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

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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)
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
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)
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

**Supported Decision-Making: Why?**

- **When denied self-determination**, people can:
  - 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).
Convention on the Rights of Persons with Disabilities


**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)
Thelma’s One Page Profile

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 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

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
- 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](http://supporteddecisionmaking.org/node/390)
NRC-SDM State Projects

- Indiana
- North Carolina
- Delaware
- Maine
- Wisconsin
EVERYONE has the Right to Make Choices
Maine’s SDM Coalition
- Including videos, guides, training initiatives, and sample SDM form
  - [http://supportmydecision.org/tools](http://supportmydecision.org/tools)

First in Families of North Carolina
- [http://www.fifnc.org/programs/connections.html](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’”


- **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/](http://supporteddecisions.org/cory/).
**SDM IN U.S. CASE LAW**

- **Ross v. Hatch**, No. CWF12000426P-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**’”


- **Cory’s Story**, Berkshire County Probate Court; Pittsfield, MA (11/17/15) – [http://supporteddecisions.org/cory/](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 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)
D.C. – Supported Decision-Making & Education

D.C. Act 20-486, (eff. March 2015) – “[S]tudent[s] who have reached 18 years of age may receive support... to aid them in their decision-making”


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.

National Resource Center for Supported Decision-Making
EVERYONE has the Right to Make Choices
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.


- **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.
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](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](http://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](http://www.supporteddecisionmaking.org/education)

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EVERYONE has the Right to Make Choices
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.
EVERYONE has the Right to Make Choices
ABOUT THIS PROJECT

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