

Supported Decision-Making:

Introduction & Update on U.S. Trends

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**Morgan K.
Whitlatch**

*Legal Director,
Quality Trust*

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

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 older people 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?

- A way for an adult with a disability to 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 to others.
- (See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

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, Rifenbark, & 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: WHY? RYAN'S STORY



“Don’t judge me before you know me”

– Ryan

For more on Ryan’s story, visit
[http://www.supporteddecisionmaking.org/
impact-stories/ryan-king](http://www.supporteddecisionmaking.org/impact-stories/ryan-king)

SUPPORTED DECISION-MAKING: WHY? RYAN'S STORY



“Ryan is a whole person. We want him to be whole. **The decision process is part of being whole . . .** If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him.**”

– Ryan’s Father

For more on Ryan’s story, visit
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Supported Decision-Making: How?

- 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?”**

SDM TOOLS

- **Effective Communication**
 - ASAN with the UCF Office of Developmental Primary Care, “Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations
 - <http://odpc.ucsf.edu/communications-paper>
- **Informal or Formal Supports**
- **Peer Support**
- **Practical Experiences**
- **Role Play and Practice**
- **Life Coaching**
- **Mediation**



SDM TOOLS

■ Written Documents

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

■ Written Agreements

- Model Forms: <http://supporteddecisionmaking.org/node/390>

■ Supported Decision-Making Guides

- <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

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 ***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)

NRC-SDM State Grantees

2015 - 2016	2016 - 2017
<p>DE – Led by Delaware Developmental Disabilities Council</p> <p>IN -- Led by The Arc of Indiana</p> <p>ME -- Led by Disability Rights Maine</p> <p>NC -- Led by First In Families of North Carolina</p> <p>WI – Led by Wisconsin Board for People with Developmental Disabilities</p> <p>For final reports and links to related SDM resources, visit: http://www.supporteddecisionmaking.org/node/425</p>	<p>FL – Led by the Northern Florida Office of Public Guardian</p> <p>GA – Led by the University of Georgia</p> <p>ME – Led by Disability Rights Maine</p> <p>NV – Led by the Second Judicial District Court, State of Nevada, Washoe County</p> <p>NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</p> <p>TN – Led by The Arc Tennessee</p>

Trends: SDM in U.S. State Courts

- **Pennsylvania** – In re Peery, 727 A.2d 539 (Pa. 1999)
- **New York** – In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct., New York County, 2012); Guardian for A. E. 2015-XXXX, 2015 NYLJ LEXIS 4377 (N.Y. Sur. Ct., Kings County, 2015); Matter of D.D., 50 N.Y. Misc. 3d 666 (N.Y. Sur. Ct., Kings County, 2015); Matter of Hytham M. G., 2016 N.Y. Misc LEXIS 2722 (N.Y. Sur. Ct., Kings County, 2016); Matter of Michelle M., 2016 N.Y. Misc LEXIS 2719 (N.Y. Sur. Ct., Kings County, 2016 7/22/16); Estate of Hilton, 2017 NYLJ LEXIS 284 (N.Y. Sur. Ct., Kings County, 2017); Estate of Albert J., 2017 NYLJ LEXIS 475 (N.Y. Sur. Ct., Kings County, 2017)
- **Virginia** -- Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct. 2013) (see <http://www.supporteddecisionmaking.org/impact-stories/jenny-hatch>)

SDM in U.S. State Courts (cont.)

- **Massachusetts** – Cory’s Story, Berkshire County Probate Court; Pittsfield, MA (11/17/15) (see <http://supporteddecisions.org/cory/>)
- **District of Columbia** – In re Ryan King, 2003 INT 247, D.C. Sup. Court Probate Div., 10/11/16) (see <http://www.supporteddecisionmaking.org/impact-stories/freedom-ryan-king>)
- **Florida** – Consent Order for M.M. (10/13/16) (see http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making)
- **Vermont** – In re C.B., Stipulation to Dismiss Guardianship In re C.B. (Superior Court, Orleans Unit 4/11/2017)
- **Kentucky** – Suzie’s Story (2017) (see <http://www.supporteddecisionmaking.org/impact-stories/freed-guardianship-kentucky-first-suzie-wins-her-rights-court-using-sdm>)
- **Nevada** – In the Matter of the Guardianship of the Person and Estate of KH, Case No PR03-00264 (2nd Judicial District Court, County of Washoe, NV, 9/11/2017)

Trends in State Legislation (Part 1)

- **SDM Agreements**
 - **Texas:** H.B. 39, 84th Leg., Reg. Sess. (enacted 5/29/15 with form); S. 1881, 84th Leg., Reg. Sess. (enacted 6/9/15 with form); S. 39, 85th Leg., Reg. Sess. (enacted 6/9/17 to define fiduciary duties of supporter and prevent conflict of interests)
 - **Delaware:** S.B. 230, 148th Gen. Assem, 2nd Year (enacted 9/15/16; form issued by state agency in 1/2018)
 - **Wisconsin:** Assem. B. 655, 103rd Leg., Reg. Sess. (enacted 4/16/18 with form)
 - **District of Columbia:** B. 22-154, 22nd Council Period, Reg. Sess. (official law in 5/5/18 with form)
 - **Missouri:** S.B. 806, 99th Gen. Assem., 2nd Reg. Sess. (Governor signed 6/1/2018, effective 8/28/18, no form)

Trends in State Legislation (Part 2)

▪ **SDM Agreements**

- **Alaska:** H.R. 336, 30th Leg., 2nd Reg. Sess. (Passed House and Senate; awaiting transmittal to Governor as of 6/1/2018; would include form)
- **Rhode Island:** H.B. 7992, 2017 Leg., Reg. Session (passed House 5/28/18, referred to Senate Committee on Judiciary 5/31/18, would include form); S. 2753, 2017 Leg. Reg. Sess. (intro 3/27/18, hearing/ consideration 4/12/18, held for further study)

Trends in State Legislation (Part 3)

▪ **SDM as Less-Restrictive Alternative Only**

- **New Mexico:** S.B. 19, 53rd Leg., 2nd Reg. Sess. (enacted 2/28/18) - Enacted UGCOPAA, which formally recognizes SDM and requires court consideration of it before ordering guardianship, conservatorship, or other protective arrangements)
- **Maine:** H.R. 91, 128th Leg., 1st Reg. Sess. (enacted 4/20/18) – Completely repealed and replaced Maine’s Probate Code and recognized and required consideration of less restrictive alternatives to guardianship, including SDM.

Trends in State Legislation (Part 4)

▪ Supported Decision-Making & Health Care

- **Maryland:** S.B. 792, 435th Gen. Assem., Reg. Sess. (enacted 5/12/15) - Incorporated “SDM services” into law concerning non-discrimination in access to organ transplantation.
- **Delaware:** H.B. 21, 149th Gen. Assem., 1st Year (enacted 9/13/17) - Similar in effect to above DE law
- **Kansas:** H.B. 2343, 87th Leg., Reg. Sess. (enacted 2/12/18) - Similar in effect to above DE law

Trends in State Legislation (Part 6)

▪ SDM in Education

- **District of Columbia:** D.C. Act 20-486 (eff. 3/2015) -States that “student[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.
 - Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).
- **Texas:** S. 748, 85th Leg. Reg. Sess. (enacted 6/9/2017); H.B. 1886, 85th Leg., Reg. Sess. (enacted 6/15/2017) – Incorporates SDM and SDMA into special education transition planning requirements

Trends in State Legislative Resolutions

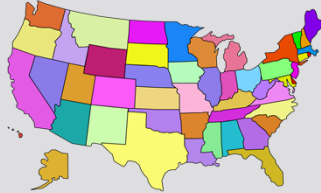
- **Studies of Supported Decision-Making**
 - **Virginia** – H.J. Res. 190, 2014 Leg., Reg. Sess. (adopted 3/4/14)
 - **Maine** – H.R. 900, 127th Leg., 1st Reg. Sess (resolved 3/29/16)
 - **Indiana** – S. Res. 44, 120th Gen. Assemb., 1st Reg. Sess (adopted 4/18/17)
 - **North Carolina** – H.B. 713 (intro. 2017)

U.S. Trends: Examples of SDM Pilots

- **California:** Saks Institute Project
- ➔ **Georgia:** Collaboration with CPR, Georgia Advocacy Office, and Citizens Advocacy Program
- ➔ **Indiana:** Disability Rights Indiana project in the court
- **Kentucky:** My Choice Kentucky
- **Maine:** NRC-SDM State Grantee SDM Pilot (2016-2017)
- ➔ **Massachusetts:** CPR and Nanotuck Resource Associates SDM Pilot (2014-2016) and New State-Wide CPR Pilots
- **New York:** SDM Pilot (2016-2021)
- **Texas:** Volunteer SDMA Advocate Pilot (2012); SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
- **Vermont:** SDM Pilot (underway, state taskforce)

More SDM Updates to Share from Your State?

- Please visit NRC-SDM's "In Your State" at:
<http://www.supporteddecisionmaking.org/states>



- Please email any state updates to NRC-SDM at
jhjp@dcqualitytrust.org

More SDM Policy & Practice Initiatives

Entity	Resource
National Guardianship Association (2016)	Position State on Guardianship, Surrogate Decision-Making, and Supported Decision-Making <ul style="list-style-type: none"> States that SDM should be considered before guardianship and incorporated as part of the guardianship, if guardianship is necessary.
Social Security Advisory Board (2016)	Representative Payees: A Call to Action <ul style="list-style-type: none"> States SSA should consider SDM as an alternative to appointing a representative payee http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
American Bar Association (2016)	PRACTICAL Tool and Resource Guide <ul style="list-style-type: none"> Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM. http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

More SDM Policy & Practice Initiatives

Entity	Resource
Uniform Law Commission (2017)	Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA) <ul style="list-style-type: none"> Model law that, among other things, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship. http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
American Bar Association (2017)	ABA Resolution 113 <ul style="list-style-type: none"> Urges legislatures to amend their guardianship statutes to require SDM “be identified and fully considered as a less restrictive alternative before guardianship is imposed” and a grounds for termination of guardianship. https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf

More SDM Policy & Practice Initiatives

Entity	Resource
AAIDD & Arc (2016)	Joint Position Statement on Autonomy, Decision-Making Supports, and Guardianship <ul style="list-style-type: none"> Promotes less restrictive means of decision-making support, including SDM. http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
U.S. Department of Education, OSERS (2017)	A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities <ul style="list-style-type: none"> Recognized SDM and other less-restrictive decision-making support for adult students in special education. https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf

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** – Report that examines guardianship and alternatives in view of the goals of the Americans with Disabilities Act.
 - <https://www.ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

Developments in Education & Outreach

- **NRC-SDM presented at events** 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!”

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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