Supported Decision-Making: Protecting Rights, Ensuring Choices
What’s Your Favorite Right?
"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
- 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).
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
“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)
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.
“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
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.”
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”
“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)
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).
Estimated number of adults under guardianship has **tripled** since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).
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, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003)
Women with intellectual disabilities exercising more self-determination are less likely to be abused
(Khemka, Hickson, and Reynolds, 2005)
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).
“[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 it's needed

Just like you and me
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)
If a person can make decisions with assistance or support, is s/he incapacitated?

ARE YOU?
Before seeking or recommending Guardianship:

What Else Have You Tried?
“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)
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
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 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.
EVERY great advance in civil rights fundamentally changed the way “things have always been”
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

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