Our Speakers

- Max Barrows is Outreach Director for Green Mountain Self-Advocates
- Laura Butler, MRC, MA, cofounder of My Choice Kentucky, works at The Human Development Institute at the University of Kentucky
- Morgan K. Whitlatch, J.D., is the Director of Supported Decision-Making (SDM) Initiatives at the Center for Public Representation
Supported Decision-Making: Overview & Update on U.S. Trends

Morgan Whitlatch, J.D.
Director of Supported Decision-Making Initiatives
Center for Public Representation

www.supporteddecisions.org

https://centerforpublicrep.org
• 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.
• 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

• [https://youth-voice.org](https://youth-voice.org)
How much do **YOU** know about Supported Decision-Making?
What is “Supported Decision-Making”?

- It is a **way of making decisions** that people with disabilities can use.
- You work with **people you choose to help you** understand your choices and make your own decisions.
- The people who give you help making decisions are called **your supporters**.
- You are the decision-maker.
Common Questions about Supported Decision-Making

- **Who** can use it?
- **Is it new?**
- **How is it different** than guardianship?
- **Is it really legal?**
- **Is it safe?**
Why Use Supported Decision-Making?

- **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*
Some Findings from the CPR 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
People with intellectual and developmental disabilities without a guardian are more likely to:

• Live in their own homes or apartments
• Be included in the community
• Have their rights respected
• Have community jobs or service plans with that goal
• Be supported to communicate with friends
• Be involved in making choices about their own lives.
• Bradley et al., National Core Indicator Data Brief, 2019
Common Questions about Using Supported Decision-Making

- How do I get started?
- Who can be a supporter?
- Do I need a lawyer?
- Do I need to use a special form?
- What if my supporter and I disagree?
More in the SDM “Toolbox”

- **Supported Decision-Making Guides**
  - Visit [https://supporteddecisions.org](https://supporteddecisions.org)
  - Visit [https://gmsavt.org/resource-library](https://gmsavt.org/resource-library)

- **Planning and Practice**
  - Vision or Dream Boards
  - Release of information Forms (“HIPAA” or “FERPA”)
  - Advance Planning Tools
  - Model Forms

- **U.S. Federal Law**
  - Americans with Disabilities Act
  - Rehabilitation Act
Looking Nationally...

- U.S. Administration for Community Living (2014 to present)
- National Guardianship Association (2016)
- Social Security Advisory Board (2016)
- AAIDD & The Arc of the U.S. (2016)
- Uniform Law Commission (2017)
- Center for Youth Voice, Youth Choice (2020 to present)
- Fourth National Guardianship Summit (2021)
- U.S. Senate Committee on the Judiciary, Subcommittee on Constitution (2021)
Thank you!

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

https://supporteddecisions.org

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My Choice Kentucky: Grassroots efforts to expand supported decision-making in Kentucky

Laura Butler, MRC, MA
Human Development Institute at
University of Kentucky
Okay, now what?

- Took the idea to Kentucky Protection & Advocacy.
- Need $...
My Choice Kentucky is Born!

October, 2015

Partners:
- Kentucky Protection & Advocacy
- National Resource Center

Goal- Spread the work across Kentucky about supported decision-making.

Attended SDM Symposium the same month- got really overwhelmed
Justice for Susie!    July 24, 2017
Spreading the word with some help from our friends!
Guardianship Data

• How many?
• Who?
• Where?
Always be on the lookout for new opportunities

WITH Foundation
Work for Inclusive and Transformative Health Foundation
(formerly Special Hope Foundation)

Request for proposals targeted toward supported decision-making.
My Choice Kentucky: Making Decisions in Healthcare/Dental Care

Partnered with the University of Louisville School of Medicine, then University of Kentucky College of Dentistry

Created teams that included:
• Young adults with intellectual & developmental disabilities
• Subject matter experts
• Family members
Lessons Learned

- Things will not go as planned
- You will hear every “what-if” scenario
- Everyone makes mistakes
- Learn from others.
Partners, Collaborators, and Funders

- Kentucky Protection & Advocacy
- National Resource Center on Supported Decision-Making
- Burton Blatt Institute
- Southeast ADA Center
- University of Louisville School of Medicine
- University of Kentucky College of Dentistry
- WITH Foundation
- Commonwealth Council on Developmental Disabilities
- KY SPIN
- YES! Self-Advocacy Group
- Child Neurology Foundation
The NEW My Choice Kentucky

Continue and expand project efforts.

- Find ways for people without typical natural supports to use supported decision-making
- Increase groups educated
- Create materials for education to large and small groups
  - Flyers
  - Videos
  - Implementation guides
Contact

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