

# Supported Decision-Making Basics

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LIFE IS LIKE A BOX OF  
CHOCOLATES



Our life is  
our choices

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## Fundamental Human and Constitutional Rights

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"I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose how we are in those circumstances."

- Jean Paul Sartre

## What If....

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- 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?

## Supported Decision Making: What?

- Empowering persons with disabilities (including changes in memory and cognition)
- To make choices
- With the help from supporters / advisors, who assist them to:
  - To **understand** and **explore** the options
  - To know the **risks and benefits** of those options
  - To get **guidance and recommendations**
  - To make and **communicate a choice**
  - To **carry out that choice**, if help is needed to do so.
- SDM mirrors how **everyone** makes decisions.
- SDM is an emerging **nationally and internationally recognized** alternative to adult guardianship.



## Supported Decision-Making: Why?

- SDM has “**strong potential for promoting favorable outcomes** in the lives of people with disabilities and older adults”
- SDM and **Human Dignity**:
  - Recognizing the **inherent value and worth** of a person as a human being
  - Honoring that person’s **unique identity**
  - Preserving any **existing capacity**
  - Ensuring **access to accommodations** as needed.



## Self-Determination

### ▶ Life Control

- ▶ People's ability and opportunity to be causal agents in their own lives.
- ▶ Studies have shown people with disabilities and **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.



## Without Self-Determination . . .

**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)



## Supported Decision-Making: How?

- **There is no “one size fits all” method.**
  - SDM is a **paradigm**, not a process or program
  - It means working with the person to **identify where help is needed and how** it can be provided.
  - The key question is: **“What will it take?”**
- **It can include**, as needed and appropriate:
  - **Informal support**
  - **Written agreements**
  - **Formal Micro-Boards and Circles of Support**



Capacity:  
The level of help we need depends on

Life Experience

Abilities

Help we have



## We All Do It

Across the spectrum of experience and abilities

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## SDM Is A Balancing Point

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On Your Own



Guardianship

## Person Centered – Person Driven

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- Person Centered Planning
- Person Centered Services and Supports
- Person Centered Health Care



- SDM is Person Driven
- Always – always – always ask the person what they want
  - Everyone has the Right to make choices
  - Everyone has the “capacity” to make choices
  - As long as a person can communicate in any meaningful way, they have the ability to make choices
  - People will make good choices for themselves with support



Communication  
is the Key

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## Communication MRPC 1.4 B

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“A lawyer shall explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation.”

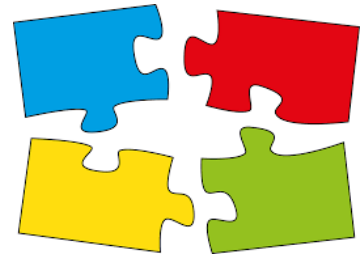
Break down into parts

Small choices add up to big choices

Offer recommendations – but allow the person to make the choice

Express concerns – but don't criticize

- “I am concerned about X”
- Not “X is a terrible, stupid, silly or bad idea.”



# Always Ask the Person

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## SDM and Dementia

Declines in Memory and Cognition

Not a single illness

Not all dementia effects people in the same way

Early Diagnosis

- Improved treatment options (still no "cure")
- Improved opportunities for planning and creating the supportive circle

## Technology is redefining our ability



## Integrating SDM into Advance Directives

I ask that my that my health care surrogate named in this document or otherwise empowered by law explain to me the nature of any illness, condition, or diagnosis. I ask that my surrogate explain to me the treatment options available, the prognosis, the risks and benefits of various treatment options, and the recommendations from my doctors, and then ask for my choice or preference. I ask that my surrogate continue to do this, even if it appears that I may not be able to understand what is being explained. I ask that any decisions that are made by my surrogate be based on what my surrogate thinks I would do if I were able to make the choice. When in doubt, please consult the attached documents for guidance. These documents reflect my instructions, my health care goals, and my personal values in making health care decisions.



## SDM and Power of Attorney



I ask that my agent named in this document, before taking any actions using this document, always discuss with me what is being considered, what the options are, make a recommendation and seek my input. Even if it appears that I am unable to understand, I ask that my agent continue to explain to me what is happening and the choice you are making and why. Third parties can rely on my agent's representation that they have followed this request. A failure to follow this request shall not invalidate any transaction entered into by agent using this document.

## Draft in limits

Financial transactions in excess of \$\_\_\_\_\_ require the signature of my agent, and either myself or \_\_\_\_\_.

My agent shall not have authority to sell, gift or otherwise transfer any interest in any real estate that I own.

Or

My agent shall only sell, transfer or gift my home, after consultation with and agreement by \_\_\_\_\_.



## The Biggest Challenges

- **Training** family, friends, caregivers, advisors, agents and guardians
- In the **principles** of person-driven decision-making



## Is SDM Always the Answer?

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### 01

SDM should be the first option

### 02

In cases of abuse or exploitation, SDM will only remedy the abuse or exploitation, if you can break the cycle of abuse and exploitation

### 03

Some Persons may become truly unable to communicate

### 04

For Persons experiencing changes in memory and cognition, the disease may reach the point that the Person is unable to communicate. If the advisors have practiced SDM up to that point, they will be well prepared to make decisions that reflect the decision the person would make.

## Important to Remember

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- Adults are allowed to make bad choices
- The more people are empowered to make choices, the better they are at it
- Empowering people to make choices improves their quality of life



## Concerns you will hear

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- Abuse and exploitation
- The choices are not “in her best interest”
- He asks the same question, over and over
- She forgets the choice that she made
- It is so hard to communicate
- Sooner or later SDM won’t work



## SDM Impetus

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- **United Nations Convention on the Rights of Persons with Disabilities (“CRPD”)**
- Article 12 requires signatory nations to:
  - “recognize that persons with disabilities enjoy **legal capacity on an equal basis to others** in all aspects of life”
  - “take **appropriate measures** to provide access by persons with disabilities to the **support** they 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”
- According to the CRPD Committee, the term “**supported decision-making**” describes one of the ways a person can be assisted in exercising legal capacity.



## Federal Support

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Americans with  
Disabilities Act

Older Americans Act

Medicaid Home and  
Community Based  
Services regulations

Administration for  
Community Living  
(ACL)

National Resource  
Center for Supported  
Decision-Making (NRC-  
SDM) since 2014



Uniform  
Guardianship,  
Conservatorship &  
Other Protective  
Arrangements Act  
(UGCOPAA)

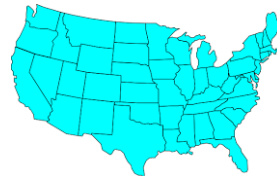
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## ABA Policy

SDM “be identified and fully considered as a less restrictive alternative before guardianship is imposed” and be considered a “grounds for termination of a guardianship and restoration of rights.”

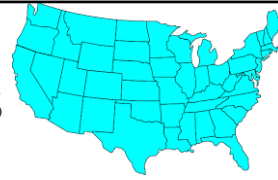
## SDM: WHERE IN U.S.?



### NRC-SDM State Grantees

2015-2016	2016-2017
<b>DE</b> – Led by Delaware Developmental Disabilities Council	<b>FL</b> – Led by the Northern Florida Office of Public Guardian
<b>IN</b> -- Led by The Arc of Indiana	<b>GA</b> – Led by the University of Georgia
<b>ME</b> -- Led by Disability Rights Maine	<b>ME</b> – Led by Disability Rights Maine
<b>NC</b> -- Led by First In Families of North Carolina	<b>NV</b> – Led by the Second Judicial District Court, State of Nevada, Washoe County
<b>WI</b> – Led by Wisconsin Board for People with Developmental Disabilities	<b>NY</b> – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)
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>	<b>TN</b> – Led by The Arc Tennessee

## Examples of U.S. State Trends



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

## More SDM Policy & Practice Initiatives




ENTITY	RESOURCE
<b>National Guardianship Association</b> (2016)	Position Statement on Guardianship, Surrogate Decision-Making, and Supported Decision-Making <ul style="list-style-type: none"> <li>States that SDM should be considered before guardianship and incorporated as part of the guardianship, if guardianship is necessary</li> </ul>
<b>Social Security Advisory Board</b> (2016)	Representative Payees: A Call to Action <ul style="list-style-type: none"> <li>States SSA should consider SDM as an alternative to appointing a representative payee</li> </ul>
<b>American Bar Association</b> (2016)	PRACTICAL Tool and Resource Guide <ul style="list-style-type: none"> <li>Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM.</li> </ul>



Stakeholders

- National Guardianship Association
- American Bar Association
- Quality Trust for Individuals with Disabilities
- Burton Blatt Institute
- Council on Quality and Leadership,
- National Resource Center for SDM



Questions?

## Contact Information

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## About this Project

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