

Supported Decision- Making: Protecting Rights, Ensuring Choices

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THERE ARE STUPID QUESTIONS

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, p. 440).

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).

ABOUT THOSE RIGHTS...

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

AND YET: 2,000 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 IN THE US

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make ALL decisions for the person.
- “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).

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

(credit: “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’re ___ years old”
- “Because you’re sick”
- “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)

STUDIES

More than **90%** of guardianships reviewed were plenary (Teaster, Wood, Lawrence, & Schmidt, 2007).

87% of guardianships reviewed were plenary (Lisi, Burns, & Lussenden, 1994).

54% of the cases reviewed resulted in plenary guardianship **but almost no difference between “plenary” and “limited” guardianship** (Millar & Renzaglia, 2002).

NUMBERS

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, p. 354)

WE'VE KNOWN FOR DECADES

- Older adults with more self-determination have improved psychological health including better adjustment to increased care needs.

(O'Connor & Vallerand, 1994)

- People 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)

ONE MORE STUDY

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
- 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).

NATIONAL GUARDIANSHIP ASSOCIATION

“[A]n individual with cognitive challenges is the ultimate decision maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual’s words and behavior to determine his or her goals and preferences.”

- - National Guardianship Association Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, 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

THINK ABOUT IT: “CAPACITY” TO MAKE DECISIONS

- 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.
- Lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity.

(Salzman, 2010)

So...

If a person can make decisions
with assistance or support, is
s/he incapacitated?

ARE YOU?

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

- 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:

- The person's Right to Make Choices on an equal basis with others;
- That a person can receive support in decision-making without giving up his or her Right to Make Choices; and
- People often need assistance in making choices and there are many ways to provide that assistance

(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)

OPPORTUNITIES ARE ALL AROUND US

- “Informed Consent” to medical care
- “Person Centered Planning” in HCBS Waivers
- “The Conversation” and “Five Wishes” for End of Life Planning

NEVER FORGET DINO AND LILLIAN

Supported Decision-Making
ONLY works if people respect
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

EVERY person the “causal agent”
in EVERY decision in his or her
life.

- We all need help making decisions
- Older adults may need more or different help but have the SAME rights

JOIN THE CONVERSATION

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

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