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 never given a chance to learn how to make decisions because others feared you would make a mistake.
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

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”

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**CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, ARTICLE 12**

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)

**Continuum of Decision-Making Supports**

- **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*

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.
- For people with intellectual and developmental disabilities, decision-making should be seen as a learned skill – people need the opportunity to practice!
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

MORE EVIDENCE

When denied self-determination, people can:

- “[F]eel helpless, hopeless, and self-critical”
  (Deci, 1975, p. 208).
- 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)
Students with disabilities who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997).

More evidence

- 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 on dates and socialize in the community
  - Practice the religion of their choice

(National Core Indicators, 2013-2014)
Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.


OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS:

Guardianship has been the default option for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).

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)

AND YET....
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 have an IQ of ___”
- “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

<table>
<thead>
<tr>
<th>Expectations</th>
<th>Life Experiences</th>
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<tr>
<td>Risk</td>
<td>Environment</td>
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<tr>
<td>Available Support</td>
<td>Preferences and Interests</td>
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Other Variables
(individual and situational)

RETHINK “HUMAN DECISION-MAKING”

- 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

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**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
SUPPORTED DECISION-MAKING: WHY?  
RYAN’S STORY

“Don’t judge me before you know me”
– Ryan King

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

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
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

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.
  - 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”
**COMMON CONSIDERATIONS**

- 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)

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**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**

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**SUPPORTED DECISION-MAKING: OPPORTUNITIES ABOUND!**

- **Informed Consent** in Medical Care
- **Person Centered Planning** in the Medicaid World
- **Student Led IEP** in Special Education
- **Informed Choice** in Vocational Rehabilitation
- **Within the Guardian/Person Relationship**

For Archived Webinars on the above, visit: [http://www.supporteddecisionmaking.org/education](http://www.supporteddecisionmaking.org/education)
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

**SUPPORTED DECISION-MAKING 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 information with the person’s supporters, so they can provide support to the person in making his or her own decisions.
- Model D.C. Durable Power of Attorney for Health Care with Special Provisions for Supported Decision-Making
  - [http://www.supporteddecisionmaking.org/node/390](http://www.supporteddecisionmaking.org/node/390) (info purposes only)
VIDEOS ON SDM IN HEALTH CARE

- "Making Healthcare Choices": Perspectives of People with Disabilities: Produced by the American Civil Liberties Union
  - https://youtu.be/QTyZrSC2I6U

- "Gabby’s Story": Funded by the WITH Foundation, formally known as the Special Hope Foundation
  - https://withfoundation.org/

SUPPORTED DECISION-MAKING IN “PERSON CENTERED PLANNING”

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
**Supported Decision-Making 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
**Supported Decision-Making 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."


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**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."

RESTORATION OF RIGHTS

“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).
**SDM: WHERE?**
**NRC-SDM State Grantees**

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<thead>
<tr>
<th>2015 - 2016</th>
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<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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<tr>
<td>IN -- Led by The Arc of Indiana</td>
<td>GA – Led by the University of Georgia</td>
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<tr>
<td>ME -- Led by Disability Rights Maine</td>
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<tr>
<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>
</tr>
<tr>
<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 of these NRC-SDM grantees, visit: [http://www.supporteddecisionmaking.org/node/425](http://www.supporteddecisionmaking.org/node/425)

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**More on U.S. State Trends: Examples**

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<th>State Courts</th>
<th>Enacted State Statutes</th>
<th>State Pilots</th>
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<td>KY (2017)</td>
<td>ME (2016)</td>
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For specific citations, please email mwhitlatch@dcqualitytrust.org
### 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.

Join the Conversation

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