Supported Decision-Making:

Introduction & Update on U.S. Trends

NDRN Conference: June 2018

National Resource Center on Supported Decision Making

- Funded in 2014 by the Administration on Community Living
- 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: What?

- A way for an adult with a disability to 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 to others.

*(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)*
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)
“Don’t judge me before you know me”

– Ryan

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.”

– Ryan’s Father

For more on Ryan’s story, visit http://www.supporteddecisionmaking.org/impact-stories/ryan-king
Supported Decision-Making: How?

- 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?”**

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](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](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

<table>
<thead>
<tr>
<th>State</th>
<th>Period</th>
<th>Lead Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>DE</td>
<td>2015-16</td>
<td>Led by Delaware Developmental Disabilities Council</td>
</tr>
<tr>
<td>IN</td>
<td>2016-17</td>
<td>Led by The Arc of Indiana</td>
</tr>
<tr>
<td>ME</td>
<td>2016-17</td>
<td>Led by Disability Rights Maine</td>
</tr>
<tr>
<td>NC</td>
<td>2016-17</td>
<td>Led by First In Families of North Carolina</td>
</tr>
<tr>
<td>WI</td>
<td>2016-17</td>
<td>Led by Wisconsin Board for People with Developmental Disabilities</td>
</tr>
</tbody>
</table>

For final reports and links to related SDM resources, visit: [http://www.supporteddecisionmaking.org/node/425](http://www.supporteddecisionmaking.org/node/425)

<table>
<thead>
<tr>
<th>State</th>
<th>Period</th>
<th>Lead Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>FL</td>
<td>2016-17</td>
<td>Led by the Northern Florida Office of Public Guardian</td>
</tr>
<tr>
<td>GA</td>
<td>2016-17</td>
<td>Led by the University of Georgia</td>
</tr>
<tr>
<td>ME</td>
<td>2016-17</td>
<td>Led by Disability Rights Maine</td>
</tr>
<tr>
<td>NV</td>
<td>2016-17</td>
<td>Led by the Second Judicial District Court, State of Nevada, Washoe County</td>
</tr>
<tr>
<td>NY</td>
<td>2016-17</td>
<td>Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</td>
</tr>
<tr>
<td>TN</td>
<td>2016-17</td>
<td>Led by The Arc Tennessee</td>
</tr>
</tbody>
</table>

### Trends: SDM in U.S. State Courts

- **Pennsylvania** – In re Peery, 727 A.2d 539 (Pa. 1999)
SDM in U.S. State Courts (cont.)

- **Massachusetts** – Cory’s Story, Berkshire County Probate Court; Pittsfield, MA (11/17/15) (see http://supporteddecisions.org/cory/)
- **Florida** – Consent Order for M.M. (10/13/16) (see http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making)
- **Vermont** – In re C.B., Stipulation to Dismiss Guardianship In re C.B. (Superior Court, Orleans Unit 4/11/2017)
- **Nevada** – In the Matter of the Guardianship of the Person and Estate of KH, Case No PR03-00264 (2nd Judicial District Court, County of Washoe, NV, 9/11/2017)

Trends in State Legislation (Part 1)

- **SDM Agreements**
  - **Delaware**: S.B. 230, 148th Gen. Assem, 2nd Year (enacted 9/15/16; form issued by state agency in 1/2018)
  - **Wisconsin**: Assem. B. 655, 103rd Leg., Reg. Sess. (enacted 4/16/18 with form)
  - **District of Columbia**: B. 22-154, 22nd Council Period, Reg. Sess. (official law in 5/5/18 with form)
  - **Missouri**: S.B. 806, 99th Gen. Assem., 2nd Reg. Sess. (Governor signed 6/1/2018, effective 8/28/18, no form)
Trends in State Legislation (Part 2)

- **SDM Agreements**
  - **Alaska:** H.R. 336, 30th Leg., 2nd Reg. Sess. (Passed House and Senate; awaiting transmittal to Governor as of 6/1/2018; would include form)
  - **Rhode Island:** H.B. 7992, 2017 Leg., Reg. Session (passed House 5/28/18, referred to Senate Committee on Judiciary 5/31/18, would include form); S. 2753, 2017 Leg. Reg. Sess. (intro 3/27/18, hearing/ consideration 4/12/18, held for further study)

Trends in State Legislation (Part 3)

- **SDM as Less-Restrictive Alternative Only**
  - **New Mexico:** S.B. 19, 53rd Leg., 2nd Reg. Sess. (enacted 2/28/18) - Enacted UGCOPAA, which formally recognizes SDM and requires court consideration of it before ordering guardianship, conservatorship, or other protective arrangements
  - **Maine:** H.R. 91, 128th Leg., 1st Reg. Sess. (enacted 4/20/18) – Completely repealed and replaced Maine’s Probate Code and recognized and required consideration of less restrictive alternatives to guardianship, including SDM.
Trends in State Legislation (Part 4)

- **Supported Decision-Making & Health Care**
  - **Delaware**: H.B. 21, 149th Gen. Assem., 1st Year (enacted 9/13/17) - Similar in effect to above DE law
  - **Kansas**: H.B. 2343, 87th Leg., Reg. Sess. (enacted 2/12/18) - Similar in effect to above DE law

Trends in State Legislation (Part 6)

- **SDM in Education**
  - **District of Columbia**: D.C. Act 20-486 (eff. 3/2015) - States that “student[s] who ha[ve] reached 18 years of age may receive support... to aid them in their decision-making”
  - Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).
Trends in State Legislative Resolutions

- **Studies of Supported Decision-Making**
  - **Maine** – H.R. 900, 127th Leg., 1st Reg. Sess (resolved 3/29/16)
  - **North Carolina** – H.B. 713 (intro. 2017)

U.S. Trends: Examples of SDM Pilots

- **California**: Saks Institute Project
- **Georgia**: Collaboration with CPR, Georgia Advocacy Office, and Citizens Advocacy Program
- **Indiana**: Disability Rights Indiana project in the court
- **Kentucky**: My Choice Kentucky
- **Maine**: NRC-SDM State Grantee SDM Pilot (2016-2017)
- **Massachusetts**: CPR and Nanotuck Resource Associates SDM Pilot (2014-2016) and New State-WideCPR Pilots
- **New York**: SDM Pilot (2016-2021)
- **Texas**: Volunteer SDMA Advocate Pilot (2012); SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
- **Vermont**: SDM Pilot (underway, state taskforce)
**More SDM Updates to Share from Your State?**

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

- Please email any state updates to NRC-SDM at jhjp@dcqualitytrust.org

---

**More SDM Policy & Practice Initiatives**

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

<table>
<thead>
<tr>
<th>Entity</th>
<th>Resource</th>
</tr>
</thead>
</table>
| **Uniform Law Commission (2017)** | Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA)  
  • 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) |

## More SDM Policy & Practice Initiatives

<table>
<thead>
<tr>
<th>Entity</th>
<th>Resource</th>
</tr>
</thead>
</table>
| **AAIDD & Arc (2016)** | Joint Position Statement on Autonomy, Decision-Making Supports, and Guardianship  
  • 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) |
## 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](http://www.supporteddecisionmaking.org/node/396)

- **National Council on Disability** – Report that examines guardianship and alternatives in view of the goals of the Americans with Disabilities Act.

## Developments in Education & Outreach

- **NRC-SDM presented at events** to thousands of people and provided **technical assistance** on SDM initiatives across the country.

- **NRC-SDM 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](http://www.SupportedDecisionMaking.org))

- **Listserv**, “Supported Decision-Making Interactive!”
Join the Conversation

National Resource Center for Supported Decision-Making:
SupportedDecisionMaking.Org
202-448-1448

Morgan K. Whitlatch
MWhitlatch@DCQualityTrust.Org
202-459-4004

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.