SUPPORTED DECISION-MAKING:

Update on U.S. Trends & Best Practices

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WHAT IF....

- Your **life decisions** were called into question by people close to you?

- Your **personal choices** were used as “evidence” that your decision-making capacity was not adequate or in decline?

- Concerns about your **health or safety** were determined to be **more important** than your personal history, beliefs, heritage and **preferences**?

- You were **not included** in discussions about where you live, what medical treatment you receive, and how your money is spent?
See https://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html?mcubz=0
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: 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)
**Supported Decision-Making**
- Advance Directive &/ or Power of Attorney
- Representative payee
- Other Substitute or Surrogate Health Care Decision Maker, depending on state law
- Court-appointed Guardian and/or Conservator
  - Temporary or Permanent
  - General/Plenary or Limited
What is “Guardianship” for Adults?

- Guardianship is:
  - A formal legal step that removes some or all decision-making from an adult and assigns it to a fiduciary, called a “guardian.”

- To be a guardian over an adult, a person has to go through a court process and get a court order.

- It can vary in scope — time-limited vs. permanent; general vs. limited.

- Guardianship laws vary by state.
Guardianship laws vary by state.

1997 Model Law: Uniform Guardianship and Protection Proceeding Act

Guardianship is ordered when:

1) An adult lacks “capacity” to make decisions for him or herself; AND

2) The person’s identified needs cannot be met by less restrictive means
WHY DO PEOPLE THINK ABOUT GETTING GUARDIANSHIP?
**Why do people think about getting guardianship?**

Family members and support teams may:

- Have been told by the person’s school to do so

- Be concerned about:
  - health care and access to a doctor.
  - financial abuse
  - linking the person to available services

- See the person in crisis or an emergency
WHY THINK ABOUT OTHER OPTIONS FIRST?

- Guardianship takes away some or all of a person’s rights to make important decisions about his or her life.
- The court will become part of both the guardian’s and the person’s life going forward.
- Guardianship can change relationships.
- Guardianship can take time and cost money.
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 disabilities 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)
- Older adults with more self-determination have improved psychological health, including better adjustment to increased care needs (O’Connor & Vallerand, 1994)
“Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”

Estimated number of adults under guardianship has **tripled** since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

90% of the public guardianship cases reviewed resulted in **plenary/general guardianship** - where the guardian is empowered to make **all decisions** for the person. (Teaster, Wood, Lawrence, & Schmidt, 2007)
GUARDIANSHIP MAY BE NEEDED:

- In emergency situations when
  - The person is incapacitated and cannot give consent
  - The person did not previously identify how decisions should be made in that situation
  - There is no one else available in the person’s life to provide consent through a Power of Attorney, Advanced Directive, or other means

- To support people:
  - Who face critical decisions and have no interest in or ability to make decisions
  - Who need immediate protection from exploitation or abuse
GUARDIANSHIP IS NEVER NEEDED JUST:

- “Because you are elderly”
- “Because you have ____ diagnosis”
- “Because you need help”
- “Because that’s the way it’s always been”

That’s not enough!
EXPLORE ALTERNATIVES FIRST

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?
Rethink “Capacity”

- Capacity is **not**
  - “all or nothing”
  - Based solely on IQ or diagnosis.

- People **may have “capacity” to**:
  - Make **some decisions** but not others.
  - Make **decisions some times** but not others.
  - **Make decisions if they get help understanding** the decision to be made.

- A **lack of opportunity** to make decisions can prevent people from developing capacity or **further decrease capacity** (Salzman, 2010)
Rethink “Assessments”

Skills/Capacity

Expectations

Life Experiences

Risk

Environment

Available Support

Preferences and Interests

Other Variables (individual and situational)
Many decisions are made every day
- Some are big, and some are small.

Typical decision-making is flawed

No standard way to measure “goodness”

Culture and personal values are important
- Most life decisions are personal

History, experience, and relationships often reflect personal preference and identity

Brain and decision making science are deepening our understanding of ways to help
DIGNITY

- Means our **inherent value and worth** as human beings
- Honors a person’s **unique identity**
- **Preserves** any existing capacity
- Ensures **access to accommodation** as needed

Indignity =

degradation, debasement, or humiliation
SUPPORTED DECISION-MAKING: WHAT?

- An approach to assisting people with making life decisions that **mirrors how everyone makes decisions**.
- Gives people the **help they need and want** to understand the situations and choices they face, so they can **make their own decisions**
- **Supported** Decision-Making ≠ **Substitute** Decision-Making
The shift from “surrogacy” to support is consistent with:
- the Older Americans Act
- the Americans with Disabilities Act, and
- Medicaid Home and Community Based Services regulations.
REMEMBER:
U.S. AMERICANS WITH DISABILITIES ACT

- Provides **civil rights protections** for people with disabilities (e.g., dementia and age-related 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
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.
- 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)
What we know

- The shift from “surrogacy” to support is consistent with the Older Americans Act, ADA DD Act and other regulatory and 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 control
Support networks can contribute in positive or negative ways

Family is dynamic

Paid vs Unpaid

Higher number of relationships can act as a safeguard
SDM Tools

- Effective Communication
- Informal or Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation
- Advance Planning
SDM Tools

- **Written Documents**
  - Release of Information forms – “HIPAA”
  - Other Written Plans

- **Written Agreements**
  - Model Forms: http://supporteddecisionmaking.org/node/390

- **Supported Decision-Making Guides**

- **Archived Webinars**
  - http://www.supporteddecisionmaking.org/education
What concerns do we hear about older adults using SDM?
WHAT CONCERNS DO WE HEAR ABOUT OLDER ADULTS USING SDM?

- Abuse and exploitation
- Undue influence by “supporters”
- The decisions he makes are not in his “best interest.”
- She asks the same question, over and over again.
- He forgets the choice that he made.
- Communicating with her is hard.
- Eventually, SDM won’t work.
SDM AND DEMENTIA

- **Declines** in Memory and Cognition
  - Not all dementia affects each person the same way

- **Early Diagnosis:**
  - Improved treatment options (no "cure")
  - Improved opportunities for **PLANNING** and building a support network

- As dementia progresses:
  - Look at **history of decisions and preferences**
  - A **history of practicing SDM will prepare** supporters
**Implementing SDM: How?**

- **Example 1**: Informed Consent in Medical Care
- **Example 2**: Person Centered Planning in the Medicaid World
- **Example 3**: Within the Guardian/Person Relationship
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
Example 1: SDM in Health Care

- Remember the **Americans with Disabilities Act**!
- Doctor must **reasonably accommodate** the person’s disability when obtaining his or her informed consent.
  - **Assistance can be provided** to help the person make and participate in medical decisions.
  - “**Explain that to me in English**”

- Remember **not all medical decisions** are the **same**!
  - Flu Shot vs. Surgery
Remember “HIPAA” Release Forms!
- The person can sign a release form to authorize the doctor to share confidential medical information with the person’s supporters, so they can provide support to the person in making his or her own decisions.

Example: Model D.C. Durable Power of Attorney for Health Care with Special Provisions for Supported Decision-Making
- http://www.supporteddecisionmaking.org/node/390
- For informational purposes only. State POA laws vary.
Medicaid HCBS Waiver programs - Final Rules
CMS 2249-F and CMS 2296-F

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

Example 2: SDM in “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.”

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
IT TAKES A NETWORK

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**
Example 3: SDM Within Guardianship

“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.”

“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.”

## SDM: WHERE?

### NRC-SDM State Grantees

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

**TN** – Led by The Arc Tennessee
# More on U.S. State Trends: Examples

<table>
<thead>
<tr>
<th>State Courts</th>
<th>Enacted State Statutes</th>
<th>State Pilots</th>
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<td>TX Volunteer SDM Advocate Pilot (2012)</td>
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<td>TX SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)</td>
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<td>MA SDM Pilot (CPR and Nonotuck Resources Associates) (2014-2016)</td>
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<td>NY SDM Pilot (2016-2021)</td>
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<td>DC (2016)</td>
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<td>ME SDM Pilot (2016-2017)</td>
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<td>VT SDM Pilot (underway, state taskforce)</td>
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<td>KY (2017)</td>
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<td>ME (2016)</td>
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For specific citations, please email mwhitlatch@dcqualitytrust.org
### MORE SDM POLICY & PRACTICE INITIATIVES

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<th>Entity</th>
<th>Resource</th>
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| 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) |
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.
To Reach the SDM Goal:

Every person should be part of every decision about his or her life.

- We all need help making decisions.

- Older adults and people with disabilities may need more or different help, but should be supported to exercise their Right to Make Choices in their own lives.
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202-448-1448

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