

## SUPPORTED DECISION-MAKING:

### Update on U.S. Trends & Best Practices

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**Morgan K.  
Whitlatch**

*Legal Director,  
Quality Trust*

*Lead Project  
Director, National  
Resource Center  
for Supported  
Decision-Making*

## 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](http://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

- <http://www.un.org/disabilities/convention/conventionfull.shtml>

### 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”

## 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!

## AND IT ALSO MAKES SENSE!

- ▶ **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**

(Powers *et al.*, 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

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## 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)

## MORE EVIDENCE

- 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)



## OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS:

“Alternatives to guardianship, **including supported decision making**, should always be identified and considered whenever possible **prior to the commencement of guardianship proceedings.**”

- National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making” (2015)

## AND YET....

- 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)

## 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 its always been**”

**That's not enough!**

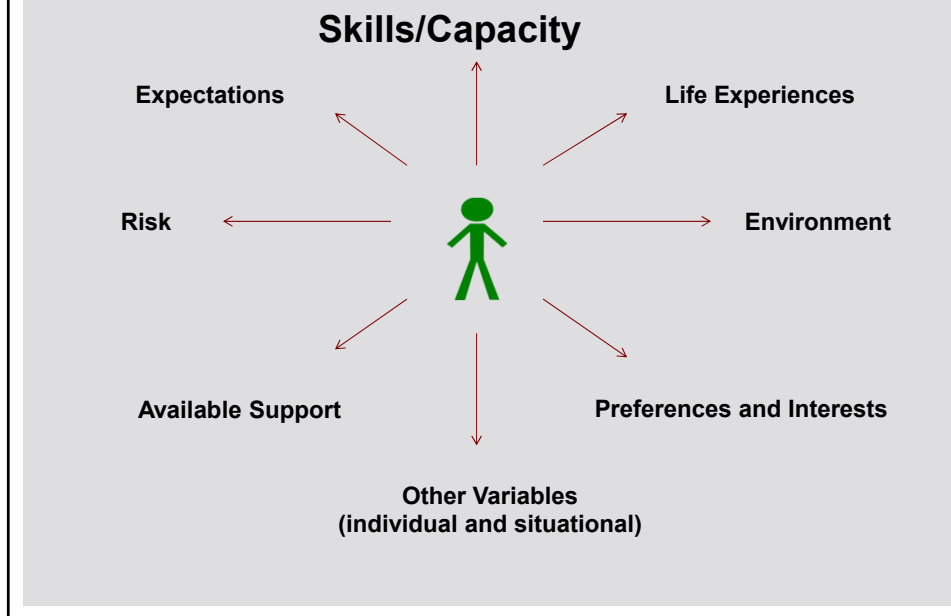
## EXPLORE ALTERNATIVES FIRST

- **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”



## 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

## 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  $\neq$  **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](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](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

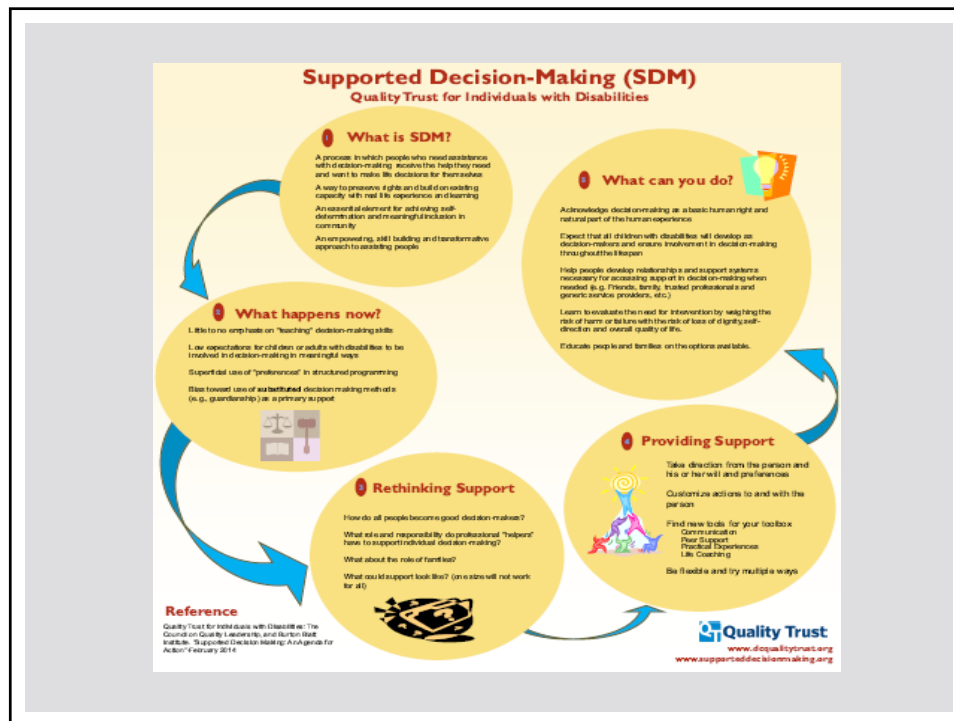
## Supported Decision-Making: How?

- 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?**”

## IN OTHER WORDS . . .

- 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)

## 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>
- **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>

### ▪ **Supported Decision-Making Guides**

- <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

## 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>

## SUPPORTED DECISION-MAKING IN HEALTH CARE

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> (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/QTyZrSC2l6U>
- **“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.”

<https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html>

## 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!**

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## 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>

## 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.”

**National Guardianship Association**, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making” (2015)

## 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.”

**National Guardianship Association**, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making” (2015)

## 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.”
  - **Robert D. Dinerstein, "Tales from a Supportive Guardianship,"** 53(2), *Court Review: The Journal of the American Judges Association*, 25-37 (forthcoming 2017)

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## 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).

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## SDM: WHERE? NRC-SDM State Grantees

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

## MORE ON U.S. STATE TRENDS: EXAMPLES

State Courts	Enacted State Statutes	State Pilots
<b>PA</b> (1999)	<b>Agreement</b> <b>TX</b> (2015)	<b>TX</b> Volunteer SDM Advocate Pilot (2012)
<b>NY</b> (2012, 2016)	<b>DE</b> (2016)	<b>TX</b> SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
<b>VA</b> (2013)	<b>Other</b> <b>DC</b> (2015)	<b>MA</b> SDM Pilot (CPR and Nonotuck Resources Associates) (2014-2016)
<b>MA</b> (2015)	<b>MD</b> (2015)	<b>NY</b> SDM Pilot (2016-2021)
<b>DC</b> (2016)	<b>MA</b> (2016)	<b>ME</b> SDM Pilot (2016-2017)
<b>VT</b> (2017)	<b>Studies</b> <b>VA</b> (2014)	<b>VT</b> SDM Pilot (underway, state taskforce)
<b>KY</b> (2017)	<b>ME</b> (2016)	

For specific citations, please email [mwhitlatch@dcqualitytrust.org](mailto:mwhitlatch@dcqualitytrust.org)

OTHER SDM POLICY & PRACTICE INITIATIVES	WEB SOURCES
<b>ABA</b> (2016 & 2017)	<ul style="list-style-type: none"> <li>• <a href="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</a></li> <li>• <a href="http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html">http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html</a></li> </ul>
<b>SS Advisory Board</b> (2016)	<ul style="list-style-type: none"> <li>• <a href="http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf">http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf</a></li> </ul>
<b>AAIDD &amp; Arc</b> (2016)	<ul style="list-style-type: none"> <li>• <a href="http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM">http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM</a></li> </ul>
<b>NRC-SDM Survey</b> (2016)	<ul style="list-style-type: none"> <li>• <a href="http://www.supporteddecisionmaking.org/node/396">http://www.supporteddecisionmaking.org/node/396</a></li> </ul>
<b>U.S. DOE, OSERS</b> (2017)	<ul style="list-style-type: none"> <li>• <a href="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</a></li> </ul>
<b>Uniform Law Comm., UGCOPAA</b> (2017)	<ul style="list-style-type: none"> <li>• <a href="http://uniformlaws.org/Committee.aspx?title=Guardianship,Conservatorship,andOtherProtectiveArrangementsAct">http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act</a></li> </ul>

## 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>
  
- **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

**National Resource Center for Supported Decision-Making:**

[www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org)

[jhjp@dcqualitytrust.org](mailto:jhjp@dcqualitytrust.org)

202-448-1448

**Morgan K. Whitlatch**

[MWhitlatch@DCQualityTrust.Org](mailto:MWhitlatch@DCQualityTrust.Org)

202-459-4004

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