SUPPORTED DECISION-MAKING: A LISTENING SESSION

TASH Conference 2018
Independent advocacy and monitoring
- Children and adults with disabilities

Dignity, respect, and autonomy
- Rights protection and decision-making supports
- Partnering with families

National Resource Center for Supported Decision-Making
- 2014 to present

www.DCQualityTrust.org
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
WAIT ..... 

Let’s start with you!!!
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
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 and life?
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”
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?

Remember: Use the Right Tool, for the Right Decision, at and for the Right Time.
**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](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](http://supporteddecisionmaking.org/node/390)

- **Supported Decision-Making Guides**

- **Law, Regulations, and Policy**
  - Americans with Disabilities Act
  - Medicaid HCBS Settings Rule

- **www.Supported Decision-Making.org**
## NRC-SDM State Grantees

<table>
<thead>
<tr>
<th>Year</th>
<th>State</th>
<th>Grantee</th>
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<tbody>
<tr>
<td>2015-2016</td>
<td>DE</td>
<td>Delaware Developmental Disabilities Council</td>
</tr>
<tr>
<td></td>
<td>IN</td>
<td>The Arc of Indiana</td>
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<tr>
<td></td>
<td>ME</td>
<td>Disability Rights Maine</td>
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<tr>
<td></td>
<td>NC</td>
<td>First In Families of North Carolina</td>
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<tr>
<td></td>
<td>WI</td>
<td>Wisconsin Board for People with Developmental Disabilities (not funded)</td>
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<tr>
<td>2016-2017</td>
<td>FL</td>
<td>Northern Florida Office of Public Guardian</td>
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<tr>
<td></td>
<td>GA</td>
<td>University of Georgia</td>
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<tr>
<td></td>
<td>ME</td>
<td>Disability Rights Maine</td>
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<tr>
<td></td>
<td>NV</td>
<td>Second Judicial District Court, State of Nevada, Washoe County</td>
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<tr>
<td></td>
<td>NY</td>
<td>Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</td>
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<tr>
<td></td>
<td>TN</td>
<td>The Arc of Tennessee</td>
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<tr>
<td>2018-2019</td>
<td>IN</td>
<td>Indiana Disability Rights</td>
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<tr>
<td></td>
<td>MN</td>
<td>Volunteers of America Minnesota</td>
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<tr>
<td></td>
<td>MS</td>
<td>The Arc of Mississippi</td>
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<tr>
<td></td>
<td>OR</td>
<td>The Arc of Oregon</td>
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<td></td>
<td>SC</td>
<td>Able South Carolina</td>
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<tr>
<td></td>
<td>TN</td>
<td>Disability Rights Tennessee</td>
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<tr>
<td></td>
<td>DC</td>
<td>DC Association of Special Education (not funded)</td>
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For more information on these projects, visit [www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)
## More on U.S. State Trends

<table>
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<th>State Courts</th>
<th>Pilot Examples</th>
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<tbody>
<tr>
<td>FL (2016)</td>
<td>VT SDM Pilot (underway, state taskforce)</td>
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<tr>
<td>VT (2017)</td>
<td>KY My Choice Kentucky</td>
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<tr>
<td>KY (2017)</td>
<td>CA Saks Institute Project</td>
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<tr>
<td>NV (2017)</td>
<td>GA (CPR, Georgia Advocacy Office)</td>
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<tr>
<td>ME (2018)</td>
<td>IN (Indiana WINGS)</td>
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<td>IN (2018)</td>
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For more information, visit [http://www.supporteddecisionmaking.org/states](http://www.supporteddecisionmaking.org/states)
# More on U.S. State Trends – Statutes & Pending Legislation

<table>
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<th>SDM Agreements</th>
<th>SDM as Less-Restrictive Alternative</th>
<th>SDM in Education</th>
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<tr>
<td>WI (2018) (with form)</td>
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<td>DC (2018) (with form)</td>
<td>SDM in Health Care</td>
<td>SDM Studies</td>
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<td></td>
<td>NY (organ transplants, pending)</td>
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For more information, visit [http://www.supporteddecisionmaking.org/states](http://www.supporteddecisionmaking.org/states)
More SDM Updates to Share from Your State?

- Please visit NRC-SDM’s “In Your State” at: http://www.supporteddecisionmaking.org/states

- Please email any state updates to NRC-SDM at jhjp@dcqualitytrust.org
## More SDM Policy & Practice Initiatives

<table>
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<tr>
<th>Entity</th>
<th>Resource</th>
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  • States that SDM should be considered before guardianship and incorporated as part of the guardianship, if guardianship is necessary. |
| Social Security Advisory Board (2016) | Representative Payees: A Call to Action  
  • States SSA should consider SDM as an alternative to appointing a representative payee  
| American Bar Association (2016) | PRACTICAL Tool and Resource Guide  
  • Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM.  
## More SDM Policy & Practice Initiatives

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• Model law that, among other things, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship.  
| American Bar Association (2017) | **ABA Resolution 113**  
• 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](https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf) |
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  • Promotes less restrictive means of decision-making support, including SDM.  
  • 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](https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf) |
  • Recommends expansion of Supported Decision-Making at state and local level  
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 human right!!!
JOIN THE CONVERSATION

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