



Center for Public Representation

## Supporting Adults with Disabilities in Decision-Making

June 14, 2023

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## Center for Public Representation

- A leading **national legal advocacy center** in the United States for over 40 years
- Work on **supported decision-making** extends to **pilot projects, training, technical assistance, resource development**, and other collaborations
- Current areas of **special focus** include supported decision-making in **medical care** and with **youth**
- Offices in Massachusetts, New York, and Washington, D.C.

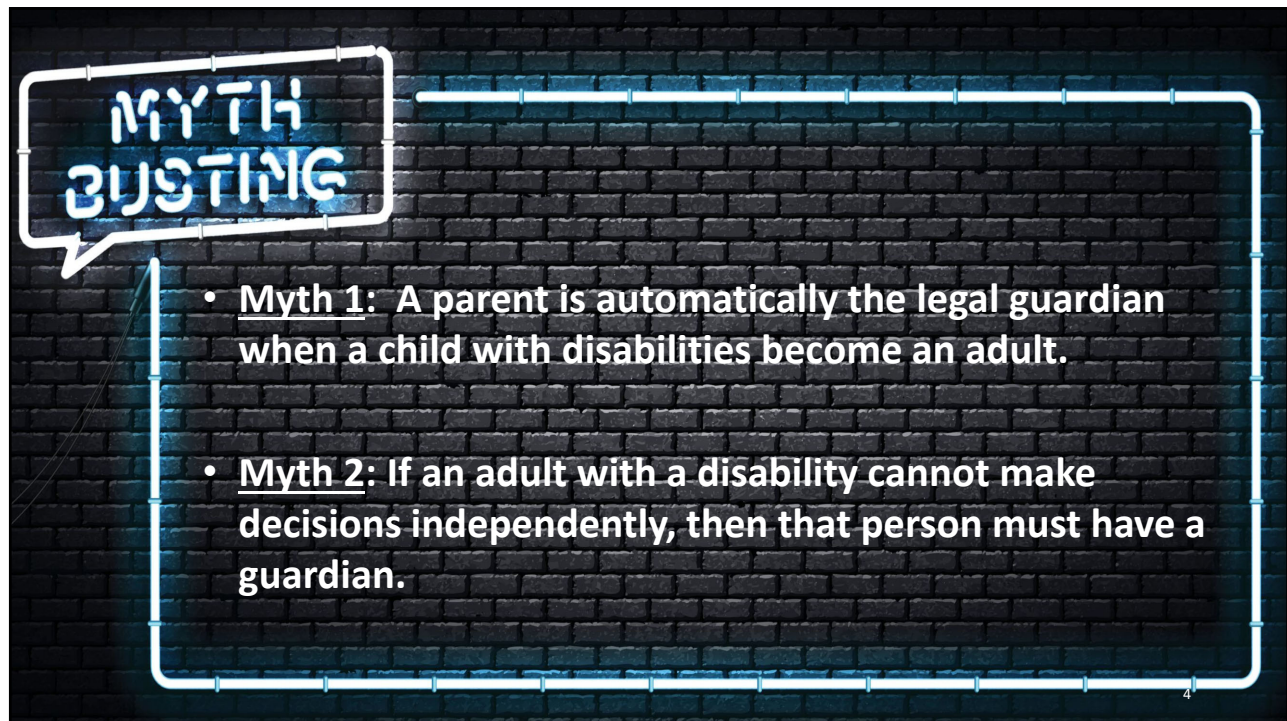
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CENTER ON  
**YOUTH VOICE**  
**YOUTH CHOICE**

- National resource center founded in Fall 2020 through a five-year grant from the Administration on Community Living
- Supports State Teams in promoting alternatives to guardianship for youth with intellectual or developmental disabilities
- Promotes youth leadership in all levels of its work
- 2023 Four-Part Parent Speakers Series
- <https://youth-voice.org>

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MYTH BUSTING

- **Myth 1:** A parent is automatically the legal guardian when a child with disabilities become an adult.
- **Myth 2:** If an adult with a disability cannot make decisions independently, then that person must have a guardian.

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## Continuum of Main Decision-Making Tools

- **Supported Decision-Making**
- **Health Care Proxy, Advance Directive, and/or Power of Attorney**
- **Shared or Delegated Educational Decision-Making Authority**
- **Representative Payee**, appointed by SSA
- **Court-appointed Guardian**
  - Limited, Temporary, Conservatorship, Plenary

There are many more, like Trusts, ABLE Accounts, Banking Options, etc.

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**MYTH BUSTING**

- **Myth 3:** Guardianship is needed to access medical or educational information when a child becomes an adult.
- **Myth 4:** Guardianship is needed to attend medical or educational planning meetings.

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**MYTH BUSTING**

- **Myth 5:** Guardianship has been proven to be the best way to protect people with disabilities from abuse.
- **Myth 6:** There are no downsides to getting guardianship.

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## “Supported Decision-Making”: What?



SDM allows people with disabilities and older adults (“decision-makers”) to make choices about their own lives with support from people (“supporters”) they choose and trust.

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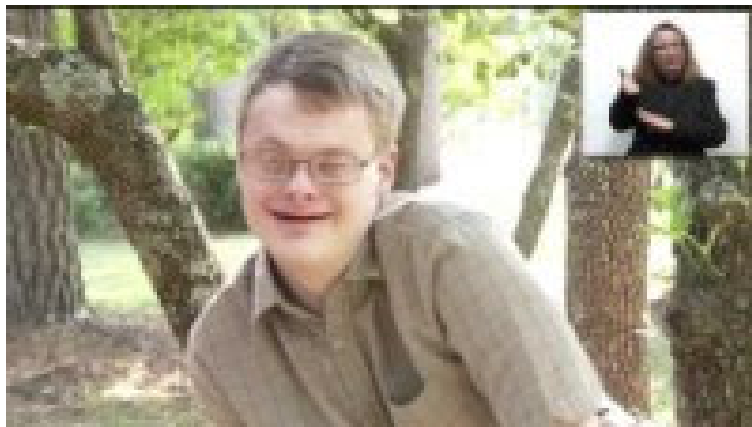
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**MYTH BUSTING**

- Myth 1: SDM is not “legal” enough.
- Myth 2: SDM is only available in states that have passed a special SDM law.
- Myth 3: People with certain IQ scores or diagnoses cannot use SDM.

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## Supported Decision-Making: Why?



“Supported Decision-Making: A Family’s Perspective”  
[Able South Carolina](#) and [SC Supported Decision-Making Project](#)

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## Supported Decision-Making: Why?

- ▶ **Self-Determination**
  - ▶ **Life control** — People’s ability and opportunity to be actors in their own lives
- ▶ **People with disabilities with greater self-determination are:**
  - ▶ More **independent**
  - ▶ More **integrated** into their communities
  - ▶ **Healthier**
  - ▶ Better able to **recognize and resist abuse**



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## Some Findings from the SDM Pilots

- Decision-makers **did not** experience abuse, neglect, or financial exploitation through use of SDM
  - Chose supporters they trusted
  - Multiple supporters



- Decision-makers reported **increases** in:
  - **Pride**
  - **Self-confidence**
  - **Happiness**
  - Willingness to **try new experiences**
  - Taking **greater control** of their health and mental health care

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## Supported Decision-Making: How?



- ▶ **One size doesn't fit all.**
  - ▶ SDM looks different for different people.
- ▶ Supporters work with the person to find out:
  - ▶ What are their **goals**?
  - ▶ What **help** do they need?
  - ▶ **Who** do they want to give them that help?
  - ▶ **How** do they want the help to be given?
  - ▶ **What will it take** to make their own decisions with support?

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## More in the SDM "Toolbox"

- ▶ **Supported Decision-Making Guides**
  - ▶ Visit <https://supporteddecisions.org>
- ▶ **Planning and Practice**
  - ▶ Vision or Dream Boards
  - ▶ Release of information Forms ("HIPAA" or "FERPA")
  - ▶ Advance Planning Tools
  - ▶ Model Forms
- ▶ **U.S. Federal Law and National Trends**
  - ▶ Americans with Disabilities Act
  - ▶ Rehabilitation Act
  - ▶ Visit <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making/>



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## Before & 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)

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## 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. . .”

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

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**Thank you!**

**For more information  
on supported decision-  
making and CPR's  
pilots:**

<https://supporteddecisions.org>



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