

# Supported Decision- Making and Fundamental Rights

Jonathan  
Martinis

Legal Director,  
*Quality Trust for  
Individuals with  
Disabilities*

Project Director,  
*National  
Resource Center  
for Supported  
Decision-Making*

# 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

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

# AND YET

Are Your Rights Worth  
ANYTHING If You're Not  
Allowed to Use Them?

# 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."

# IN VIRGINIA

- “Unguarded” Investigative report from Richmond Times Dispatch
- Explored the use of private guardianships by Virginia Commonwealth University Health System
  - Found that VCU triggered guardianships to remove poor patients from hospital beds, and sought to have patients under the guardianship of a lawyer whose firm worked for the health system.
  - A review of more than 250 cases found instances of inadequate care for people under the lawyer’s care, and life-ending decisions that went against family’s wishes — or locked them out altogether.

[https://richmond.com/news/state-and-regional/after-a-times-dispatch-investigation-state-watchdog-recommends-changes-to-woefully-inadequate-guardianship-system/article\\_94721492-03a5-5716-aa0e-b3e28e9b2606.html](https://richmond.com/news/state-and-regional/after-a-times-dispatch-investigation-state-watchdog-recommends-changes-to-woefully-inadequate-guardianship-system/article_94721492-03a5-5716-aa0e-b3e28e9b2606.html)

# 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 who exercise more control over their lives have a **better quality of life**.
  - Mallery, 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

# AND

People with 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 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**

# WHERE DO WE GO FROM HERE WHEN IS GUARDIANSHIP APPROPRIATE?

If, after considering the evidence presented at the hearing, the court or jury determines on the basis of **clear and convincing evidence that the respondent is incapacitated and in need of a guardian** or conservator, the court shall appoint a suitable person, who may be the spouse of the respondent, to be the guardian or the conservator or both

Va Code Ann. 64.2-2007(D)

# TWO STEPS

(1) Is the person “incapacitated”

If so,

(2) Is guardianship “necessary”

Supported Decision-Making should be part of the analysis for each!

# WHEN IS A PERSON “INCAPACITATED”

"Incapacitated person" means an adult who has been found by a court to be **incapable** of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that **the individual lacks the capacity** to (i) **meet the essential requirements for his health**, care, safety, or therapeutic needs without the assistance or protection of a guardian or (ii) **manage property** or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator. A finding that the individual displays poor judgment alone shall not be considered sufficient evidence that the individual is an incapacitated person within the meaning of this definition.

# WHEN IS GUARDIANSHIP “NECESSARY”

In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors: (i) the limitations of the respondent; (ii) the development of the respondent's maximum self-reliance and independence; (iii) **the availability of less restrictive alternatives, including advance directives, supported decision-making agreements, and durable powers of attorney**; (iv) the extent to which it is necessary to protect the respondent from neglect, exploitation, or abuse; (v) the actions needed to be taken by the guardian or conservator; (vi) the suitability of the proposed guardian or conservator; and (vii) the best interests of the respondent.

Va Code Ann 64.2-2007(c)

# “INCAPABLE” AND “NECESSARY”

- How do you know?
- In the VAST majority of cases, the court should not assume that, just because a person has a particular diagnosis, s/he is “incapable.”
- Unless there is evidence that something was tried to make the person “capable,” how can you know, but clear and convincing evidence, that the person isn’t?



# THINK ABOUT “CAPACITY”

- People may have “capacity” to make some decisions but not others.
  - Or be able to make decisions some times but not others.
  - Or be unable to make decisions unless they get help understanding the decision to be made.
- Salzman, 2010

So...

If people only have the “capacity” to “meet” their needs or “manage” their finances **with assistance or support**, are they incapacitated?

ARE YOU?

# 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

# THE PRACTICAL METHOD BY AMERICAN BAR ASSOCIATION

**PRESUME** that guardianship is not needed.

**REASONS** for concern – “What’s the problem?”

**ASK** if the problem is temporary or easily addressable- “What’s the root cause?”

**COMMUNITY** Connect with resources – “What would it take to solve the problem?” and “Who can provide that?”

**TEAM** Has the person already identified people s/he wants to work with?

**IDENTIFY** If the person does not have a team, examine abilities, limitations, wants, needs, and contacts to see if a team can be made or supports provided

**CHALLENGES** Are there potential problems with team members or resources?

**APPOINT** If the person wants to give someone else the power to support or make decisions, help the person do it consistent with his or her wishes

**LIMIT** As a last resort, seek a guardianship limited to **ONLY** those areas the person **cannot** make decisions with or without support

# SUPPORTED DECISION-MAKING CAN HELP PEOPLE “MANAGE” MONEY AND MEET” THEIR NEEDS

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



# CASE LAW

- *Ross and Ross v. Hatch*, Va. Cir. (Newport News), Case No. CWF-120000-426
- *In Re: Ryan Herbert King*, D.C.Sup.Ct. (Probate) Case No.: 2003 INT 249
- *In Re: Tecora Mickel*, DC Probate Case No: 2015 INT 000291;
- *In re: Tanya Powell*, DC Probate Case No. 2015 INT 529;
- *In Re: Beck*: Circuit Court, Wayne County, Indiana, Case No: 89CO1-1011-GU-025;
- *In Re: Conservatorship of Marie Bergum*: Superior Court, Santa Cruz (CA), Case No: 19PR00378;
- *In re: the Guardianship of Tyler Borjas*, Probate Court, Miami-Dade County (FL), Case No.:2017002056GD02;
- *In the Matter of the Guardianship and Conservatorship of Emery Scott Olson*, District Court, Laramie County (WY), Docket No.: No. 45-341

# 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

Older adults provided with support to make decisions regarding treatment for kidney disease showed increased knowledge of the risk, benefits, and symptoms of dialysis, allowing them to make more informed decisions consistent with their personal values.

- Brown, 2017

# 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>

# LAWYERS, YOU'RE ALREADY DOING IT (OR SHOULD BE)

VSB Code of Professional Guidelines

Rule 1.14

When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

# LAWYERS, YOU REALLY SHOULD BE DOING IT

## Rule 1.14, Comment 1

The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. . . . [A] client with diminished capacities often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. For example . . . some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

# OPPORTUNITIES FOR SDM ARE ALL AROUND US

- “Informed consent”
- “Informed choice”
- “Person Centered Planning”

Are ALL forms of SDM!

# SDM OPPORTUNITY

## “LIFE PLANNING”

“It is my and my agent’s intent that we will work together to implement this [Power of Attorney/Advanced Directive/Agreement/Plan]. That means that **I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities.** I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions.”



# 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.”**

# MEDICAL POWER OF ATTORNEY PART 2

“If I am found to be incapable of making my own health care decisions as described above, my attorney-in-fact shall make decisions and take actions on my behalf as directed below or (if not directed below) in accordance with **preferences I made known to her prior to my incapacity. If I had not previously made my preferences known, then, in making any decisions or taking any actions under the terms of this instrument, my attorney-in-fact will first discuss the situation and the decision to be made/action to be taken with me and give primary consideration to my express wishes before making the decision or taking action. If I am not capable of discussing the situation with my attorney-in-fact and I have not previously made my preferences known, my attorney-in-fact must use her best judgement to make the decision I would have made/take the action I would have taken in that situation, even if it is different from what she would have done in that situation.”**

# 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.**

# SDM OPPORTUNITY BANKING

I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts – including checking and savings accounts, as well as credit and debit cards – that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than \$X from any account, write a check for more than \$X, or otherwise cause more than \$X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

# SDM OPPORTUNITY

## END OF LIFE PLANNING

“The Conversation” and “Five Wishes”

A facilitated process where the Person makes decisions about the types of hospice, palliative care, and services s/he wants.

# 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).

**NEVER FORGET:  
DINO, LILLIAN, AND OVER 250 PATIENTS**

Supported Decision-Making  
ONLY works 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

Older adults and People with Disabilities having “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

**National Resource Center for Supported Decision-Making:**  
[SupportedDecisionMaking.Org](http://SupportedDecisionMaking.Org)

**The Burton Blatt Institute at Syracuse University:** [BBI.Syr.Edu](http://BBI.Syr.Edu)

**Jonathan Martinis, Senior Director for Law and Policy:** [JGMartin@Law.Syr.Edu](mailto:JGMartin@Law.Syr.Edu)