

MISSOURI SYMPOSIUM ON
SUPPORTED DECISION MAKING

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Missouri Symposium on Supported Decision Making
Consensus Document

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On September 12, 2018, a 133-member group of people with disabilities, family members, supporters, and leaders in the legal, health, education, and financial sectors gathered to begin a coordinated effort to increase knowledge and use of Supported Decision-Making (SDM) in Missouri.

GUIDING PRINCIPLES

The Symposium began with the group unanimously agreeing to three guiding principles¹ for its present and future discussions and actions:

1. Recognize and respect that everyone has an equal right to make their own decisions, regardless of their diagnosis or functional challenges.
2. Be respectful of the various opinions and deeply held beliefs that have led parents and advocates to choose different options for decision-making support, including SDM.
3. Promote the use and development of practices that will provide people in need of support with individualized decision-making assistance in a way that imposes the absolute minimum restriction of rights.

The meeting was facilitated by nationally recognized SDM leaders, Jonathan Martinis² and Morgan Whitlatch³.

DISCUSSION TOPICS

IDENTIFYING STRENGTHS AND POTENTIAL FOR SUCCESS

- What must happen in order for our effort to be considered successful?
 - What should SDM look like?
 - What are things we do well that can make that happen?
 - Where should SDM be used?
 - Who needs to be part of the discussion to accomplish that?
 - One year from now, what do we want to say we accomplished?
 - Over the next year, what are some specific things we can do, or specific examples of opportunities we have/people and professionals we can talk to, to make that happen?
 - How do we translate our strengths and opportunities into action?
 - What are the challenges and obstacles to success?
 - How will we define failure?
 - What must not happen?
 - What specific things must we avoid?
- What mistakes have been made before that we can't repeat?
 - What are the dangers of SDM?
 - What are the biggest obstacles to making SDM accepted and available?
 - What partners do we need that we don't have now?
 - Is anyone "against us"?
 - If so, why and what can we do to try to work with them?

SETTING PRIORITIES

- What have we discovered about SDM in Missouri?
- How do we prioritize where to begin?

NEXT STEPS:

- How do we enhance successes and overcome the challenges and obstacles to implementing SDM in Missouri?
- What are some "products" Symposium members should create – educational materials, pilot projects, outside-of-the-box ways to increase knowledge, access, and use of SDM in Missouri?

FINDINGS AND RECOMMENDATIONS

After the full group discussed each topic, participants broke into smaller groups to develop recommendations, which they reported back to the full group. Notes from the 15 small groups, organized by topic, as well as a CART caption file were collected and provided to the Symposium facilitators, who produced the following consensus findings and recommendations.

DEFINING SUCCESS

First, Symposium members identified achievements that will demonstrate successful increases in knowledge and use of Supported Decision-Making in Missouri:

Customized education and training programs about the theory, practice, and benefits of Supported Decision-Making for people and professionals, including:

- People with intellectual and developmental disabilities
- Parents and families
- Guardians
- Attorneys
- Judges
- Doctors and health care professionals
- Teachers and educational professionals
- Public Administrators
- Case managers
- Social workers
- Adult Protective Services workers
- Financial professionals and other “nontraditional” organizations; and
- Other professionals and organizations, as appropriate.

Educational programs and materials on Supported Decision-Making provided in a variety of formats and settings, including:

- Outreach, education, and training for people with disabilities and families;
- Education and certification programs for guardians;
- College, social work, law school, nursing, and other post-secondary and graduate programs;

- Professional certification programs for direct support professionals, certified nursing assistants, case managers, and other professionals working directly with people with disabilities;
- Professional development courses, including Continuing Legal Education for attorneys, Continuing Education Units for counselors and social workers, and other required training for professionals;
- Introductory material and periodic updates for Public Administrators;
- Bench Cards and other reference materials for Judges; and
- Educational programs and guides for case managers, teachers, and adult protective services workers.

Greater respect for people with disabilities and their right to make decisions and direct their own lives, including:

- Increased opportunities for people with intellectual and developmental disabilities to make decisions and have those decisions honored across systems and programs;
- A comprehensive review and, as needed, amendment of state policies and procedures to ensure that agencies, organizations, and professionals employed, funded, or regulated by Missouri provide maximum opportunity for people with disabilities to make decisions and direct their services and supports; and
- Rethinking language and practice to discourage phrases like “my/your own guardian” which suggest that guardianship is the norm for people with disabilities.

Guides, templates, and other written material designed to help people, families, and professionals explore and use Supported Decision-Making.

Changes in guardianship numbers:

- A decrease in the number of people with intellectual and developmental disabilities entering into any type of guardianship.
- A reduction in the number of people with intellectual and developmental disabilities entering or remaining in full guardianship

BARRIERS TO SUCCESS

Next, Symposium members identified systemic and practical barriers to achieving greater knowledge and use of Supported Decision-Making in Missouri:

Culture and historical practices that favor guardianship for people with intellectual and developmental disabilities, including:

- Teachers and educational professionals recommending guardianship when students with intellectual and developmental disabilities turn 18 without discussing other options like Supported Decision-Making;
- Doctors and healthcare professionals recommending guardianship of people with intellectual and developmental disabilities as a way to secure “informed consent” for treatment without exploring whether they can use Supported Decision-Making or other options to provide consent;
- Attorneys recommending and Judges ordering full guardianship without exploring whether other options, including limited guardianship and Supported Decision-Making are more appropriate;
- Service providers recommending guardianship because they are afraid they will be held liable if people with intellectual and developmental disabilities make “bad” choices; and

- An increase in the use of limited or tailored guardianship for people with intellectual and developmental disabilities who need guardianship.

New case law demonstrating and protecting people with intellectual and developmental disabilities’ rights to use Supported Decision-Making instead of being Ordered into overbroad or undue guardianships.

Shared success stories through social media and other outlets to increase awareness of Supported Decision-Making.

- People and professionals feeling that guardianship is the only way to keep people with intellectual and developmental disabilities “safe.”

Availability and effectiveness of support. How can parents and others know that effective and appropriate support is available or will be available when needed?

Fear of undue influence from supporters. How can we ensure that supporters will not take advantage of people with intellectual and developmental disabilities? How can we help people with intellectual and developmental disabilities identify and avoid abuse, neglect, and exploitation from people they trust?

Lack of funding for support. Who will pay for Supported Decision-Making education, training, supports, and services?

“Groupthink.” Parents and professionals pressure people to seek guardianship because that is what they did or what they heard is the right thing to do.

Challenges identifying and communicating with potential Supported Decision-Making users. Many people who could benefit from Supported Decision-Making are not in the intellectual and developmental disabilities “services system.” How can we identify, reach out to, and educate them?

NEXT STEPS

REVIEW AND EXPAND EXISTING PROJECTS AND RESOURCES ADVANCING SDM

Symposium members then identified existing projects designed to increase knowledge and use of Supported Decision-Making in Missouri. These projects should be monitored and, if proven effective, expanded:

- The Missouri Developmental Disabilities Council project to educate people and families about SDM using short, targeted brochures. The brochures introduce SDM concepts and ways people can use Supported Decision-Making in several areas and programs.
- WITH project with Mosaic Medical System to educate doctors, nurse practitioners, and care coordinators about Supported Decision-Making and identify ways to empower patients to make health care decisions, with support.
- WITH project in the St. Joseph area to educate people with disabilities, professionals, family members, and direct support professionals on using SDM in health care. The project is also

developing tools to help improve communication between people with disabilities and health care professionals.

- St Louis Arc education program to educate people with intellectual and developmental disabilities. The program includes workshops on SDM, alternatives to guardianship, and the role of guardians.
- Assessment, planning, and evaluation tools that can help people explore and use SDM including the Missouri Stoplight tool, Charting the LifeCourse tools, and the Missouri Quality Outcomes Measurement tool.
- Professionals and organizations providing education and training for attorneys and other professionals about ways Supported Decision-Making can fit into their practice, including the American Bar Association and National Guardianship Association.

DEVELOP PROJECTS AND RESOURCES THAT WILL ADVANCE SDM

Finally, Symposium members identified Action Steps, including projects and resources to develop, in order to increase knowledge and use of Supported Decision-Making in Missouri:

Create Supported Decision-Making tools and resources, including:

- Templates for SDM Agreements;
- Model language for Powers of Attorney, Advanced Directives, Person Centered Plans, Individualized Education Plans, and Individualized Plans for Employment that include Supported Decision-Making;
- Education and training on Supported Decision-Making for people with disabilities, families, guardians, attorney and judges, doctors and

healthcare professionals, teachers and educational professionals, social workers, case managers, Public Administrators, and others.

- A local or state "hotline" that people, families, and professionals can contact with questions about Supported Decision-Making, to request training or other resources;
- A statewide speakers/trainers list of people who can present on Supported Decision-Making to organizations/professionals/audiences;
- Educational material for legislators/local government to help them understand the importance and benefits of Supported Decision-Making and create new law, policy, and practice that encourages Supported Decision-Making and other alternatives to guardianship;

- “Bench Cards” for judges, probate commissioners, and public administrators to help them understand the requirements of Missouri’s guardianship statutes and their obligation to consider and use SDM and other alternatives to guardianship;
- Guides for guardians to help them understand their responsibilities to support people to make their own decisions and have their guardianships terminated, if appropriate;
- Work Groups on Supported Decision-Makings targeted to specific professions – including teachers, health care providers, attorneys, judges, and public administrators – that can provide profession-specific education and resource materials on Supported Decision-Making; and
- An online home for Missouri Supported Decision-Making resources and information.

Expand outreach to professions and organizations that have not been part of this discussion, including financial planners, bankers, and trustees.

Review and amend state and local policies and procedures to encourage self-determination and SDM including licensure requirements for educational, health care, and legal professionals.

SUMMARY

Using these overarching values and goals as a guide, the Consortium will develop concrete plans that will build on our strengths, overcome barriers to greater knowledge and use of Supported Decision-Making, and ensure that all Missourians have full, equal, and meaningful opportunities to make their own decisions and direct their lives.

Review and amend continuing education requirements for teachers, doctors, nurses, social workers, attorneys, and others to include material on self-determination and Supported Decision-Making.

Develop for-credit college/community college classes on guardianship and options like Supported Decision-Making.

Conduct research and collect data to determine the parts of Missouri that have the least number of people under guardianship and identify best practices and strategies that result in less guardianships.

Review research and data from other states with lesser rates of guardianship than Missouri to identify best practices and strategies that reduce unnecessary guardianships.

Identify and train peer mentors for people with disabilities and families to share their experiences using Supported Decision-Making and help explore options.

Develop and disseminate videos, using social media, about people who have successfully used Supported Decision-Making.

Implement and assess pilot projects on Supported Decision-Making and document best practices.

¹ These principles were first identified in Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, and The Council on Quality and Leadership. (2015). Supported decision-making: An agenda for action. Retrieved from <http://jennyhatchjusticeproject.org/node/264> (last visited February 12, 2019).

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