

**AN INTRODUCTION TO SUPPORTED
DECISION-MAKING FOR I&R/A
PROFESSIONALS**

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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

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?”

IN OTHER WORDS. . .

- Supported Decision-Making “**solutions also are different for each person.** Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With supported decision-making the **possibilities are endless.**”

Administration for Community Living, “Preserving the Right to Self-determination: Supported Decision-Making”

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)

CONTINUUM OF DECISION-MAKING SUPPORTS

- The person
 - ➔ **“Supported Decision-Making”**
- Advance Directive &/ or Power of Attorney
- Representative payee
- Substitute or Surrogate Health Care Decision-Maker, depending on state law
- Court-appointed Guardian and/or Conservator:
 - Temporary or Permanent
 - General/Plenary or Limited

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 & Shwartz, 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)

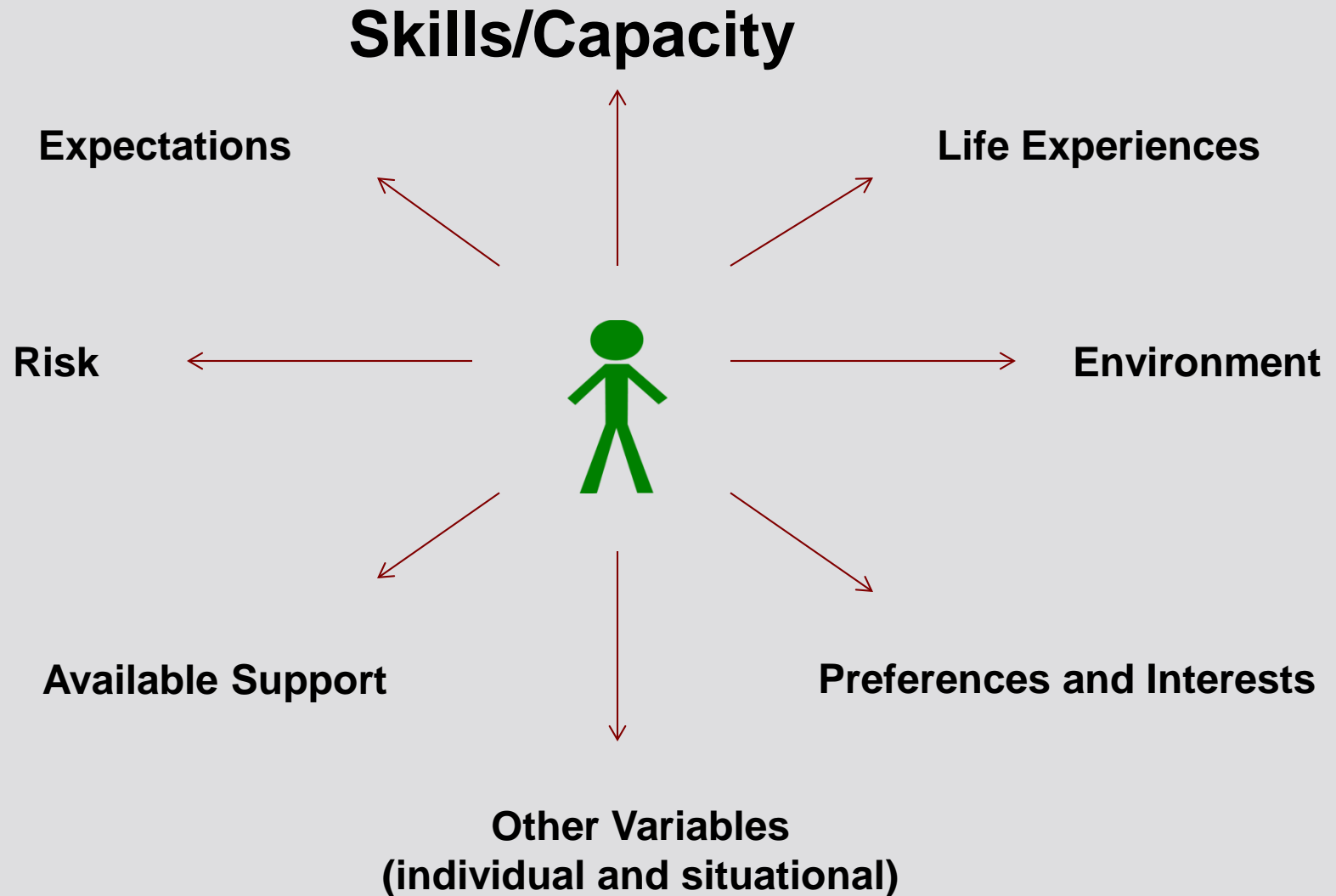
SUPPORTED DECISION-MAKING: HOW?

- Issue #1: Human Decision-Making
- Issue #2: Assessment
- Issue #3: Tools

ISSUE #1: HUMAN DECISION MAKING

- **Many decisions made every day** – Some big, some small.
- Capacity is **not “black and white”**
 - It is not based solely on IQ or diagnosis
 - People may be able to make some decisions, and not others. Or at some times, and not others.
- **No standard process or measure of “goodness”**
 - “Good” decision making seems part science and part art?
 - Who decides if our decisions are “good”?

Issue #2: Assessment



ISSUE #3: SDM TOOLS

- Effective Communication
- Informal or Formal Supports
- Peer Support
- Practical Experiences
- Role Play and Practice
- Life Coaching
- Mediation



ISSUE #3: SDM TOOLS (CONT.)

- Written Documents
 - Release of Information forms – “HIPAA” or “FERPA”
 - Other Written Plans
- Written Agreements
 - Model Forms:
<http://supporteddecisionmaking.org/node/390>
- Supported Decision-Making Guide
 - <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>

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>

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.

TRENDS: SDM IN U.S. CASE LAW

- **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. 2012); Matter of Hytham M. G., 2016 N.Y. Misc LEXIS 2722 (N.Y. Sur. Ct., Kings County, 4/14/16); Matter of Michelle M., 2016 N.Y. Misc LEXIS 2719 (N.Y. Sur. Ct., Kings County 7/22/16)
- **Virginia** -- Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct. 2013) (see <http://www.supporteddecisionmaking.org/impact-stories/jenny-hatch>)

SDM IN U.S. CASE LAW

- **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 (10/2016) (see <http://www.supporteddecisionmaking.org/impact-stories/ryan-king>)

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

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

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SupportedDecisionMaking.Org

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