

The National Resource Center on Supported Decision-Making

Tina Campanella
CEO, *Quality Trust for
Individuals with
Disabilities*
Principle Investigator,
*National Resource
Center for Supported
Decision-Making*

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NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING (NRC-SDM)

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about SDM
- Addressing the issues of people who are aging and people with disabilities
- Linking development and reform efforts throughout the country
- www.supporteddecisionmaking.org

GOALS FOR THE PROJECT

- A national conversation on SDM leading to consensus
- Changing attitudes regarding decision making and capacity
- Local, State and National adoption of SDM as the preferred option for support
- Interdisciplinary support across the lifespan for people of varying abilities, challenges and life situations.
- Increased collaboration and information sharing for implementing the principles of SDM.
- Increased access to a research, training and TA network promoting practices consistent with SDM

THE RIGHT TO CHOOSE

- Life control
- Never losing Legal Capacity
- 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).

RIGHTS=CHOICE

CHOICE=SELF-DETERMINATION

”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

WHAT DO AVERAGE PEOPLE KNOW ABOUT “GUARDIANSHIP” ?

[Namenda XR TV Spot, 'Be a Guardian](#)



WHAT IS THE CURRENT USE OF GUARDIANSHIP?

(credit: “To Collect Debts, Seizing Control Over Patients”
New York Times, 1/25/15)



Dino and Lillian Palermo

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."

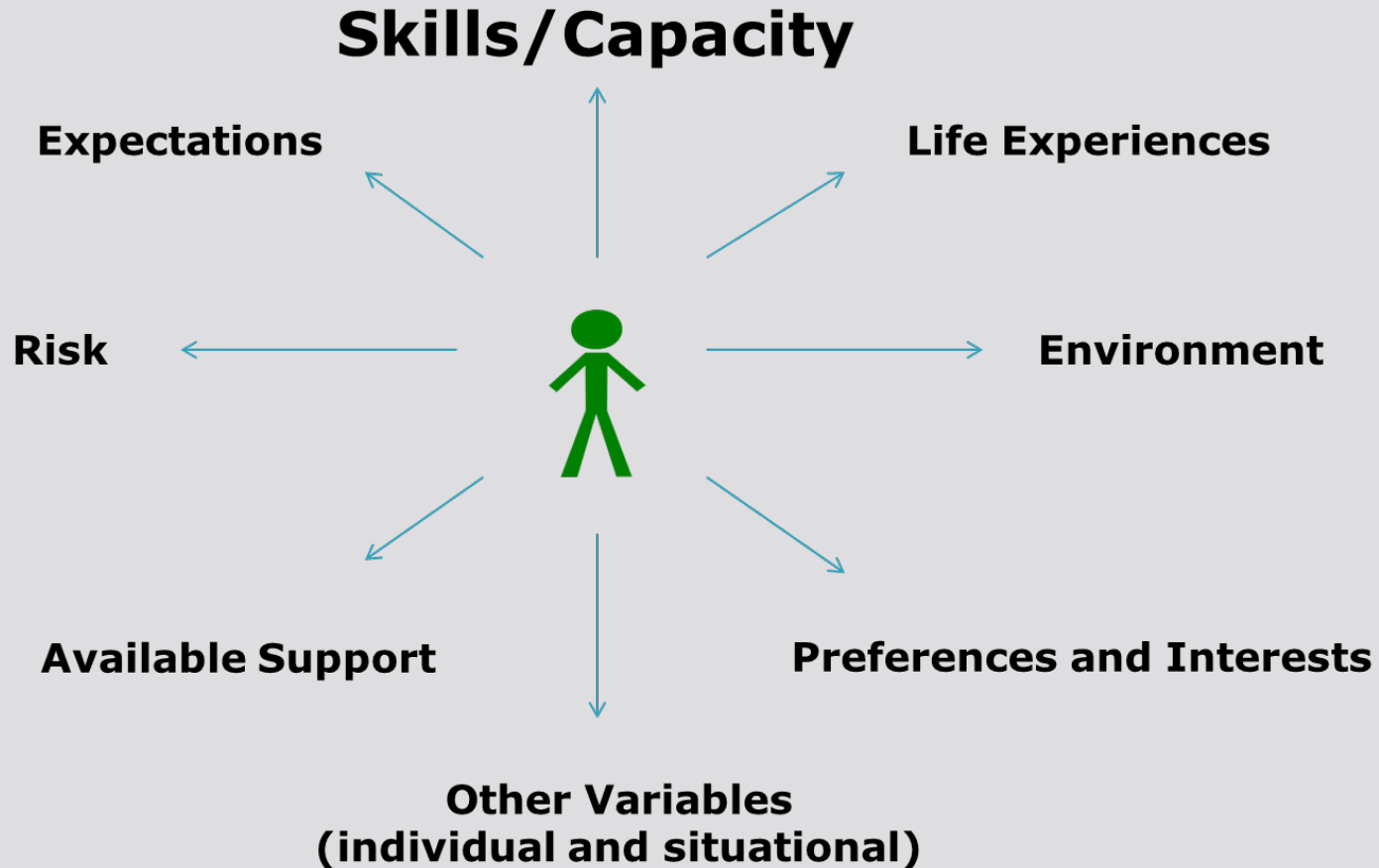
WHAT CHANGES ARE NEEDED TO INCORPORATE SDM INTO PRACTICE?

- How do people develop and maintain good decision-making skills?
- What role and responsibility do professional “helpers” have to support decision-making?
- What about the role of families?
- What should support look like?
- How does guardianship fit in?

ISSUE #1: HUMAN DECISION MAKING

- Many decisions made every day
- Some big, some small
- No standard process or measure of “goodness”
- “Good” decision making seems part science and part art
- Who decides if our decisions are “good”?

ISSUE #2: ASSESSMENT



“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)

ISSUE # 3: TOOLS

- Effective Communication
- Peer Support
- Written Documents
- Agreements
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation

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).

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. Support “may” include:

- Informal support in various forms from friends, family or professionals
- Written agreements, like Powers of Attorney, or Representation Agreements identifying the support needed and who will give it
- Formal structures such as Micro-Boards to assist people to exercise the right to choice

NATIONAL GUARDIANSHIP ASSOCIATION

“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

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)

THE ULTIMATE GOAL

EVERY person is 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(NRC-SDM)**
SupportedDecisionMaking.Org

**Tina M. Campanella, CEO, Quality Trust
Principle Investigator, NRC-SD**
Tcampanella@dcqualitytrust.org

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