Supported Decision-Making: From Theory to Practice

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What If....

- Your **life decisions** were called into question by people close to you?
- Your **personal choices** were used as "evidence" that your decision-making capacity was not adequate or in decline?
- Concerns about your health or safety were determined to be **more important** than your personal history, beliefs, heritage and preferences?

Dino and Lillian - 2015

See https://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html?mcubz=0

National Resource Center on Supported Decision Making

- Funded in 2014 by the **Administration on Community Living** and led by **Quality Trust**
- 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

- An approach to assisting people with making life decisions that **mirrors how everyone makes decisions**.
- Giving people the **help they need and want** to understand the situations and choices they face, so they can **make their own decisions**.
- Starts with acknowledging that people with disabilities and older adults have **the right to make their own decisions**.

What is "Guardianship" for Adults?

- Guardianship is:
  - A **formal legal step** that removes some or all decision-making from an adult and assigns it to a fiduciary, called a "**guardian**."
- To be a guardian over an adult, a person has to go through a **court process** and get a **court order**.
- In DC, a judge decides if the person with a disability is **"incapacitated"** **AND**, if so, whether the **guardianship is "necessary."**

Why Do People Think About Getting Guardianship?

Why do people think about getting guardianship?

Family members and support teams may:

- Have been told by the person's **school** to do so
- Be concerned about:
  - **health care** and access to a doctor.
  - **financial abuse**
  - linking the person to available **services**
- See the person in **crisis** or an **emergency**

Why Think about Other Options First?

- Guardianship **takes away** some or all of a person's rights to make important decisions about his or her life.
- The **court** will become part of both the guardian's and the person's life going forward.
- Guardianship can **change relationships**.
- Guardianship can take **time and cost money**.
- For many people with disabilities, decision-making should be seen as a **learned skill** – people need the opportunity to practice!

And It Also Makes Sense!

- **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 disabilities 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)

More evidence

- **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)

More evidence

- Students with disabilities who have self-determination skills are **more likely to successfully make the transition to adulthood**, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997)
- **Older adults with more self-determination** have improved psychological health, including better adjustment to increased care needs (O'Connor & Vallerand, 1994)

More evidence

- **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 on dates and **socialize** in the community
  - Practice the **religion of their choice**

(National Core Indicators, 2013-2014)

Or, As the National Guardianship Association Says

"Alternatives to guardianship, **including supported decision making**, should always be identified and considered whenever possible **prior to the commencement of guardianship proceedings**."

- National Guardianship Association, "Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making" (2015)

And Yet....

- Guardianship has been the **default option** for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).
- Estimated number of adults under guardianship has **tripled** since 1995 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).
- **90%** of the public guardianship cases reviewed resulted in plenary/general guardianship - where the guardian is empowered to make **all decisions** for the person. (Teaster, Wood, Lawrence, & Schmidt, 2007)

Guardianship may be needed:

- In emergency situations when
  - The person is incapacitated and cannot give consent
  - The person did not previously identify how decisions should be made in that situation
  - There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means
- To support people:
  - Who face critical decisions and have no interest in or ability to make decisions
  - Who need immediate protection from exploitation or abuse

Guardianship is never needed just:

- “Because you have an IQ of ___ ”
- “Because you are elderly”
- “Because you have ____ diagnosis”
- “Because you need help”
- “Because that’s the way its always been”

That’s not enough!

Explore Alternatives First

- **Finding the Right Support:**
  - What **kind of decision** needs to be made?
  - How much **risk** is involved?
  - How hard would it be to **undo** the decision?
  - Has the person made a **decision like this** before?
  - Is the decision likely to be **challenged**?
- **Ask**: What is the **least restrictive** support that might work?

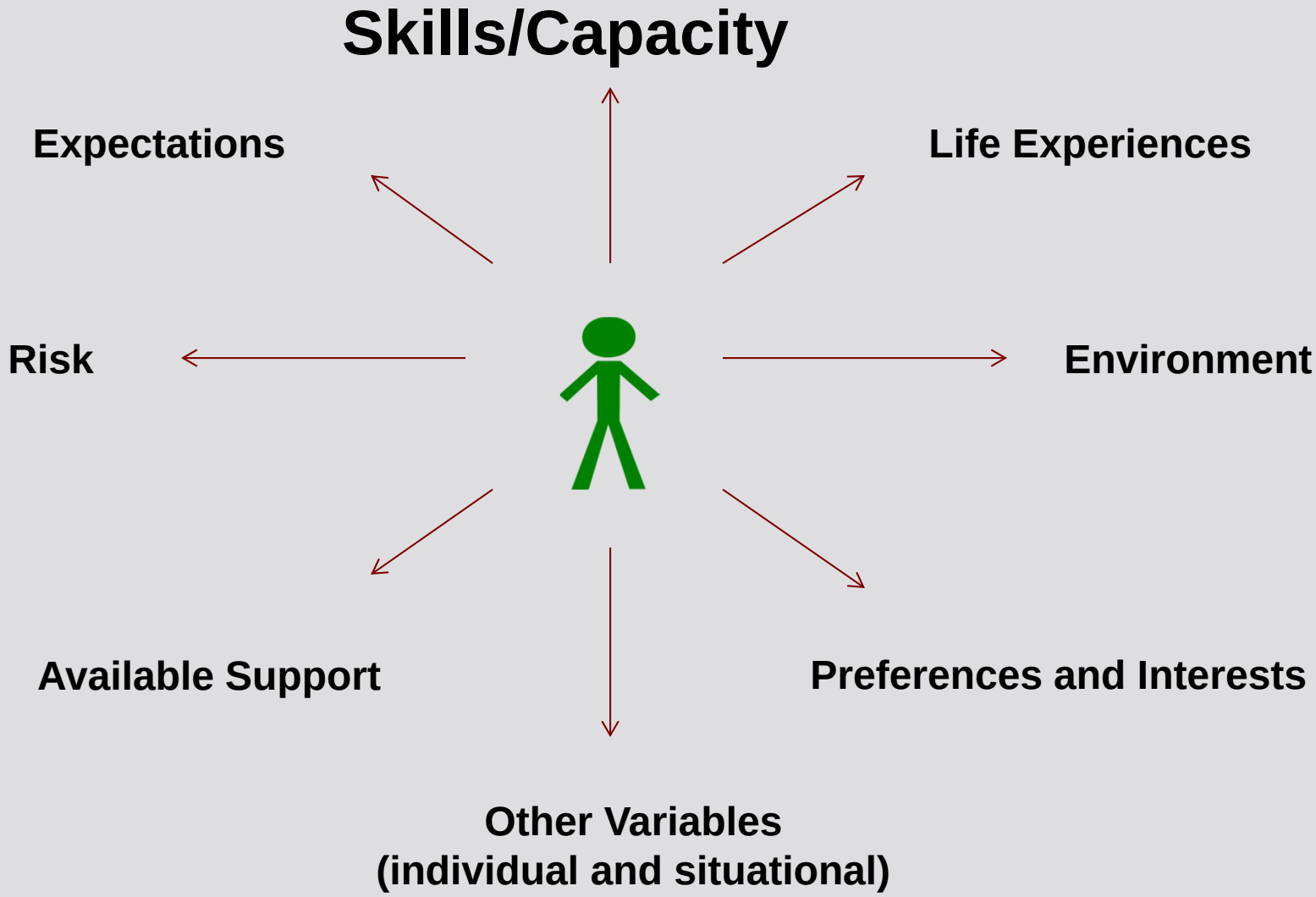
RETHINK "CAPACITY"

- Capacity is **not**
  - **"all or nothing"**
  - Based solely on **IQ or diagnosis.**

- People **may have "capacity" to**:
  - Make **some decisions** but not others.
  - Make **decisions some times** but not others.
  - **Make decisions if they get help understanding** the decision to be made.

- A **lack of opportunity** to make decisions can prevent people from developing capacity or **further decrease capacity** (Salzman, 2010)

RETHINK "ASSESSMENTS"



Human Decision-Making

- Typical decision-making is **flawed**
- **No standard way to measure "goodness"**
- **Culture and personal values** are important
  - **Most** life decisions are **personal**
- **History, experience and relationships** often reflect personal preference and identity
- **Brain and decision making science** are deepening our understanding of ways to help

DIGNITY

- Means our **inherent value and worth** as human beings
- Honors a person's **unique identity**
- **Preserves** any existing capacity
- Ensures **access to accommodation** as needed
- "Don't judge **my choices** without knowing **my reasons**"

Indignity =
degradation, debasement or humiliation

Continuum of Decision-Making Supports

Supported Decision-Making

- **Advance Directive &/or Power of Attorney**
- **Educational Representative**, appointed by OSSE
- **Substitute Health Care Decision-Maker** under DC Code§21-2210
- **Representative payee**, appointed by SSA
- **Court-appointed Guardian or Conservator**
  - Time-limited Emergency or Health Care Guardian
  - Permanent Limited Guardian
  - Conservator
  - Permanent General Guardian

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)

Or, as Defined in DC Bill 22-0154

- "Supported decision-making" means "a process of **supporting and accommodating** an adult with a disability to **enable the adult to make life decisions**, including decisions related to
  - where and with whom the adult wants to **live**,
  - the **services, supports, and medical care** the adult wants to receive, and
  - where the adult wants to **work**,
- **without impeding the self-determination** of the adult."

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.**"

– Herbert King

For more on Ryan's story, visit http://www.supporteddecisionmaking.org/impact-stories/ryan-king

Freedom for Ryan King

Court terminated 15-year guardianship in favor of SDM.

See D.C. Superior Court Probate Division Order (10/11/2016) & Press Release at http://www.supporteddecisionmaking.org/node/427

For more on Ryan's story, visit http://www.supporteddecisionmaking.org/impact-stories/ryan-king

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

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?"

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)

Supported Decision-Making: How?

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

Supported Decision-Making: How?

- 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

Supported Decision-Making: Opportunities Abound!

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

For Archived Webinars on the above, visit:
http://www.supporteddecisionmaking.org/education

Supported Decision-Making in "Person Centered Planning"

Medicaid HCBS Waiver programs -**Final** Rules CMS 2249-F and CMS 2296-F

Services MUST:

- Be **Driven by the person**
- Include **people chosen by the person**
- Occur at times/locations convenient to the person

Supported Decision-Making in "Person Centered Planning"

Person Centered Plan MUST:

- Address "health and long-term services and support needs in a manner that reflects **individual preferences and goals**."
- Result "in a **person-centered plan** with **individually identified goals and preferences**, including those related community participation, employment, income and savings, health care and wellness, education and others."

https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html

Supported Decision-Making in Health Care

- **Remember the Americans with Disabilities Act!**
  - Doctor must **reasonably accommodate** the person's disability when obtaining his or her **informed consent**.
  - **Not all medical decisions are the same** → Flu Shot vs. Surgery
- **Remember "HIPAA" Release Forms!**
  - The person can sign a release form to authorize the doctor to share confidential information with the person's supporters, so they can provide support to the person in making his or her own decisions.
- **Model D.C. Durable Power of Attorney for Health Care** with Special Provisions for Supported Decision-Making
  - http://www.supporteddecisionmaking.org/node/390

What About Education? SDM is Already in D.C. Law & Policy

- **Special Education Student Rights Act of 2014**
  - "[S]tudent[s] who ha[ve] reached 18 years of age may receive support from another competent and willing adult to aid them in their decision-making"
  - See D.C. Act 20-486, Sec. 104(b)(1) & (2) (March 2015)
- **Office of the State Superintendent of Education Regulations (July 2016)**
  - Includes a definition of Supported Decision-Making and a section to implement it.
  - See D.C. Mun. Regs. Title 5-E, Secs. 3001.1, 3034.1-3034.3
  - Available at https://osse.dc.gov/service/education-decision-making

What About Education? SDM is Already in D.C. Law & Policy

- **D.C. Public Schools, *Transfer of Rights Guidelines*** (Aug. 2013)
  - Recognizes supported decision-making as an alternative to guardianship for adult students with disabilities in D.C.
  - Available at: https://transitioncentral.files.wordpress.com/2011/12/transfer-of-rights-guidelines.pdf
- **DCPS Supported Decision-Making Form**
  - Available at http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form.pdf
- **OSSE Supported Decision-Making Model Form**
  - Available at https://osse.dc.gov/service/education-decision-making

What about Money?

- **Supported Decision-Making**
- **Direct deposit and payment**
- **Joint bank accounts**
- **ABLE Accounts (www.ablenrc.org)**
- **Financial Power of Attorney**
- **Representative payee**
- **Trusts**
  - Special Needs Trust vs. Pooled Trust
  - Third Party vs. Self-Settled

Supported Decision-Making Within Guardianship

- "**Supported decision making** should be considered for the person **before guardianship**, and the supported decision-making process should **be incorporated as a part of the guardianship** if guardianship is necessary."

  National Guardianship Association, "Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making" (2015)

Supported Decision-Making Within Guardianship

Guardians are required to:

- "**Include the [person] in the decision-making process** to the maximum extent of the [person's] ability" and
- "Encourage the [person] to **act on his or her own behalf** whenever he or she is able to do so, and to **develop or regain capacity** to make decisions in those areas in which he or she is in need of decision-making assistance, to the maximum extent possible."
- D.C. Code §21-2047(a)(7) & (8):

Supported Decision-Making Within Guardianship

- **Guardian Decision-Making Standards**
  - **General Rule:** "Substituted Judgment" Standard.
  - **Exception:** "Best Interest" Standard **only if** the person's wishes are unknown and remain so after reasonable efforts.
  - D.C. Code § 21-2047(a)(6):
- **Definition of "Substituted judgment"**
  - "making a decision that **conforms as closely as possible with the decision that the individual would have made**, based upon the knowledge of the beliefs, values, and preferences of the individual."
  - D.C. Code § 21-2011(25A)

SDM Within Substitute Health Care Decision-Making

- **Substitute Health Care Decision-Maker Standard**
  - ". . . based on the **known wishes** of the person or, if the person's wishes are unknown and cannot be ascertained, on a good faith belief as to the person's best interest."
  - D.C. Code § 21-2210(b)

Supported Decision-Making: Where?

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

Supported Decision-Making: Where?

State Courts	Enacted State Statutes		State Pilots
PA (1999)	Agreement	TX (2015)	TX Volunteer SDM Advocate Pilot (2012)
NY (2012, 2016)		DE (2016)	TX SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
VA (2013)	Other	DC (2015)	MA SDM Pilot (CPR and Nonotuck Resources Associates) (2014-2016)
MA (2015)		MD (2015)	NY SDM Pilot (2016-2021)
DC (2016)		MA (2016)	ME SDM Pilot (2016-2017)
VT (2017)	Studies	VA (2014)	VT SDM Pilot (underway, state taskforce)
		ME (2016)	

For specific citations, please email mwhitlatch@dcqualitytrust.org

Other SDM Policy & Practice Initiatives	Web Sources
ABA (2016 & 2017)	• https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf • http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
SS Advisory Board (2016)	• http://ssab.gov/Portals/0/ OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
AAIDD & Arc (2016)	• http://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
NRC-SDM Survey (2016)	• http://www.supporteddecisionmaking.org/node/396
U.S. DOE, OSERS (2017)	• https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf
Uniform Law Comm., UGCOPAA (2017)	• http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act

To Reach the SDM Goal:

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

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

Jenny Hatch Justice Project

- Formed in 2013, JHJP is dedicated to **protecting and advancing the rights of people with disabilities** to make their own decisions.

- Thanks to the generous funding of the **D.C. Bar Foundation**, we provide free legal services to low-income D.C. residents at risk of or under overly restrictive and/or undue adult guardianships.

Quality Trust
FOR INDIVIDUALS WITH DISABILITIES

When should you call us?

Is the person a DC resident who:

- Has **questions about** his or her **decision-making rights**?
- Is **unhappy with his or her guardian** and want help?
- Wants help with **less-restrictive forms of decision-making support**?
  - Supported Decision-Making
  - Powers of Attorney
  - Advance Directives

Contact: Jessica A. Bronson, JHJP Staff Attorney
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Quality Trust
FOR INDIVIDUALS WITH DISABILITIES

Ask Questions Now or Later

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