

SUPPORTED DECISION-MAKING: A LISTENING SESSION

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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

WAIT.....

Let's start with you!!!

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'S A LISTENING SESSION?

- An opportunity to learn from the experience of people in the field
- A way to evaluate what has been accomplished and what still needs work
- A strategy for getting input about ways to help more people who are interested to use SDM as a decision-making tool

THE RULES FOR TODAY

- We will share information – but listening is the primary goal for the session
- There are no wrong answers – we are asking for your input
- All input will be recorded and used
- We are grateful for your time and interest



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?



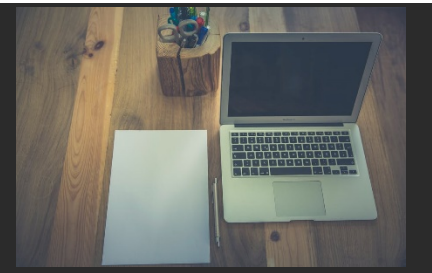
QUESTION FOUR:



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?

No “ONE SIZE FITS ALL”

- 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”

TOOLS THAT ADVANCE SDM

■ 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



MORE TOOLS THAT ADVANCE SDM

■ 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>

NRC-SDM STATE GRANTEEES

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 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)
IN (2018)	

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

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/states>

MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
Social Security Advisory Board (2016)	Representative Payees: A Call to Action <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)	PRACTICAL Tool and Resource Guide <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

THINGS TO REMEMBER....

- 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

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ACL PROGRAMS IMPACTED BY SDM

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The Legal Assistance Network

- The [Legal Assistance for the Elderly Program](#) network can assist older adults in accessing long-term care options and protect older adults against direct challenges to their independence, choice, and financial security.
- [Model Approaches to Statewide Legal Assistance Systems](#) grants help states develop and implement effective approaches for integrating low-cost legal mechanisms into statewide legal/aging service delivery networks to enhance overall service delivery capacity.
- The [National Center on Law and Elder Rights \(NCLER\)](#) empowers aging and legal professionals with the tools and resources they need to provide older clients and consumers with high-quality legal assistance in areas of critical importance to their independence, health, and financial security.

Supportive Services Programs (Title III-B of the OAA)

- Access to services (transportation, outreach, information and assistance, and case management services);
- In-home services (homemaker and home health aides, visiting and telephone reassurance, chore maintenance); and
- Legal Assistance: As SDM practices becomes more prevalent through aging/legal network, attorneys can better address guardianship cases and help avoid unnecessary guardianships all together.

**ALZHEIMER'S DISEASE SUPPORTIVE
SERVICES PROGRAM
AND
ALZHEIMER'S DISEASE INITIATIVE –
SPECIALIZED SUPPORTIVE SERVICES**

Examples of using SDM with Persons with Dementia, Caregiver, and Community Education

- Outreach Specialist implementing a *Crossing Bridges* educational discussion group for people with mild memory loss to educate on memory loss related issues, including future planning.
- Offering legal and financial planning seminars to individuals with mild cognitive impairment/memory loss and Alzheimer's disease and related dementias (ADRD) to provide an overview of legal and financial issues for future consideration.
- Collaboration with hospice & palliative care organization offers Speakers Bureau to the community on various dementia related topics, including end of life and palliative care issues.

Case Management Examples:

- Making Dementia Outreach Specialists available to work with persons with dementia (PWD) and caregivers (CG) to provide education and support and to connect with resources to help plan for the future.
- Care Team Navigator's coach the PWD and caregivers to complete tasks such as advance directives, and referrals for caregiver respite.
- Memory Care Navigators are trained on advance care planning, advanced dementia and resources for palliative care to assist PWD and CG in navigating care options.

Legal Assistance Example

Voucher programs for individuals newly diagnosed with ADRD to consult with attorneys trained in ADRD to begin to plan their future legal needs

OFFICE OF CONSUMER ACCESS AND SELF-DETERMINATION

Aging and Disability Resource Centers

- Raise visibility about the full range of available options
- Empower people to make informed decisions about their long-term services and supports (LTSS) by helping people with all levels of income access public and private programs.

No Wrong Door

- A collaborative effort of the ACL, the CMS, and the Veterans Health Administration (VHA) building on the ADRCs and CMS' Balancing Incentive Program
- Serve as the entry point to publicly administered LTSS, including those funded under Medicaid, the OAA, VHA and state revenue programs
- Supporting state efforts to streamline access to LTSS for older adults and individuals with disabilities. NWD Systems simplify access to LTSS, and are a key component of LTSS systems reform.
- Provides information and assistance not only to individuals needing either public or private resources, but also to professionals seeking assistance on behalf of their clients and to individuals planning for their future long-term care needs.

Transit Planning for All

- A collaboration with the Community Transportation Association of America (CTAA) of Washington, DC, along with Easter Seals, n4a, and Westat
- Establish partnerships with national organizations and people with expertise in planning and developing coordinated transportation systems and with experience empowering people with disabilities and older adults to improve systems;
- Conduct an environmental scan to identify best practices based on scenarios where persons with disabilities and older adults have been actively engaged in the planning, development, and implementation of transportation systems;
- Design and commence implementation of a “small grants” demonstration program to community organizations

AIDD PROGRAMS

Protection and Advocacy Systems

- Each P&A tries to incorporate the SDM into the process for working with clients, particularly those who might have guardians or want to have the guardianship removed.
- Some P&As work with consortiums in their state like WINGS or other organizations that are doing specific support decision making work and policy.

EXAMPLES

- Maine: Disability Rights Maine has a website about SDM with resources and news stories. <http://supportmydecision.org>
- New York: The Developmental Disabilities Council and the P&A are collaborating to educate a wide variety of stakeholders about SDM and, through two pilot projects, to demonstrate how SDM can be used as an alternative to guardianship for people with intellectual or developmental disabilities (I/DD). <http://sdmny.org/wp-content/uploads/2017/08/170509-Factsheet-for-pilot-participants.pdf>
- Texas: Disability Rights Texas has developed a toolkit on SDM. https://www.disabilityrightstx.org/files/The_Right_to_Make_Choices_jan_2018.pdf

THANK YOU

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