

SUPPORTED DECISION-MAKING:

Empowering Older Adults with Intellectual Disabilities

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WHAT IF....

- 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?

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

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

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

WHAT WE KNOW

- The **shift from “surrogacy” to support** is consistent with the Older Americans Act, ADA, DD Act, and other 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 **personal control**

HUMAN DECISION-MAKING

- Typical decision-making is flawed
- No standard process or measure of “goodness”
- Culture and personal values are important
 - Most life decisions are personal
- 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

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?

CAPACITY....

- **Capacity is not “all or nothing”**
 - 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.
- A **lack of opportunity** to make decisions can prevent people from developing capacity or **further decrease capacity**. (Salzman, 2010)

Skills/Capacity

Expectations

Life Experiences

Risk

Environment

Available Support

Preferences and Interests

Other Variables
(individual and situational)



DIGNITY...

- Means our **inherent value and worth** as human beings
- Honors a person's **unique identity**
- **Preserves** any existing capacity
- Ensures **access to accommodation** as needed

Indignity = degradation,
debasement or humiliation

RELATIONSHIPS...

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

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 disabilities with greater self-determination are:**

- ▶ More **independent**
- ▶ More **integrated** into their communities
- ▶ **Healthier**
- ▶ Better able to **recognize and resist abuse**

(Powers *et al.*, 2012; Shogren, Wehmeyer, Palmer, Rifenshark, & Little 2014; Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

SELF-DETERMINATION...

- **Older adults with more self-determination** have improved psychological health, including better adjustment to increased care needs (O'Connor & Vallerand, 1994)
- **When denied self-determination**, people can:
 - “[F]eel **helpless, hopeless, and self-critical**” (Deci, 1975, p. 208).
 - Experience “**low self-esteem**, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).

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

GUARDIANSHIP IN THE US

“Plenary” or “Full” Guardianship

- Gives the Guardian power to make **ALL** decisions for the person.
- Used in the **vast** majority of cases (Teaster, Wood, Lawrence, & Schmidt, 2007).
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**” (Frolik, 1998)
- **Most commonly recommended** course of action by professionals (Jameson, et al. 2015)

AS A RESULT

Guardians have “**substantial and often complete authority** over the lives of vulnerable [people].”

4 NAELA J. 1, 7 (2008).

This includes **power** to make the most basic health, personal, and financial decisions.

AARP, Guardianship Monitoring: A National Survey of Court Practices 1-2 (2006).

GUARDIANSHIP IN THE U.S.

- Estimated number of adults under guardianship has **tripled** since 1995
 - (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).
- **Publicity** of overuse/misuse of guardianship
 - Public Source Article (2013):
<http://publicsource.org/as-pa-ages-the-state-examines-guardianships-and-abuse/>
 - GAO Report on Guardianship & Elder Abuse (2016): <https://www.gao.gov/products/GAO-17-33>

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)
- ▶ **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 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 older”
- “Because you have _____ diagnosis”
- “Because you need help”
- “Because that’s the way its always been”

That’s not enough!

EXPLORE ALTERNATIVES FIRST

■ 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?

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
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SUPPORTED DECISION-MAKING: WHAT?

- Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to:
 - **Help understand** the issues and choices;
 - **Ask questions**;
 - **Receive explanations** in language he or she understands; and
 - **Communicate** his or her own decisions to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

SUPPORTED DECISION-MAKING: WHAT?

- There is **no “one size fits all” method** of Supported Decision-Making
- **It is a paradigm**, not a process or program
 - It means working with the person to identify where help is needed and finding a way to provide any help that’s needed.
 - Solutions are different for each person.
 - The key question is “what will it take?”

IN OTHER WORDS. . .

- 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”

COMMON CONSIDERATIONS

- All forms of SDM recognize:
 - The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others;
 - That **a person can take part in a decision-making process** that does not remove his or her decision-making rights; and
 - **People will often need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein, 2012)

SUPPORTED DECISION-MAKING: HOW?

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



SDM TOOLS (CONT.)

- Written Documents
 - Release of Information forms – “HIPAA” or “FERPA”
 - Other Written Plans
- Written Agreements
 - Model Forms: <http://supporteddecisionmaking.org/node/390>
- Supported Decision-Making Guides
 - <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- Plan for the Future!

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

PA CASE LAW

- **In re Peery**, 727 A.2d 539 (Pa. 1999) – Reversing guardianship order because the person “has in place a **circle of support** to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety”

SUPPORTED DECISION-MAKING: OPPORTUNITIES ABOUND!

- ▶ **Informed Consent** in Medical Care
- ▶ **Person Centered Planning** in the Medicaid World
- ▶ **Financial Planning**
- ▶ **Informed Choice** in Vocational Rehabilitation
- ▶ **Within the Guardian/Person or Substitute Decision-Making Relationship**

For Archived Webinars on the above, visit:

<http://www.supporteddecisionmaking.org/education>

EXAMPLE: SDM IN HEALTH CARE

Key Concept: “Informed Consent”

Like “Capacity” is to guardianship, **informed consent** is the lynchpin of self-determination in medical care

Three Key Parts:

- **Information** to the person
- **Understanding** by the person
- **Choice** by the person

SDM IN HEALTH CARE

- **Assistance** can be provided to help the person make medical decisions:
 - **“Explain that to me in English”**
- Doctor must **reasonably accommodate** the person’s disability when obtaining his or her informed consent
- Role of **“HIPAA” Release Forms**
- Remember that the ability to make decisions is a **continuum** – ex.: flu shot versus open heart surgery.

ENABLE INFORMED CONSENT IN WAYS THAT:

- **Are Flexible**
- **Improve Dr-Patient communication and collaboration**
- Increase the **role of family, friends, and people close** to the person
- **Plan** for the Future

NRC-SDM STATE GRANTEES

2015 - 2016

DE – Led by Delaware Developmental Disabilities Council

IN -- Led by The Arc of Indiana

ME -- Led by Disability Rights Maine

NC -- Led by First In Families of North Carolina

WI – Led by Wisconsin Board for People with Developmental Disabilities

For **final reports** and links to related **SDM resources**, visit:

<http://www.supporteddecisionmaking.org/node/425>

2016 - 2017

FL – Led by the Northern Florida Office of Public Guardian

GA – Led by the University of Georgia

ME – Led by Disability Rights Maine

NV – Led by the Second Judicial District Court, State of Nevada, Washoe County

NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)

TN – Led by The Arc Tennessee

MORE SDM TRENDS IN U.S.

State Courts	Enacted State Statutes		State Pilots
PA (1999)	Agreement	TX (2015)	TX Volunteer SDM Advocate Pilot (2012)
NY (2012, 2016)		DE (2016)	TX SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
VA (2013)	Other	DC (2015)	MA SDM Pilot (CPR and Nonotuck Resources Associates) (2014-2016)
MA (2015)		MD (2015)	NY SDM Pilot (2016-2021)
DC (2016)		MA (2016)	ME SDM Pilot (2016-2017)
VT (2017)	Studies	VA (2014)	VT SDM Pilot (underway, state taskforce)
		ME (2016)	

TRENDS IN POLICY & PRACTICE IN U.S.

- **National Guardianship Association (May 2015)** – Policy statement endorsing SDM, advising that it should be used before and within guardianship
 - http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
- **Social Security Advisory Board (March 2016)** – Issue brief recognizing SDM as an alternative to SSA appointment of representative payee.
 - See http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf

TRENDS IN POLICY & PRACTICE IN U.S.

- **Joint AAIDD & Arc Position Statement (2016)** – “Autonomy, Decision-Making Supports, and Guardianship”
 - See http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
- **ABA PRACTICAL Tool (2016)** – Developed with the assistance of NRC-SDM, this tool helps lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship.
 - See http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

UNIFORM LAW COMMISSION

- Revisions to **Uniform Guardianship and Protective Proceedings Act**
 - Draft language will include recognition of SDM
 - Revisions to the Act will have to be approved by the Uniform Law Commission
 - [http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act](http://uniformlaws.org/Committee.aspx?title=Guardianship,Conservatorship,andOtherProtectiveArrangementsAct)

DEVELOPMENTS IN RESEARCH

- **NRC-SDM Sponsored Studies**
 - To determine best practices in SDM
 - To determine whether use of SDM is correlated with improved life outcomes.
- **NRC-SDM Survey** on Supported Decision-Making in Practice
 - <http://www.supporteddecisionmaking.org/node/396>
- **National Council on Disability** – Developing a report that examines guardianship and alternatives in view of the goals of the Americans with Disabilities Act.

DEVELOPMENTS IN EDUCATION & OUTREACH

- **NRC-SDM has presented at events** to thousands of people and provided **technical assistance** on SDM initiatives across the country.
- **NRC-SDM has archived webinars** on moving SDM from theory to practice in education and youth in transition; vocational rehabilitation; services, supports, and health care; finances; etc. (**www.SupportedDecisionMaking.org**)
- **NRC-SDM Listserv**, “Supported Decision-Making Interactive!”

TO REACH THE SDM GOAL:

Every person should be part of every decision about his or her life.

- **We all need help** making decisions.
- People with disabilities may need more or different help, but should be supported to exercise their **Right to Make Choices** in their own lives.

JOIN THE CONVERSATION

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SupportedDecisionMaking.Org

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ABOUT THIS PROJECT

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