

# SUPPORTED DECISION-MAKING:

## From Theory to Practice

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# 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)

# QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES

- **Mission:** To be an **independent catalyst for change**, partnering with people with disabilities, their families, advocates, professionals, and providers to **create a community where everyone is respected and valued**, belongs and contributes, and shapes their own present and future.
- **Experience:** Demonstrated knowledge and expertise related to guardianship and other decision-making support strategies for people with disabilities over the past 15 years of operation

# 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 many people with 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 & Shwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

# 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)

# OR, AS THE U.S. DEPARTMENT OF EDUCATION HAS SAID:

- “A student [who is an adult] **need not be placed under guardianship** in order for his or her family to remain involved in educational decisions. **Guardianship places significant restrictions on the rights** of an individual. Students and parents are urged to **consider information about less restrictive alternatives.**”
  - DOE OSERS, “A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities” (2017)
  - <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>

# 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**?

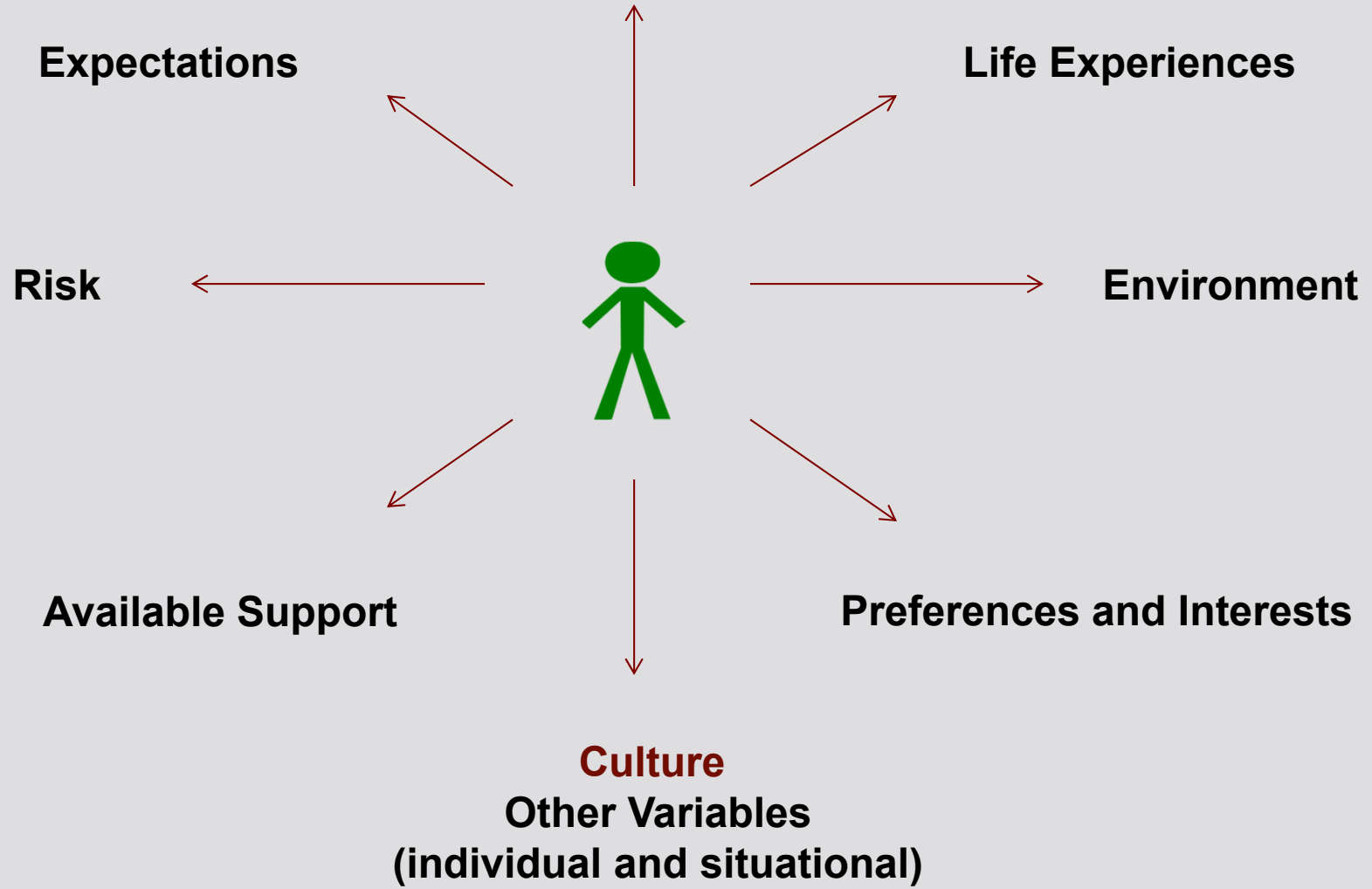
- Ask: What is the **least restrictive** support that might work?

# 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”

## Skills/Capacity



# 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

# 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

For more on Ryan’s story, visit  
<http://www.supporteddecisionmaking.org/>



# 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.**”

For more on Ryan's story, visit  
<http://www.supporteddecisionmaking.org/>

– Ryan's father

# SUPPORTED DECISION-MAKING: HOW?

- There is **no “one size fits all” method** of Supported Decision-Making
  - SDM **looks different** for different people and families
- **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”

# Supported Decision-Making (SDM)

## Quality Trust for Individuals with Disabilities

### 1 What is SDM?

A process in which people who need assistance with decision-making receive the help they need and want to make life decisions for themselves.

A way to preserve rights and build on existing capacity with real life experience and learning.

An essential element for achieving self-determination and meaningful inclusion in community.

An empowering, skill building and transformative approach to assisting people.



### 2 What can you do?

Acknowledge decision-making as a basic human right and natural part of the human experience.

Expect that all children with disabilities will develop as decision-makers and ensure involvement in decision-making throughout the lifespan.

Help people develop relationships and support systems necessary for accessing support in decision-making when needed (e.g. friends, family, trusted professionals and generic service providers, etc.).

Learn to evaluate the need for intervention by weighing the risk of harm or failure with the risk of loss of dignity, self-direction and overall quality of life.

Educate people and families on the options available.

### 3 What happens now?

Little to no emphasis on "teaching" decision-making skills.

Low expectations for children or adults with disabilities to be involved in decision-making in meaningful ways.

Superficial use of "preferences" in structured programming.

Blatant use of substituted decision-making methods (e.g., guardianship) as a primary support.



### 4 Rethinking Support

How do all people become good decision-makers?

What roles and responsibility do professional "helpers" have to support individual decision-making?

What about the role of families?

What could support look like? (one size will not work for all)



### 5 Providing Support

Take direction from the person and his or her will and preferences.

Customize actions to and with the person.

Find new tools for your toolbox:  
Communication  
Peer Support  
Practical Experiences  
Life Coaching

Be flexible and try multiple ways.



### Reference

Quality Trust for Individuals with Disabilities, The Council on Quality Leadership, and Burton Blatt Institute. "Supported Decision-Making: A Roadmap for Action" February 2014.

 **Quality Trust**

[www.dqualitytrust.org](http://www.dqualitytrust.org)  
[www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

# 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!

- ▶ **Student Led IEP** in Special Education
- ▶ **Informed Consent** in Medical Care
- ▶ **Person Centered Planning** in the Medicaid World
- ▶ **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 EDUCATION

- “If State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that **student can become the educational rights holder** who invites family members to participate in the IEP meeting.”
- “If the adult student does not want to have that role, he or she can **execute a power of attorney** authorizing a family member to be the educational decision-maker.”
- “Alternatively, . . . a **supported decision-making arrangement** can be established consistent with applicable State procedures, in which the parents (or other representatives) assist the student in making decisions, if the student has not been determined to be incompetent but does not have the ability to provide informed consent with respect to his or her educational programs.”

**More from U.S. DOE Transition Guide**

# SDM IN EDUCATION: HOW?

- Help the adult student sign a **FERPA Release Form**
- **Help the student get ready** for meetings ahead of time.
- Make sure IEP team meetings are **student-friendly.**
- Slow the conversation down – **No rushing decisions.**
- Support the student in **leading** or **participating** his or her own IEP meeting.
- **Start Early!**

# DC's Example: SDM & FERPA

- In 2013, **D.C. Public Schools adopted SDM** for adult students in special education – **without any special law or regulatory change.**
- ▶ **D.C. Public Schools, *Transfer of Rights Guidelines*** (Aug. 2013)
  - ▶ Recognizes supported decision-making as an alternative to guardianship for adult students with disabilities in D.C.
  - ▶ Available at: <https://transitioncentral.files.wordpress.com/2011/12/transfer-of-rights-guidelines.pdf>
- ▶ **DCPS Supported Decision-Making Form**
  - ▶ Available at [http://supporteddecisionmaking.org/sites/default/files/dcps\\_supported\\_decision\\_making\\_form.pdf](http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form.pdf)

## Supported Decision Making Form

Adult Student: \_\_\_\_\_

Address: \_\_\_\_\_  
Street Cell Phone Home Phone  
Washington, DC Zip Code

I understand that I may create a network of individuals to help me inform my educational decisions related to my Individualized Education Program (IEP) once I reach the age of majority. I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to the documents listed below.

NAME	RELATIONSHIP	HOME ADDRESS	EMAIL ADDRESS	PHONE NUMBER
1.				
2.				

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENT	ACCESS
IEP meeting invitations, and agendas	
Requests for assessments	
Requests for changes in placement	
Requests for changes in services	
Exit requests	
Progress reports	
Report cards	
Attendance information	
Assessment results	
Other	

It is my understanding that I make the final decisions about my educational future after communicating with members in my network, and can remove a member from my network, or their access to my educational documents at any time.

\_\_\_\_\_  
 Adult Student Signature Date

\_\_\_\_\_  
 Network Member Signature Date

\_\_\_\_\_  
 Network Member Signature Date

■ **Q: What does this DCPS SDM Form look like?**

■ **A: A modified FERPA Form!**

# WHERE IS SDM IN THE LAW?

- ▶ **SDM doesn't need to be expressly in state law** for you to use it!
- ▶ Remember the **Americans with Disabilities Act** and **Section 504 of the Rehabilitation Act.**
- ▶ Think of **supports** that a student uses to make his or her own decisions as disability-related **accommodations.**

# SUPPORTED DECISION-MAKING IN EDUCATION

- **Include the student in IEP meetings**, starting in elementary school.
- **Support IEP goals and objectives** related to self-determination and decision-making.
  - For every goal, there should be an application of self-determination to get there. Use “I statements”
  - Promote student involvement and accountability.

# 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/QTyZrSC2I6U>
- **“Gabby’s Story”** : Funded by the WITH Foundation, formerly known as the Special Hope Foundation
  - <https://withfoundation.org/>

# 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

- <http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

# **SUPPORTED DECISION-MAKING: MORE STORIES FROM D.C.**

- **Quality Trust for Individuals with Disabilities**
- **Outreach to the Latino Communities in D.C. on alternatives to guardianship**
- **Lessons Learned**

# SDM: WHERE?

## NRC-SDM State Grantees

### 2015 - 2016

**DE** – Led by Delaware Developmental Disabilities Council

**IN** -- Led by The Arc of Indiana

**ME** -- Led by Disability Rights Maine

**NC** -- Led by First In Families of North Carolina

**WI** – Led by Wisconsin Board for People with Developmental Disabilities

For **final reports** of these NRC-SDM grantees, visit:

<http://www.supporteddecisionmaking.org/node/425>

### 2016 - 2017

**FL** – Led by the Northern Florida Office of Public Guardian

**GA** – Led by the University of Georgia

**ME** – Led by Disability Rights Maine

**NV** – Led by the Second Judicial District Court, State of Nevada, Washoe County

**NY** – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)

**TN** – Led by The Arc Tennessee

# 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>NV</b> (2017)		<b>ME</b> (2016)	<b>KY</b> My Choice Kentucky <b>CA</b> Saks Institute SDM Project

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/cr/sj/supported_decision_making_newspiece.authcheckdam.pdf">https://www.americanbar.org/content/dam/aba/administrative/cr/sj/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://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM">http://aaidd.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>



## 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)

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