

# Introduction to Supported Decision- Making

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# FIRST PRINCIPLE

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

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

## ANOTHER STUPID 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

# 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 **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

- 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

# AND

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

- Khemka, Hickson, and Reynolds, 2005

# 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 . . . 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 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

# 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 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

# 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

# **SDM OPPORTUNITY**

## **MEDICAL DECISION-MAKING**

**“[M]y agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability, with me being the final decision maker.”**

# SDM OPPORTUNITY FINANCIAL AUTHORITY

I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X without my agent's agreement. For example, if I want to buy or sell a car for \$20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than X, **my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree.**

# 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).



# IN JUST 10 YEARS: CHANGES IN 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 –  
[www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org)
- Projects in every state focused on increasing access to Supported Decision-Making
- In Nebraska:  
<https://www.unmc.edu/mmi/family-resources/community-services/sdm.html>