

SUPPORTED DECISION-MAKING IN REAL LIFE

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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 their 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**

SUPPORTED DECISION-MAKING

- **“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.”

National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making” (May 2015)
http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf

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BUT WAIT.....

Let's start with
input from you!!!



QUESTION ONE:

What do you think about using
Supported Decision-Making
(SDM) in your work?

QUESTION TWO:



How has your understanding
and/or use of SDM changed
over time?

QUESTION THREE:



What challenges have you experienced or do you expect to see with using SDM with the people you support?



QUESTION FOUR:



What are the biggest barriers you see to using SDM with the people you support?



QUESTION FIVE:



What tools would you like to have to help you use SDM with the people you support?

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?



MR. SMITH

Mr. Smith 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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MR. JOHNSON

Mr. Johnson is 82 years old. He lost his wife 5 years ago and has been living alone in the family home ever since. He has three children who visit occasionally, but is on his own most of the time. Mr. Johnson still drives and goes to his doctor's appointments without any of his kids. His son is becoming concerned about his father's eating habits and adherence to his medication regime. He is also concerned that the house is too much for Mr. Johnson to care for – even with the assistance of a monthly housekeeper and someone to maintain the yard. The son wants Mr. Johnson to sell the house and move in with him. Mr. Johnson says he will only leave the house feet first.

MRS. JONES

Mrs. Jones resides in a nursing home that is closing and all residents are being moved to alternative placements. She does not speak and requires total assistance from nursing home staff. She was known to have a son, but staff indicated that there has been no recent contact with the son. Reportedly phone calls and letters sent did not receive responses. Staff working with Mrs. Jones consider her incapable of making informed decisions regarding her health care and well-being, but there has been no court action on this issue.

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A FINAL SITUATION TO CONSIDER

You are supporting a young woman (28) with ID. She has expressed her strong desire to get married and has a history of getting sexually involved with men she has not known very well.

**How might you support her
with decision-making?**

FINDING A PATH FORWARD....

- Be proactive
- Assess each person's situation
- Identify opportunities for
 - Learning more about options
 - Getting experience with decision-making
 - Respecting the person as the primary decision-maker
 - Involving family and others as supporters

SDM TOOLS

- **Effective Communication**
 - ASAN with the UCF Office of Developmental Primary Care, "Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations
 - <http://odpc.ucsf.edu/communications-paper>
- **Informal or Formal Supports**
- **Peer Support**
- **Practical Experiences**
- **Role Play and Practice**
- **Life Coaching**
- **Mediation**



SDM TOOLS

■ 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>
- <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

PRACTICAL ASSUMPTIONS

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 needs assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein 2012)

SDM WITHIN GUARDIANSHIP

- **“Under all circumstances**, efforts should be made to encourage every person under guardianship:
 - 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.”

National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making” (2015)

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HOW GUARDIANS ADVOCATE

The guardian shall identify and **advocate for the person’s goals, needs, and preferences.**

- 1) The guardian shall **ask the person what s/he wants**
- 2) If the person has difficulty expressing what he/she wants, the guardian shall **do everything possible to help the person express his or her goals, needs, and preferences.**
- 3) **Only when** the person, even with assistance, cannot express his or her goals and preferences, shall the guardian **seek input from others** familiar with the person to determine what the individual would have wanted.
- 4) **Only when the person’s goals and preferences cannot be ascertained**, may the guardian make a decision in the person’s **best interest.**

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LIMITATION/TERMINATION OF GUARDIANSHIP OVER TIME

- Guardians **should seek termination or limitation** when, for example:
 - The person has **developed or regained capacity** in areas in which he or she was found incapacitated by the court
 - When **less restrictive alternatives** exist,
 - When “the person **expresses the desire to challenge** the necessity of all or part of the guardianship,”
 - When “the **guardianship no longer benefits** the person.”
- See *NGA 2013 Standards of Practice #21(III)*.

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NRC-SDM STATE GRANTEEES

2015 - 2016	2016 - 2017
<p>DE – Led by Delaware Developmental Disabilities Council</p> <p>IN -- Led by The Arc of Indiana</p> <p>ME -- Led by Disability Rights Maine</p> <p>NC -- Led by First In Families of North Carolina</p> <p>WI – Led by Wisconsin Board for People with Developmental Disabilities</p> <p>For final reports and links to related SDM resources, visit: http://www.supporteddecisionmaking.org/node/425</p>	<p>FL – Led by the Northern Florida Office of Public Guardian</p> <p>GA – Led by the University of Georgia</p> <p>ME – Led by Disability Rights Maine</p> <p>NV – Led by the Second Judicial District Court, State of Nevada, Washoe County</p> <p>NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</p> <p>TN – Led by The Arc Tennessee</p>

MORE ON U.S. STATE TRENDS

State Courts	Pilot Examples
PA (1999)	TX Volunteer SDM Advocate Pilot (2012)
NY (2012, 2015, 2016, 2017)	TX SDM Law Clinic Pilot (2014 and on)
VA (2013)	MA SDM Pilot (CPR & Nonotuck) (2014-2016)
MA (2015)	NY SDM Pilot (2016-2021)
DC (2016, 2018)	ME SDM Pilot (2016-2017)
FL (2016)	VT SDM Pilot (underway, state taskforce)
VT (2017)	KY My Choice Kentucky
KY (2017)	CA Saks Institute Project
NV (2017)	GA (CPR, Georgia Advocacy Office)
ME (2018)	IN (Disability Rights Indiana)
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For more information, visit <http://www.supporteddecisionmaking.org/statestates>

MORE ON U.S. STATE TRENDS – STATUTES & LEGISLATION

SDM Agreements	SDM as Less-Restrictive Alternative	SDM in Education
TX (2015) (with form)	NM (2018)	DC (2015)
DE (2015) (form 2018)	ME (2018)	TX (2017)
WI (2018) (with form)		
DC (2018) (with form)	SDM in Health Care	SDM Studies
MO (2018) (no form)	MD (2015) (organ transplants)	VA (2014)
AK (pending)	DE (2017) (organ transplants)	ME (2016)
RI (pending)	KS (2018) (organ transplants)	IN (2017)

For more information, visit <http://www.supporteddecisionmaking.org/statestates>

MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
Social Security Advisory Board (2016)	<p>Representative Payees: A Call to Action</p> <ul style="list-style-type: none"> States SSA should consider SDM as an alternative to appointing a representative payee http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
American Bar Association (2016)	<p>PRACTICAL Tool and Resource Guide</p> <ul style="list-style-type: none"> Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM. Being used by social workers at the Center for Excellence in Supported Decision-Making, led by Volunteers of America of Minnesota http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
Uniform Law Commission (2017)	Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA) <ul style="list-style-type: none"> • Model law that, among other things, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship. • http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
American Bar Association (2017)	ABA Resolution 113 <ul style="list-style-type: none"> • Urges legislatures to amend their guardianship statutes to require SDM "be identified and fully considered as a less restrictive alternative before guardianship is imposed" and a grounds for termination of guardianship. • https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf

MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
AAIDD & Arc (2016)	Joint Position Statement on Autonomy, Decision-Making Supports, and Guardianship <ul style="list-style-type: none"> • Promotes less restrictive means of decision-making support, including SDM. • http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
U.S. Department of Education, OSERS (2017)	A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities <ul style="list-style-type: none"> • Recognized SDM and other less-restrictive decision-making support for adult students in special education. • https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf

JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making

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ABOUT THIS PROJECT

This project is supported, in part, by grant number HHS-2014-ACL-AIDD-DM-0084, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.