Supported Decision-Making (SDM)

National Resource Center for Supported Decision-Making

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INTRODUCTIONS

- Me
- Quality Trust
- National Resource Center on SDM
- Your turn….

Background

- UN Convention on Rights of People with Disabilities
- Margaret "Jenny" Hatch won a landmark legal battle protecting her right to make her own life decisions using SDM, instead of being subjected to guardianship
- Invitational Symposium on Supported Decision-Making

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Supported Decision-Making

- Emphasis on legal capacity as a "right"
- Provides for Meaningful Involvement by the Person needing support in Decision-Making
- Discusses the needs for self advocacy support and new strategies for safeguards
- Identifies Guardianship as the Most Restrictive Intervention

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National Resource Center on Supported Decision Making (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

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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).

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Guardianship

- What is it?
- Why do it?
- What are the benefits and drawbacks?

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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

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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)

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What do average people know about "guardianship" ?

Namenda XR TV Spot, 'Be a Guardian'

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What is the current use of guardianship?

To Collect Debts, Nursing Homes Are Seizing Control Over Patients

Dino and Lillian Palermo

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Guardianship Facts

- Guardianship is a legal action that removes some or all decision-making from an adult
- It is based on a decision that the adult person to be placed under guardianship lacks capacity for decision-making
- Guardianship is held by the court and an agent is appointed and called the "**guardian**."
- It can vary in **scope** -- time-limited vs. permanent; general vs. limited.
- Guardianship laws vary by state

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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)

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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

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Numbers

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

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

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One Size Does NOT Fit All

- There are many ways to support people to make decisions
- Guardianship AND SDM are both "tools" to be used to assist people
- Goal = right tool, in the right amount, at the right time for each person

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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)

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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

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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)

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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

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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).

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Common Supports

(1) Help people to understand relevant information, issues, and available choices

(2) Focus attention in making decisions

(3) Assist people to weigh options

(4) Base decisions on preferences and expressed desires

(5) Facilitate interpretation and communicate decisions

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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?

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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"?

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"Enemies" of Good Decisions

- Addressing the wrong question
- Looking only for information that "confirms" our thinking
- Emotions
- Being too confident
- Lack of engagement
- No creative exploration of options

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Bernie

Bernie is 52 years old and has lived in supervised settings all his life. He has finally achieved his goal of living in his own apartment with just drop in staff. He has many skills, is eager to learn but has never lived on his own. He does not always identify the things he needs help with. Staff learns about this after things have gone wrong, such as….

- He has been bouncing checks for rent because he has withdrawn money using the ATM card.
- He has been inviting people over to his apartment that staff are worried are taking advantage of him. One young man moved in and had other friends over to party.
- He isn't keeping his apartment clean and has no schedule to follow.

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Denice

Denice is 42 and lives in an apartment with a roommate. She has lived there for just about two years. She uses a wheelchair and needs assistance with most all daily living activities. She does not work, although she does attend a "day program".

Her roommate is a friend that she wanted to live with and moved to this apartment with from the group home. She says she now wants a change because she is unhappy with being told what to do and having to spend all her time with her roommate. When asked what she wants, she responds "I want to move. I don't like it anymore." She can't really describe what it is she wants because her experience is so limited having lived in an institution and group home for most of her life.

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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

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CONSCIOUSLY SUPPORT PEOPLE TO DEVELOP DECISION-MAKERS

- Involve youth in decisions early
- Support decision-making skill development
- Use the support approach that imposes the least restriction on rights
- Benchmark to the process and experience of typical young people
- Always plan ahead – documenting and updating plans as the person's preferences develop

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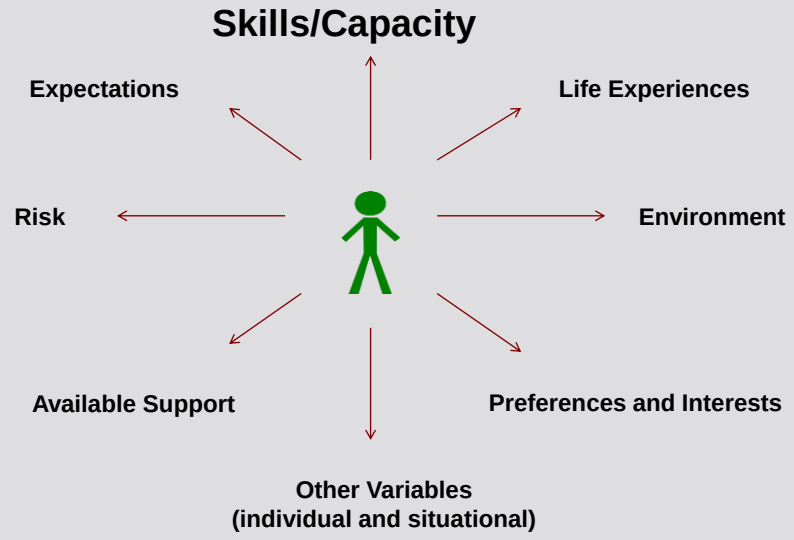
Issue #2: Assessment



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Consider this Real Life Scenario

Mom is considering pursuing guardianship when her son turns 18 to make him stay in school.

Person is:

- 16
- Has Autism and Mental Health Issues
- Has a tested IQ of 76

What issues need to be discussed?

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Another Real Life Scenario

Parents say they've been recommended to seek guardianship - but want their young adult son to develop independent living skills.

Person:

- Is 19 years old
- Has Intellectual Disabilities
- Has limited verbal abilities

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One more scenario…

Person is:

- 25 and has intellectual disabilities
- does not have a job and does not want to work
- is living on her own and does not follow her budget

Parents are concerned about her ability to manage daily living and finances. They are not sure what to do….what should they try?

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Critical Questions

- How do you assess capacity for decision-making?
- How do you determine what support will help?
- What practical steps do you take to help?
- What do you recommend if you believe the person lacks capacity?

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Your Turn

- What people or situations are most challenging in your experience?
- What resources or types of resources would be most helpful to you?
- Other questions?

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Remember

- Capacity and competence are not "black and white"
- A person may be able to make some decisions and not others
- Or they can make decisions at some times, but not others

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Issue # 3: Tools

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

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Learning to Listen

- Not being able to talk doesn't mean you don't have anything to say
- Not know how to express yourself should not mean you are ignored
- Everything people do communicates
- Our job as supporters is to move beyond assumptions
- Try many different approaches until one works

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Peer Support

- Occurs when people provide knowledge, experience, emotional, social or practical help to each other
- Creates relationships where people learn and grow together
- Exposes people to others with relevant experience from people who have experienced similar situations

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Life Coaching

- Is NOT therapy, consulting, counseling, or advice.
- Is a process priorities in the person's life
- Helps the person discover barriers, challenges and select a course of action in to make life better
- Involves a relationship between the coach and the person of them, giving all the power to the person.
- Believes that the person knows the answers to questions or problems he or she may be facing in his or her life
- Asks questions to empower people to help them get to the answers already have within

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Mediation

- A voluntary, collaborative process that uses a trained, neutral third party to facilitate the negotiation of disputes
- The goal is to reach an agreement that everyone supports
- Each participant has complete decision-making power and a veto over each and every provision of any mediated agreement

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SDM Around the World

- UN Convention has many places thinking about decision-making supports
- The United Nations Handbook on the CRPD recognizes that supported decision-making can take many forms
- The common goal is seeing the a person with significant disabilities as someone capable of exercising his/her legal capacity

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SDM IN SWEDEN

PO-Skåne or Personal Ombudsman is a national system (2000) that provides supports in decision-making for persons with severe mental or psychosocial disabilities.

The Personal Ombudsman is a professional who…

- Establishes a relationship with the person
- Assists the person to take control of their life
- Does NOT make decisions for the person but does represent the person
- Must be 100% on the side of the person

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SDM IN THE UNITED KINGDOM…

Mental Capacity Act (2005) includes:

- A **presumption of capacity**
- The **right** to be supported to make decisions
- The **right to make what might be seen as eccentric or unwise decisions**
- Anything done for or on behalf of people without capacity must be in their **best interests**
- Anything done for or on the behalf of people without capacity should be the l**east restrictive of their basic rights and freedoms**

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SDM in British Columbia

Representative Agreement

- A person with cognitive challenges authorizes a third party to act on his or her behalf for a broad range of personal and financial decisions
- The person retains legal capacity, must be consulted by the representative,
- And can revoke the agreement at any time

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So what do YOU think?

- About practices that need to change?
- About challenges that need to be addressed?
- About barriers that will impede the implementation of SDM principles?

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Final Thoughts…..

All support should be focused on the person and grounded in demonstrating respect for the dignity of all involved.

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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.

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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

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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

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Remember The Challenge

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

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Remember The Goal

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

- We all need help making decisions
- People with disabilities and older adults may need more or different help but have the SAME rights

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Stay Tuned…..

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