, California, Ohio, Tennessee, New York, Virginia, Kentucky, California, Nevada, Maine, Massachusetts, Florida, Georgia, and others focused on increasing access to Supported Decision-Making

JOIN THE CONVERSATION

**The National Resource Center for
Supported Decision-Making:**

SupportedDecisionMaking.Org

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