WHAT TOOLS TO USE?

DECISION-MAKING SUPPORTS FOR PEOPLE WITH DISABILITIES AND OLDER ADULTS

Tina M. Campanella
CEO, Quality Trust for Individuals with Disabilities

Morgan K. Whitlatch
Lead Project Director, National Resource Center for Supported Decision-Making!
Your life decisions were called into question by people close to you?

Your personal choices were used as “evidence” that your decision-making capacity was not adequate or in decline?

Concerns about your health or safety were determined to be more important than your personal history, beliefs, heritage and preferences?
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

wwwSupportedDecisionMaking.org
GOALS FOR THE PROJECT

- Build **national consensus** on SDM
- **Change attitudes** regarding decision making and capacity
- Identify and develop **principles and tools for interdisciplinary support** across the lifespan for with people of varying abilities, challenges and life situations.
- **Increase collaboration** and information sharing for implementing of SDM principles.
- Bring together **training and technical assistance network** promoting practices consistent with SDM
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.
• The shift from “surrogacy” to support is consistent with the Older Americans Act, ADA DD Act and other regulatory and legal requirements
• Trusted people may be fewer as we age
• Ageism and disability bias are real
• Risk of undue influence may increase over time
• Institutions are “risk adverse”
• Safeguards linked to “protection” may eliminate control
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
MOST LIFE DECISIONS ARE PERSONAL

YOU CAN'T JUDGE MY CHOICES WITHOUT KNOWING MY REASONS

diaryoflittlesecrets
CRITICAL QUESTIONS

- How do you assess capacity for decision-making?
- How do you determine which supports will help?
- What practical steps can you take to help?
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. (Salzaman, 2010)
Our inherent value and worth as a human beings
Honors person’s unique identity
Preserves any existing capacity
Ensures access to accommodation as needed

Indignity = degradation, debasement or humiliation
Support networks can contribute in positive or negative ways
Family is dynamic
Paid vs Unpaid
Higher number of relationships can act as a safeguard
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
**What is “Guardianship” for Adults?**

- **Guardianship is:**
  - A *formal legal step* that removes some or all decision-making from an adult and assigns it to a fiduciary, called a “guardian.”

- To be a guardian over an adult, a person has to go through a *court process* and get a *court order*.

- It can vary in *scope* -- time-limited vs. permanent; general vs. limited.
Guardianship laws vary by state.

Uniform Guardianship & Protection Proceeding Act:

Guardianship is ordered when:

1) An adult lacks “capacity” to make decisions for him or herself; AND

2) The person’s identified needs cannot be met by less restrictive means
Why do people think about getting guardianship?
Why do people think about getting guardianship?

Parents, family members, support teams may:

- Have been told by the person’s doctor or health/home care provider to do so.
- Be concerned about:
  - health care and access to a doctor.
  - financial abuse
  - linking the person to available services
- See the person in crisis or an emergency.
Why should you think about other options first?

- Guardianship takes away some or all of a person’s rights to make important decisions about his or her life.

- The court will become part of both the guardian’s and the person’s life going forward.

- Guardianship can change relationships.

- Guardianship can take time and cost money.

- For many people with disabilities, decision-making should be seen as a learned skill – people need the opportunity to practice!
Rights that May be Lost or Affected by Guardianship

- Voting
- Marriage and reproductive rights
- Residence and travel
- Association
- Health care and medical decisions
- Access to own money
- Right to contract
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)

People with greater self-determination are:
- More **independent**
- More **integrated** into their communities
- **Healthier**
- Better able to **recognize and resist abuse**
When denied self-determination, people can:

- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick 1995, p. 21).

Decreased Life Outcomes

- Overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354)
Students with disabilities who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997).

Older adults with more self-determination have improved psychological health, including better adjustment to increased care needs (O’Connor & Vallerand, 1994).
People with intellectual and developmental disabilities who do not have a guardian are more likely to:
- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the religion of their choice

(National Core Indicators, 2013-2014)
Guardianship has been the default option for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).

Estimated number of adults under guardianship has tripled since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

90% of the public guardianship cases reviewed resulted in plenary/general guardianship - where the guardian is empowered to make all decisions for the person. (Teaster, Wood, Lawrence, & Schmidt, 2007)
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 have an IQ of ____”
- “Because you are elderly”
- “Because you have _____ diagnosis”
- “Because you need help”
- “Because that’s the way it’s always been”

That’s not enough!
Finding the Right Support:
- What kind of decision needs to be made?
- How much risk is involved?
- How hard would it be to undo the decision?
- Has the person made a decision like this before?
- Is the decision likely to be challenged?

Ask: What is the least restrictive support that might work?
Supported Decision-Making “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”
“Ryan is a whole person. We want him to be whole. The decision process is part of being whole . . . If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him.**”

– Herbert King

For more on Ryan’s story, visit http://www.supporteddecisionmaking.org/impact-stories/ryan-king
SDM Tools

- Effective Communication
- Informal or Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation
**Written Documents**
- Release of Information forms – “HIPAA” or “FERPA”
- Other Written Plans

**Written Agreements**
- Model Forms: [http://supporteddecisionmaking.org/node/390](http://supporteddecisionmaking.org/node/390)

**Supported Decision-Making Guides**
Remember: U.S. Americans with Disabilities Act

- Provides **civil rights protections** for people with disabilities, including requiring “**reasonable modifications** to policies, practices, and procedures” to avoid discrimination.

- Link to *Olmstead v. L.C.*
  - Greater Self-Determination = Greater Community Integration
  - People with Intellectual and Developmental Disabilities who do not have a guardian are more likely to have a **paid job**, **live independently**, have friends other than staff or family go and dates and **socialize in the community**, and practice the religion of their choice. (2013-2014 National Core Indicators)
# NRC-SDM State Grantees

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For **final reports** and links to related **SDM resources**, visit: [http://www.supporteddecisionmaking.org/node/425](http://www.supporteddecisionmaking.org/node/425)
NRC-SDM Delaware Grantee
## More SDM Trends in U.S.

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## Other Policy and Practice Initiatives

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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
What is a POA?

A legal paper where an adult ("principal") agrees that someone else (an "agent" or "attorney-in-fact") will make decisions for him/her under certain circumstances and in certain areas of his/her life.

How’s a POA different from guardianship?

- The principal decides what power to give away and who gets it, not a court.
- The principal can cancel or change the POA.
Health Decision
- Deciding to have open heart surgery

Health Care Power of Attorney
- Deciding who you would trust to make that decision for and with you.
Forms and Requirements **Vary by State**

- **May be broad or narrow** in scope (financial, educational, health care, etc.)
- **May be limited** in time or purpose
- Without a special provision ("**durability clause**"), the POA authority generally ends if the principal becomes unable to make decisions.

**A POA may go into effect:**

- Immediately
- At a later specified date
- At a specified future event
CONTINUUM OF DECISION-MAKING SUPPORTS

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- **Representative payee**
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What are options that can be used for decisions about finances?

- Supported Decision-Making
- Direct deposit and payment
- Joint bank accounts
- Financial power of attorney
- Representative payee
  - Manages a person’s social security benefits and is appointed by the Social Security Administration, not a court.

- Trusts
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

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STATE HEALTH CARE DECISIONS ACTS

- Varies from state to state

- See ABA Commission on Law and Aging, “Default Surrogate Consent Statutes” by State (Sept. 2016)
  - Available at: http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf
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“Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”

SDM Principles Within Guardianship

“Under all circumstances, efforts should be made to encourage every person:
- to **exercise his/her individual rights** retained and participate, to the maximum extent of the person's abilities, 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** to the maximum extent possible.”

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!!!
National Resource Center for Supported Decision-Making
www.SupportedDecisionMaking.org
202-448-1448
JHJP@DCQualityTrust.Org

Tina M. Campanella
TCampanella@DCQualityTrust.org

Morgan K. Whitlatch
MWhitlatch@DCQualityTrust.org
*Licensed to Practice Law in D.C. and Maryland
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