

**Supported
Decision-Making (SDM):
Protecting Rights,
Ensuring Choices,
Securing Safety**

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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?

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)

WHAT DO AVERAGE PEOPLE KNOW ABOUT “GUARDIANSHIP” ?

Namenda XR TV Spot, 'Be a Guardian'



WHAT IS THE CURRENT USE OF GUARDIANSHIP?

*To Collect Debts, Nursing Homes Are
Seizing Control Over Patients*



Dino and Lillian Palermo

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)

SUPPORTED DECISION-MAKING

- UN Convention on the Rights of Persons with Disabilities (CRPD), Article 12
- Emphasis on legal capacity as a “right”
- Provides for Meaningful Involvement by the Person needing support in Decision-Making
- Emphasizes self advocacy support and new strategies for safeguards
- Identifies Guardianship as the Most Restrictive Intervention

WHAT HAPPENS NOW?

- Not enough documentation of individual preferences and directives for the future
- Avoidance of direct discussion of the future – especially in families
- Emphasis on compliance with protocols around identified health and medical issues
- Bias toward the use of substituted decision making as a primary support to resolve differences

NUMBERS

Estimated number of adults under guardianship has **tripled** since 1995

(Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

ONE SIZE DOES NOT FIT ALL

Supported Decision-Making “is not a program. Rather, it is a process of working with the person to identify where help is needed and devising an approach for providing that help.”

“The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless.”

Administration for Community Living, **“Preserving the Right to Self-determination: Supported Decision-Making”**

A Paradigm not a Process

Supported Decision-Making relationships can be “of more or less formality and intensity” ranging from informal support by people who “speak with, rather than for, the individual with a disability” to more formalized “micro-board[s]” and “circles of support”

(Dinerstein, 2012)

(Kohn et al., 2013)

USING A SUPPORTED DECISION MAKING APPROACH MEANS....

- People's right to choose is presumed
- Full control of decisions impacting their life, is supported by services and natural support networks;
- Assistance with decision making is available when needed.

THREE CORE ELEMENTS OF SUPPORTED DECISION-MAKING METHODS

- (1) They recognize the person's right to make decisions on an equal basis with others;
- (2) They recognize that people can create a decision-making process that does NOT result in the removal of their decision-making rights; and
- (3) They recognize that people will often need assistance in decision-making through various means

(Dinerstein, 2012)

COMMON SUPPORTS

- (1) To understand relevant information, issues, and available choices;
 - (2) To focus attention in making decisions
 - (3) To help weigh options;
 - (4) To ensure that decisions are based on their own preferences
 - (5) If necessary, to interpret and/or communicate decisions to other parties.
- (Salzman, 2011)

WHERE CAN WE INCLUDE THEM?

ANYWHERE!

Elements of Supported Decision-Making can be included in any document where a person needs to make decisions.

Remember: It's a Paradigm, not a Process

SO, WHAT NEEDS TO CHANGE?

- Thinking about decisions and decision – making
- Thinking about capacity and support for decision-making
- Thinking about the array of options for decision-making support

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”?

IMPROVING DECISION MAKING

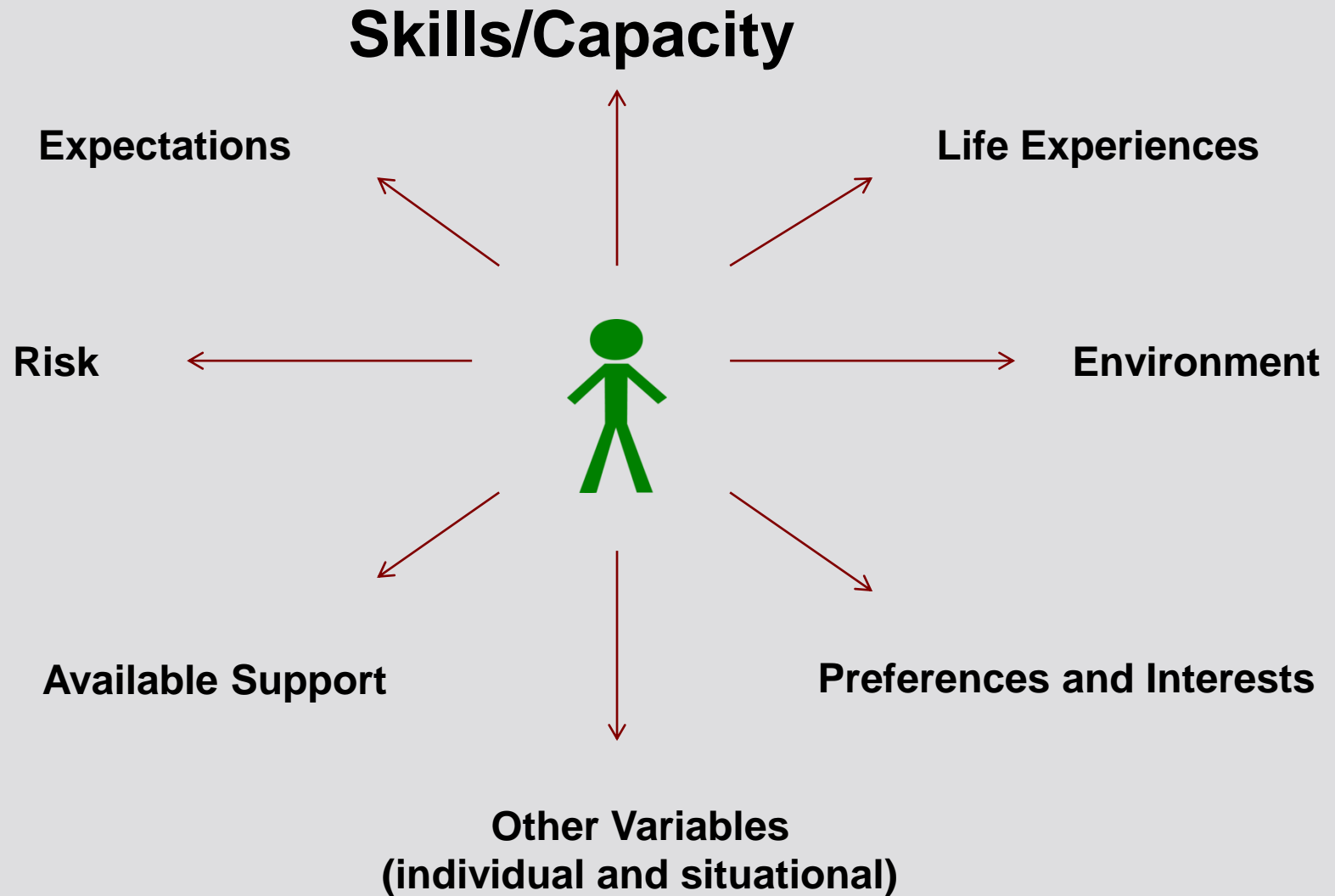
Poor decisions often:

- Focus on limited aspects of a problem or situation
- Consider only immediate benefits
- Oversimplify issues ie., good/bad, right/wrong
- Are influenced by emotional factors
- Are reactive

Better decisions often:

- Reflect an understanding of different perspectives
- Focus on both short and long range goals
- Look at multiple potential outcomes
- Include a process for analysis and thinking
- Use tools and resources for making decisions

Issue #2: Assessment



ISSUE # 3: TOOLS

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



NATIONAL ASSOCIATION ON GUARDIANSHIP – POLICY ON SDM

- NGA supports maximizing the participation of the person and providing every opportunity for the person to exercise rights.
- Encourage every person under guardianship to exercise rights retained and participate in all decisions that affect him or her, to act on his or her own behalf in all matters in which the person is able to do so, and to develop or regain his or her own capacity when possible.
- SDM should be considered for the person **before** guardianship, and the SDM process should be incorporated as a part of the guardianship if guardianship is necessary.
- SDM occurs when the person is the ultimate decision maker with support from one or more persons who explain issues to the individual or interprets the individual's words and behavior to determine his or her goals and preferences.

AND FINALLY.....

- Every guardianship should be focused on the person and grounded in demonstrating respect for the dignity of all involved.

REAL LIFE SCENARIO

Person and parent are considering entering into Power of Attorney with Supported Decision-Making language

Parent is:

- 82
- Has signs of dementia
- Health is declining

Capacity to enter into the POA or Not?

CRITICAL QUESTIONS

How do you know?

What did you review?

What practical steps did you take to determine capacity?

CRITICAL ISSUES FOR FAMILY MEMBERS

- Explore the connection between decision-making and life experience
- Develop a vision for the future
- Have a plan...don't wait until an important decision must be made
- Understand all options for decision support
 - Power of attorney
 - Trusts
 - Representative Payee
 - Supported Decision-Making (SDM)
 - Guardianship

SAMPLE LANGUAGE

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. 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.”

FINANCIAL ISSUES

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.

ETHICAL CONSIDERATIONS

“A guardian shall exercise authority **only as necessitated by the ward’s limitations** and, to the extent possible, shall encourage the ward to participate in decisions, act on the ward’s own behalf, **and develop or regain the capacity to manage the ward’s personal affairs**. A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian.”

Uniform Guardianship Act, Section 314(A)

Another Scenario

Person is:

- 75 years old
- Lives alone in own home
- Receives no formal in-home support

The children are concerned about Dad's ability to manage his daily living and finances. They are especially concerned about his smoking and driving – so are considering guardianship.

THINGS TO THINK ABOUT

What are your Ethical Obligations?

If You Recommended Guardianship, shape it

If you Recommend an alternative, shape it

What influenced your decision most?

What methods did you use to come to your decision?

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)

REMEMBER THE CHALLENGE

EVERY great advance in civil rights fundamentally changed the way “things have always been”

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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