

**SUPPORTED
DECISION-MAKING
AND THE ROLE OF SIBLINGS**

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

TODAY

- What decisions does your brother or sister make everyday in his or her life?
- What decisions do they need help with?
- What kind of help do they need?
- What questions do you have?

What is Supported Decision-Making???



SUPPORTED DECISION-MAKING

- An approach to assisting people with making life decisions that mirrors how everyone makes decisions.
- Giving people the help they need and want to understand the situations and choices they face, so they can make their own decisions.
- Starts with acknowledging that people with disabilities and older adults have the right to make their own decisions

WHY SUPPORTED DECISION-MAKING?

- The “right” to make choices is fundamental
- We all need help sometimes
- Support needed may be different for different decisions or at different times
- Best practice ALWAYS considers the person’s opinion and preferences (even in guardianship)

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

JAY SMITH

Jay Smith is 52 years old and has lived at home with his parents all his life. His Dad passed away last year and Mom wanted him to try living on his own. He recently moved to his own apartment with just drop in staff. He has many skills, is eager to learn but has never lived on his own. The following events have happened during the first 6 months on his own....

- He has bounced checks for rent because he has withdrawn money using the ATM card.
- He has been inviting people over to his apartment that that no one else knows.
- He isn't keeping his apartment clean and on more than one occasion has run out of food.
- He has a job, but has recently been calling in sick.

HUMAN DECISION-MAKING



- Typical decision-making is flawed
- No standard process or measure of “goodness”
- Culture and personal values are important
- History, experience and relationships often reflect personal preference and identity
- “Good” decision making seems part science and part art
- Brain and decision making science are deepening our understanding of ways to help

CAPACITY....



- 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)

RELATIONSHIPS...



- Support networks can contribute in positive or negative ways
- Family is dynamic
- Paid vs Unpaid Support
- Higher number of relationships can act as a safeguard



WHAT DOES A SUPPORTER DO?

- Make information accessible
- Help research and explain options
- Attend appointments or meetings
- Facilitate communication with others
- Defend right to choice
- Provide “moral support”
- And....much more!!

BEING AN EFFECTIVE SUPPORTER

- Have clear boundaries
- Ground action in respect
- Focus on what can be done
- Seek common ground
- Manage the role of emotion



HEALTHY ADULT RELATIONSHIPS

- Talk about respect and boundaries
- Expect differences of opinion and world view
- Make room for change
- Focus on the present and future (not the past)
- Think about how to disagree

DO THIS SOUND FAMILIAR?

Sarah Majors just turned 40. She has Down Syndrome and her Mom and Dad have had been her guardians since she was 18. Mom and Dad are now in their late 70's and are looking to Sarah's two brothers to assume responsibility for assisting Sarah with decision-making. Where should they start?

CONTINUUM OF DECISION-MAKING SUPPORTS

- Supported Decision-Making
- Advance Directive &/ or Power of Attorney
- Representative payee
- Other Substitute or Surrogate Health Care Decision Maker, depending on state law
- Court-appointed Guardian and/or Conservator
 - Temporary or Permanent
 - General/Plenary or Limited

TOOLS THAT ADVANCE SDM

- Effective Communication
- Informal or Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation



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

LIFE COACHING

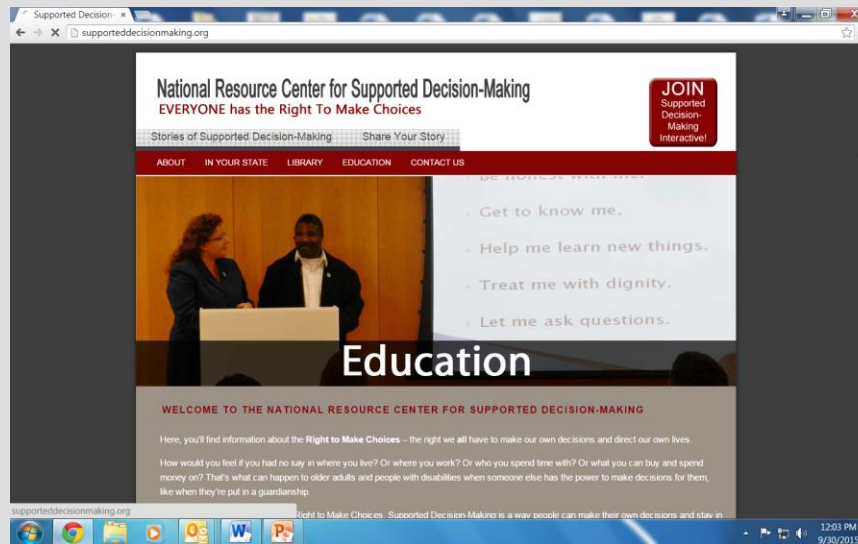
- Is NOT therapy, consulting, counseling, or advice.
- Focuses on identified priorities in the person's life
- Helps the person discover barriers, challenges and select a course of action in to make life better
- Involves a facilitative relationship between the coach and the "client"
- Assumes that the person knows the answers to questions or problems he or she may be facing in his or her life
- Asks questions to empower the person to discover their own answers

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING

- Funded in 2014 by the **Administration on Community Living** and led by **Quality Trust**
- Focused on **Research, Training and Information Sharing** about Supported Decision Making (SDM)
- Addressing the issues **of older people and people with disabilities**
- **Linking** development efforts throughout the country
- www.SupportedDecisionMaking.org

WWW.SUPPORTEDDECISIONMAKING.ORG

- Resources state by state
- References useful by topic
- Links to tools and projects



FINDING A PATH FORWARD....

- Be proactive
- Assess each person's situation
- Identify opportunities for
 - Learning more about options
 - Including people in all decisions
 - Respecting the person as the decision-maker
 - Having family discussions about what works (and doesn't)

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)

<https://www.guardianship.org/>

IN CLOSING....

- One strategy won't fit all situations
- Decision-making requires learning and adaptation throughout life
- We all need support sometimes
- The right to make choices is a fundamental human right!!!!



JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making

www.SupportedDecisionMaking.org

202-448-1448

JHJP@DCQualityTrust.Org

Tina M. Campanella

TCampanella@DCQualityTrust.org

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