

**SUPPORTED DECISION-
MAKING IN ACTION:
Tracking U.S. Trends**

**Morgan K.
Whitlatch**

*Legal Director,
Quality Trust
Project Director,
National
Resource Center
for Supported
Decision-Making*

Thelma Green

*Executive Board,
Project ACTION!*

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about Supported Decision Making (SDM)
- Addressing the issues of people who are aging and people with disabilities
- Linking development efforts throughout the country
- www.SupportedDecisionMaking.org

GOALS FOR THE PROJECT

- Build **national consensus** on SDM
- **Change attitudes** regarding decision making and capacity
- Identify and develop **principles and tools for interdisciplinary support** across the lifespan for with people of varying abilities, challenges and life situations.
- **Increase collaboration** and information sharing for implementing of SDM principles.
- Bring together **training and technical assistance network** promoting practices consistent with SDM

SUPPORTED DECISION-MAKING: WHAT?

- Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts to:
 - **Help understand** the issues and choices;
 - **Ask questions**;
 - **Receive explanations** in language he or she understands; and
 - **Communicate** his or her own decisions to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

SUPPORTED DECISION-MAKING: WHAT?

- There is **no “one size fits all” method** of Supported Decision-Making
- **It is a paradigm**, not a process or program
 - It means working with the person to identify where help is needed and finding a way to provide any help that’s needed.
 - Solutions are different for each person.
 - The key question is “what will it take?”
 - The possibilities are endless

COMMON CONSIDERATIONS

- All forms of SDM recognize:
 - The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others;
 - That **a person can take part in a decision-making process** that does not remove his or her decision-making rights; and
 - **People will often needs assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein, 2012)

SUPPORTED DECISION-MAKING: WHY?

▶ **Self-Determination**

- ▶ Life control — People's ability and opportunity to be “causal agents . . . Actors in their lives instead of being acted upon”

(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

▶ **People with greater self-determination are:**

- ▶ More **independent**
- ▶ More **integrated** into their communities
- ▶ **Healthier**
- ▶ Better able to **recognize and resist abuse**

(Powers *et al.*, 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

SUPPORTED DECISION-MAKING: WHY?

- **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: INTERNATIONAL BACKDROP

Convention on the Rights of Persons with Disabilities

- <http://www.un.org/disabilities/convention/conventionfull.shtml>

Article 12 – Sets out that **people with disabilities:**

- “have the right to recognition everywhere as **persons before the law.**”
- “enjoy **legal capacity on an equal basis with others** in all aspects of life”

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES, ARTICLE 12

State parties shall:

- “take **appropriate measures** to provide access by persons with disabilities to the **support** they may 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.”

REMEMBER: U.S. AMERICANS WITH DISABILITIES ACT

- Provides **civil rights protections** for people with disabilities, including requiring “**reasonable modifications** to policies, practices, and procedures” to avoid discrimination.
- Link to U.S. Supreme Court case, *Olmstead v. L.C.*
 - Greater Self-Determination = Greater Community Integration.
 - People with intellectual and developmental disabilities who do not have a guardian are more likely to have a **paid job, live independently**, have friends other than staff or family go and dates and **socialize in the community**, and practice the religion of their choice. (2013-2014 National Core Indicators)

SUPPORTED DECISION-MAKING: WHAT IT MEANS TO ME

Thelma's One Page Profile

Created with support in a
People Planning Together
Workshop

Important to me:

(Favorite things and what I don't like)

- Looking stylish
- Having my own money
- Going out with friends and boyfriend
- To see and talk with family
- Going to church
- Attending meetings and conferences
- Learning computer skills

What people like and admire about me!

- Great advocate for myself and others
- Outspoken and loving
- Great friend
- Smart. Knows a lot about rights.
- Great trainer - especially for doctors and lawyers!



Important for me:

(Supports I need and want)

- Healthy diet
- Going to gym 3 times a week
- Taking my medicine
- Having assistance at home with cooking, cleaning, and getting ready for each day.

SUPPORTED DECISION-MAKING: TOOLS

- Effective Communication
- Supported Decision-Making Guide
 - <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- Informal of Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation

SUPPORTED DECISION-MAKING: TOOLS

- Written Documents
 - Release of Information forms – “HIPAA” or “FERPA”
 - Other Written Plans

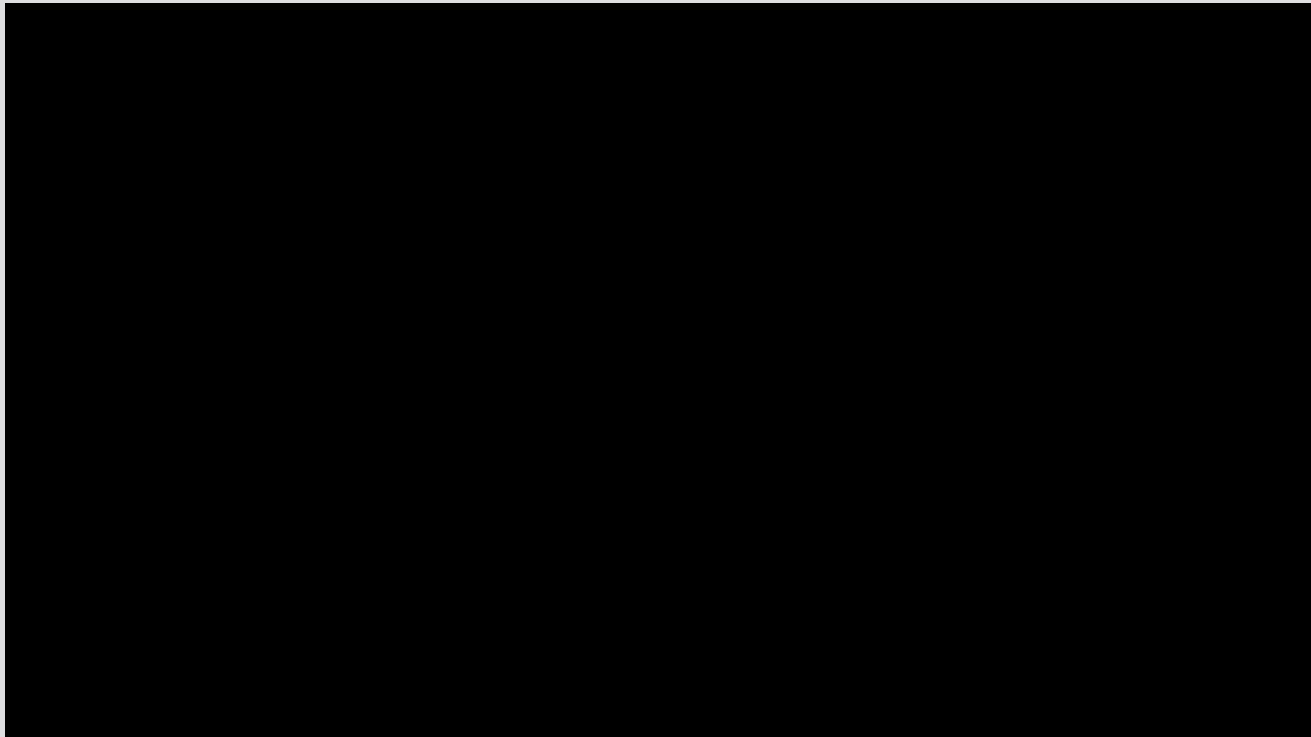
- Written Agreements
 - Statutory Forms in TX and DE
 - Model Forms
 - <http://supporteddecisionmaking.org/node/390>

NRC-SDM STATE PROJECTS

- Indiana
- North Carolina
- Delaware
- Maine
- Wisconsin

DELAWARE STATE GRANTEE

YOUR SUPPORT, MY DECISIONS!



OTHER NRC-SDM STATE GRANTEE PRODUCTS

- Maine's SDM Coalition
 - Including videos, guides, training initiatives, and sample SDM form
 - <http://supportmydecision.org/tools>
- First in Families of North Carolina
 - <http://www.fifnc.org/programs/connections.html>

TRENDS: SDM IN U.S. CASE LAW

- **In re Peery**, 727 A.2d 539 (Pa. 1999) – Reversing guardianship order because the person “has in place a **circle of support** to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety”
- **In re Dameris L.**, 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012) – Terminating the guardianship of a person with an intellectual disability because she was “able to engage in **supported decision making**”

SDM IN U.S. CASE LAW

- **Ross v. Hatch**, No. CWF120000426P-03 (Va. Cir. Ct. 2013) – Appointing temporary limited guardians for only one year and charging them to “assist [the person] in making and implementing decisions we have heard termed ‘**supported decision making**’”
- **Matter of D.D.**, 19 N.Y.S.3d 867 (N.Y. Sur. Ct. 2015) – **Dismissing petition** for appointment of a guardian in favor of supported decision-making
- **Cory’s Story**, Berkshire County Probate Court; Pittsfield, MA (11/17/15) – Removing guardian and stating “[t]he SDM Agreement provides to Mr. C. a sensible, reasonable and workable arrangement to assist him to make his own decisions about all aspects of his life.” See <http://supporteddecisions.org/cory/>.

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- **Cory’s Story**, Berkshire County Probate Court; Pittsfield, MA (11/17/15) – <http://supporteddecisions.org/cory/>

SDM IN U.S. CASE LAW

- **Matter of Hytham M. G.**, 2016 N.Y. Misc LEXIS 2722 (N.Y. Sur. Ct., Kings County, April 14, 2016) – **Dismissing guardianship petition** against a person with a developmental disability because of the availability of SDM.
- **Matter of Michelle M.**, 2016 N.Y. Misc LEXIS 2719 (N.Y. Sur. Ct., Kings County July 22, 2016) – **Dismissing guardianship petition** against a person with an intellectual disability because of disability because of the availability of SDM.

TRENDS: LEGISLATION & STATUTES IN U.S.

- **Statutory Supported Decision-Making Agreements**
 - **Tex. Estate Code** Title 3, Chapter 1357 (eff. Sept. 2015)
 - **Del. Senate Bill No. 230** (House passed July 1, 2016)
 - **Pending: D.C. Bill 21-0385** (Intro. Sept. 2015)

LEGISLATION & STATUTES IN U.S.

- **D.C. – Supported Decision-Making & Education**
 - **D.C. Act 20-486**, (eff. March 2015) – “[S]tudent[s] who ha[ve] reached 18 years of age may receive support... to aid them in their decision-making”
 - Law reform preceded by **D.C. Public Schools, Transfer of Rights Guidelines (Aug. 2013)**, recognizing SDM and advancing use of SDM Form.
 - See <http://www.supporteddecisionmaking.org/impact-stories/supporting-decision-making-students-disabilities-dc>.
 - Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).
 - See <http://osse.dc.gov/service/education-decision-making>

LEGISLATION & STATUTES IN U.S.

- **Supported Decision-Making & Health Care**
 - **Maryland** – S.B. 792 (enacted May 2015): Incorporated **SDM in the medical context** into proposed legislation concerning non-discrimination in access to organ transplantation.
 - **Massachusetts** – H.B. 3271 (Intro. March 2015; HB 4332, Intro. May 2016): To do the same as above.

LEGISLATION & STATUTES IN U.S.

- **Studies of Supported Decision-Making**
 - **Virginia** – H.J. Res. 190 Reg. Sess (2014): Ordered **study of SDM**, which recommended it be implemented in all service systems.
 - **Maine** – H.B. 900 (enacted March 2016): Resolving that the Probate and Trust Law Advisory Commission will **examine SDM** and make recommendations about inclusion within Probate Code, with report due 1/15/17.

TRENDS IN POLICY & PRACTICE IN U.S.

- **National Guardianship Association (May 2015)** – Policy statement endorsing SDM, advising that it should be used before and within guardianship
- **Center for Parent Information and Resources (Oct. 2015)** – Funded through U.S. Dept. of Education, CPIR released guidelines for parents on students reaching the age of majority, which included SDM principles

TRENDS IN POLICY & PRACTICE IN U.S.

- **Social Security Advisory Board (March 2016)** – Issue brief recognizing SDM as an alternative to SSA appointment of representative payee.
 - See http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
- **Joint AAIDD & Arc Position Statement (2016)** – “Autonomy, Decision-Making Supports, and Guardianship”
 - See http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
- **ABA PRACTICAL Tool (2016)** – Developed with the assistance of NRC-SDM, this tool helps lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship.
 - See http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

DEVELOPMENTS IN RESEARCH

- **NRC-SDM Sponsored Studies**
 - To determine best practices in SDM
 - To determine whether use of SDM is correlated with improved life outcomes.
- **NRC-SDM Survey** on Supported Decision-Making in Practice
 - <http://www.supporteddecisionmaking.org/node/396>
- **National Council on Disability** – Developing a report that examines guardianship and alternatives in view of the goals of the Americans with Disabilities Act.

DEVELOPMENTS IN EDUCATION & OUTREACH

- In last 6 months, **NRC-SDM presented at over 60 events** across the country to thousands of people and provided **technical assistance** on SDM initiatives across the country.
- **NRC-SDM Archived webinars** on moving SDM from theory to practice in education and youth in transition; vocational rehabilitation; services, supports, and health care; finances; etc. (**www.SupportedDecisionMaking.org**)
- **Listserv**, “Supported Decision-Making Interactive!”

SUPPORTED DECISION-MAKING: OPPORTUNITIES ABOUND!

- ▶ **Person Centered Planning** in the Medicaid World
- ▶ **Student Led IEP** in Special Education
- ▶ **Informed Consent** in Medical Care
- ▶ **Informed Choice** in Vocational Rehabilitation
- ▶ **Within the Guardian/Person Relationship**

For Archived Webinars on the above, visit:

<http://www.supporteddecisionmaking.org/education>

TO REACH THE SDM GOAL:

Every person should be part of every decision about his or her life.

- **We all need help** making decisions.
- People with disabilities may need more or different help, but should be supported to exercise their **Right to Make Choices** in their own lives.

JOIN THE CONVERSATION

**National Resource Center for
Supported Decision-Making:**
SupportedDecisionMaking.Org

202-448-1448

Morgan K. Whitlatch

MWhitlatch@DCQualityTrust.Org

202-459-4004

ABOUT THIS PROJECT

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