

# Supported Decision-Making in the Medical Context

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# Learning Objectives

- Overview of SDM concepts and how SDM works in practice
- Challenges of using SDM in health care settings
- Strategies to improve health care interactions when using SDM

# Supported Decision-Making

- SDM is an alternative to guardianship that allows an individual with a disability to work with a team of chosen supporters and make decisions about his or her own life.
- Distinguish from “shared decision-making”

# How does SDM work in practice

- Individuals with a disability receive **necessary supports** to make a decision on issues – big or small – affecting their lives
- Individuals **choose** one or more **trusted people** to assist them to make decisions – friends, family members, relatives
- **Relationship** between individual, supporter is built on **trust and commitment**
- SDM recognizes that **will and preferences** are the core of decision making abilities
- SDM is consistent with concepts that people may be **competent in some areas** even if not in others

# Role of SDM Supporter

- Supporters and individual with a disability **discuss** possible decisions and the ramifications of those choices/decisions.
- Individual with a disability reaches his/her **own decision**.
- Supporters **honor/respect** individual's decision. No requirement to agree with a person's preference or decision.
- Where necessary, supporters **help to communicate** the individual's decision to involved community members.

# SDM Agreement Can Address...

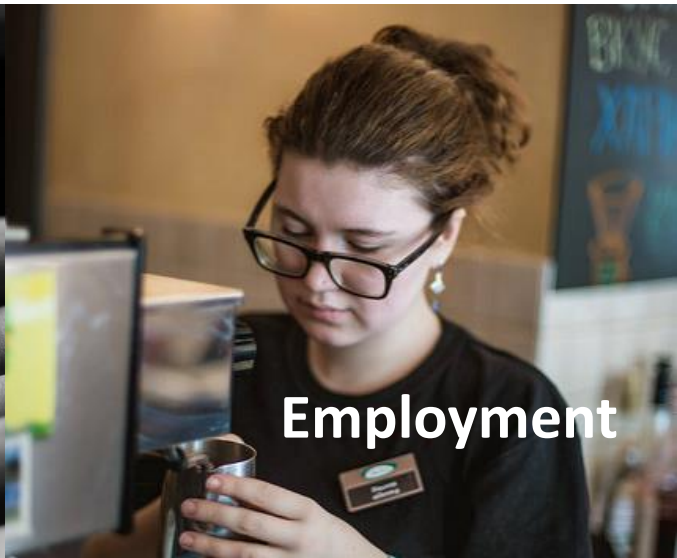
**Healthcare**



**Relationships**



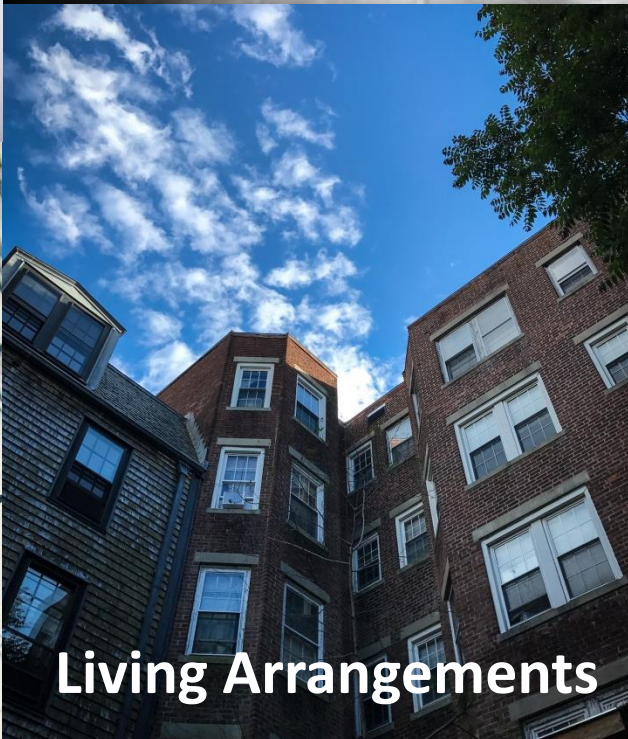
**Employment**



**Finances**



**Living Arrangements**



**Education**



**Center for Public Representation  
Supported Decision-Making Agreement**

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**This is the Supported Decision-Making Agreement of**

Name : \_\_\_\_\_ Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

A. I need supporter(s) to help me make decisions about:

- Taking care of my financial affairs, like banking
- Hiring a lawyer if I need one and working with the lawyer
- My health care, including large and small health care decisions
- Personal care (like where I live, the support services I need, managing the people who work with me, my diet, exercise, education, safety and activities)
- Other matters: \_\_\_\_\_

D. I designate the following individual(s) to be part of my Supported Decision-Making Network to assist me in making decisions.

### Network Supporter #1

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship: \_\_\_\_\_

Areas of Assistance for Supporter #1: *Check all that apply:*

Finances  Healthcare  Living Arrangements

Relationships/Social  Employment  Legal Matters

Other (*please specify*):

Areas I don't want Supporter #1 to assist me with:

Network Supporter #2



Supported  
Decision  
Making  
Agreement



Release of  
information  
(HIPAA)

Health Care  
Proxy

Durable  
Power of  
Attorney



# How SDM interacts with a Health Care Proxy

- Coexisting documents
- Health Care Proxy provides added security to families, individuals, and providers
- Designation of Health Care Proxy in advance is consistent with choice and self direction
- Designated Health Care Proxy is almost always also a supporter
- Create a communication plan

# Typical Challenges for People with Disabilities in the Health Care Context

- Understanding potentially complex health care subject matter in a brief period of time
- Being asked to respond and /or make decisions on short notice
- The limits medical personnel may have in terms of their time with the person and possible supporters
- Questions at to the competency and legal capacity of the person with a disability

# Typical Challenges for People with Disabilities in Health Care Context

- An absence of long-term relationships; person with a disability and the medical personnel unfamiliar with each other
- Communication difficulties and lack of appropriate support
- Inadequate preparation of the person with a disability for medical appointments

# Challenges of Using SDM in the Health Care Context

- The person with the disability is not used to being their own decision maker, particularly in the presence of people with authority
- Medical personnel and people with disabilities who are unfamiliar with supported decision-making
- It takes time to build supportive/trusting relationships between persons with disabilities and others
- The absence of specific policy in medical organizations and settings that recognizes supported decision-making

# Challenges of Using SDM in the Health Care Context

- Unwillingness of some human service providers, families and medical personnel to properly respect the voice and decisions of the person
- Failure of informal supporters, SDM supporters, and health care proxies to adequately prepare both the person with a disability and medical personnel for medical appointments.
- Confusion between Supported Decision-Making and “Shared Decision-Making”

# Challenges of Using SDM in the Health Care Context

- Negative historical assumptions in both medical and community contexts concerning persons with disability that are predicated upon an emphasis on the lack of competency of the person rather than a presumption of competency
- Skepticism as to whether the presence of good support sufficiently offsets the limitations of a particular person with a disability
- Many persons with disabilities may present in such a way that they appear to be less competent than they are, particularly with support

# Factors that Contribute to the Adoption of SDM in the Medical Context

- National movement in favor of supported decision-making with pilots, legislation, and endorsement by mainstream organizations
- Supported decision-making is highly consistent with other widespread features of “best practice” in multiple service fields (e.g. self determination, self direction, person centered practice)
- Families involved with supported decision-making have seen meaningful progress with their family member with a disability despite their initial skepticism
- Supported decision making has been a catalyst for broader life enrichment of the person with a disability much beyond just decision making
- The emphasis in current medical training on values and ethics, partnering with service users, holistic and individualized approaches, shared decision making etc. has been highly consistent with supported decision-making principles.



# Strategies for Using SDM in Health Care Settings

- Thorough of preparation with all parties *before* appointments
- Continuity of key persons involved in medical appointments on an ongoing basis
- Thorough follow-up with matters raised
- Education of participants with the principles of supported decision-making

## Role of Supporters: steps supporters can take to assist with a medical appointment

- Identify and discuss the primary purpose of the meeting with the person with the disability
- Determine what aspects of the meeting are unclear to the person with disability; determine ways to address
- Explore the specific concerns, questions, fears, and anxieties the person with the disability has re: the medical appointment; can the supporter provide support to assist with any of these issues?
- List the person with the disability's concerns and questions for future reference in the medical appointment
- Discuss the limits of the meeting: what can be accomplished, what cannot

# Role of Supporters: Steps supporters can take to assist with a medical appointment

- Identify what information needs to be collected in advance and brought to the meeting; decide who collects and organizes the needed information
- Discuss and resolve what are the appropriate roles/tasks of the person being supported and the supporter(s) in the medical appointment
- Discuss and resolve who will record what occurs in the medical appointment, follow up items, and unresolved questions
- Discuss who is the best supporter to attend the meeting

# Educating a Health Care Provider about Supported Decision-Making

- Decide how to discuss SDM with the health care provider:
  - Does the provider have any experience with SDM? Do you know if it is positive or negative?
  - Consider: Who will explain the concept of SDM? How will you explain the role of the supporter?
  - Will you provide written materials? (SDM Agreement, Health care Proxy Form, other background materials on SDM)
  - If the person previously had a guardianship, distinguish difference
  - Timing: is it an option to discuss SDM with the provider before the meeting?
- Release of Information: if the office requires a release to be signed for the supporter to be present, can you do this in advance?

# Stumbling blocks

- Discuss how to handle situation where a provider will not allow a supporter to participate in a medical appointment
  - Identify the reasons this occurred: fear about concept of SDM? personality conflict? Belief that the person with the disability lack competency? Etc.
  - Is there a supervisor who you can discuss this with or some complaint process? The person with the disability determines whether to go this route.

# Questions?

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