SUPPORTED DECISION-MAKING: Practical Tips for Implementation

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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
- Addressing the issues of older adults 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: International Backdrop

Convention on the Rights of Persons with Disabilities


**Article 12** – Sets out that **people with disabilities**:

- “have the right to recognition everywhere as **persons before the law**.”
- “enjoy **legal capacity on an equal basis with others** in all aspects of life”
State parties shall:

- “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”

- “ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards that prevent abuse in accordance with international human rights law.”
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)
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?”
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”
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 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.”

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
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:

- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).
Supported Decision-Making: Why?
Ryan’s Story

“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.**”

– Herbert King

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

OPPORTUNITIES ABOUND!

- “Student Led” IEP in Special Education
- “Informed Consent” in Medical Care
- “Informed Choice” in Vocational Rehabilitation
- “Person Centered Planning” in the Medicaid World
- Role of Counsel in Guardianship Proceedings
- Within the Guardian/Person Relationship
Supported Decision-Making: How?

- **Issue #1**: Human Decision-Making
- **Issue #2**: Assessment
- **Issue #3**: Tools
- **Issue #4**: SDM within Guardianship

**Video & Discussion**: SDM in Health Care

**Discussion**: SDM in Person Centered-Planning
Many decisions made every day
  - Some big, some small.

No standard process or measure of “goodness”
  - Isn’t “good” decision-making part science and part art?
  - Who decides if our decisions are “good”?

Human decision-making is personal, often flawed, and significantly influenced by:
  - culture, values, others, and personal experience.

Brain and decision-making science are depending our understanding of ways to help.
Capacity Can Change

- Capacity is not “all or nothing.”

- A person may be able to:
  - Make **some decisions**, but not others.
  - Make some decisions at **some times**, but not others
  - Make some decisions only if they get help understanding the decision to be made.

- **Lack of opportunity** to make decisions can prevent people from developing capacity or further decrease capacity. (Salzman, 2010)

- Capacity should **not be based solely on IQ or diagnosis**.
Issue #2: Assessment

Skills/Capacity

Expectations
Life Experiences
Risk
Environment
Available Support
Preferences and Interests
Other Variables
(individual and situational)
NGA Standard 3(I) promotes treating the person subject to guardianship with "dignity."

Dignity:
- Means our inherent value and worth as human beings
- Honors a person’s unique identity
- Preserves any existing capacity
Support networks can contribute in positive or negative ways.

Family is dynamic.

Paid vs Unpaid.

Higher number of relationships can act as a safeguard.
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**.
Critical Questions

- How do you help someone exercise decision-making?
- How do you determine which supports will help?
- What practical steps can you take to help?
Issue #3: SDM Tools

- Effective Communication
- 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
Issue #4: 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.”

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**.
“Nothing is – or should be – forever, including guardianship. Guardianship is a powerful decision-making tool, one that may be more powerful than needed. . . [E]ven if the order appointing a guardian is valid at the time of initial entry, circumstances can change, especially for people under guardianship [without] dementia.”

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).
Video and Discussion:
SDM in Health Care

“Making Healthcare Choices: Perspectives of People with Disabilities”
Produced by the American Civil Liberties Union
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 and participate in 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.
“Person-Centered Planning” is REQUIRED in Medicaid HCBS Waiver programs

Services MUST:
- Be driven by the person
- Include people chosen by the person
- Occur at times/locations convenient to the person

See Final Rules CMS 2249-F & 2296-F
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What Is “Person Centered Planning”?

- Person Centered Plan **MUST**:  
  - Address "health and long-term services and support needs in a manner that **reflects individual preferences and goals**."  
  - Result "in a person-centered plan with **individually identified goals and preferences**, including those related community participation, employment, income and savings, health care and wellness, education and others."

What Is “Person Centered Planning”?

- “A family of approaches designed to guide change in a person’s life. This type of planning is carried out in alliance with the person, their family and friends and is grounded in demonstrating respect for the dignity of all involved.

- Recognized approaches seek to discover, understand and clearly describe the unique characteristics of the person, so that the person:
  - Has positive control over the life he/she desires and finds satisfying;
  - Is recognized and valued for their contributions (current and potential) to their communities; and
  - Is supported in a web of relationships, both natural and paid, within their communities.

- See Definition in 2013 NGA Standards of Practice at p. 27
You Can Use Supported Decision-Making

- To help the person understand all components of the plan
- To help the person prioritize what is important to him/her
- To help the person build a network of supporters for the plan and beyond
- To help the person communicate and implement his or her choices
Supported Decision-Making can work in a number of contexts.

If it requires decisions, Supported Decision-Making can help the person exercise the Right to Make Choices.
A Supported Decision-Making Team can include:

- The Person
- The Person's chosen Friends, Family, Professionals
- Case Manager
- Providers
- Advocates
- Anyone Else who Can Contribute!

THINK BROADLY!
Teamwork

- **Review!**
  - Go through each area of the individual's life.
  - Example: Financial, Medical, Social, Employment

- **Brainstorm!**
  - Does the person need support in these areas?
  - If so, talk about what support could help, who could provide it, and how

- **Write!**
  - As you develop support solutions, create a written plan or “road map” for the person and team to use.

- **See Tool:** [http://supporteddecisionmaking.org/sites/default/files/SDM-BRAINSTORMING-GUIDE.PDF](http://supporteddecisionmaking.org/sites/default/files/SDM-BRAINSTORMING-GUIDE.PDF)
# SDM: Where?
## NRC-SDM State Grantees

<table>
<thead>
<tr>
<th>2015 - 2016</th>
<th>2016 - 2017</th>
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<tbody>
<tr>
<td>DE – Led by Delaware Developmental Disabilities Council</td>
<td>FL – Led by the Northern Florida Office of Public Guardian</td>
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<td>IN -- Led by The Arc of Indiana</td>
<td>GA – Led by the University of Georgia</td>
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<td>ME -- Led by Disability Rights Maine</td>
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<td>NC -- Led by First In Families of North Carolina</td>
<td>NV – Led by the Second Judicial District Court, State of Nevada, Washoe County</td>
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<td>WI – Led by Wisconsin Board for People with Developmental Disabilities</td>
<td>NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</td>
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For final reports: [http://www.supporteddecisionmaking.org/node/425](http://www.supporteddecisionmaking.org/node/425)
Trends: SDM in U.S. State Courts

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

- **Massachusetts** – Cory’s Story, Berkshire County Probate Court; Pittsfield, MA (11/17/15) (see http://supporteddecisions.org/cory/)

- **District of Columbia** – In re Ryan King (10/11/16) (see http://www.supporteddecisionmaking.org/impact-stories/ryan-king)

- **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)
Trends:
Legislation & Statutes in U.S.

- **Statutory Supported Decision-Making Agreements**
  - **Tex. Estate Code** Title 3, Chapter 1357 (eff. Sept. 2015)
    - **Pending:** Tex. H.B. 3847/S.B. 3847 would amend the above to include provisions on the fiduciary relationship and duties of the supporter (sent to Governor on 5/28/17)
  - **Del. Senate Bill No. 230** (Signed by Governor 9/14/16)
  - **Pending:** Tenn. House Bill 941 (intro. 2/18/17) & Senate Bill 264 (intro. 1/31/17, currently deferred to summer study)
  - **Pending:** D.C. Bill 22-0154 (intro. 3/13/17)
Legislation & Statutes in U.S.

- **Supported Decision-Making & Health Care**
  - **Maryland** – S.B. 792 (signed into law 5/12/15): Incorporated “SDM services” into law concerning non-discrimination in access to organ transplantation.
  - **Pending: Delaware** – H.B. 21 (passed House 3/28/17 and Senate 5/17/17, sent to Governor for action): Similar to Maryland Bill
  - **Pending: Kansas** – H.B. 2343 (passed House 3/17/17; pending in Senate): Similar to Delaware Bill

EVERYONE has the Right to Make Choices
Legislation & Statutes in U.S.

- Studies of Supported Decision-Making
  - Maine – H.B. 900 (enacted March 2016)
Pending: Washington – 2017 H.B. 1139, S.B. 5447 (would require the public guardian administrator to establish an **SDM assistance program**)

Pending: Texas – 2017 H.B. 4027, S.B. 748 (would an SDM requirement to special education transition planning) (sent to Governor on 5/30/17)

Pending: California – 2017 A.B. 437 (would define SDM within the context of a **Voluntary Online At-Risk Community Network**)

D.C. – Supported Decision-Making & Education

D.C. Act 20-486, (eff. March 2015) – “[S]tudent[s] who ha[ve] reached 18 years of age may receive support... to aid them in their decision-making”

Law reform preceded by D.C. Public Schools, Transfer of Right guidelines (Aug. 2013), recognizing SDM and advancing use of SDM Form.


Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).

- See http://osse.dc.gov/service/education-decision-making
Revisions to **Uniform Guardianship and Protective Proceedings Act**

- Will include formal recognition of SDM
- Revisions to the Act were approved by the ULC on 7/19/17 and will go to the ABA HOD in February 2018.
Trends in Policy & Practice in U.S.

  - [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)

- **National Guardianship Association (May 2015)** – Policy statement endorsing SDM, advising that it should be used before and within guardianship
Trends in Policy & Practice in U.S.

- **Social Security Advisory Board (March 2016)** – Issue brief recognizing SDM as an alternative to SSA appointment of representative payee.


- **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.
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** – 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 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

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About this Project

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