SUPPORTED DECISION-MAKING:

Update on U.S. Trends & Best Practices

Consumer Voice Conference
November 7, 2017

Morgan K. Whitlatch

Legal Director, Quality Trust

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

Quality Trust
FOR INDIVIDUALS WITH DISABILITIES

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**?
- You were **not included** in discussions about where you live, what medical treatment you receive, and how your money is spent?

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: 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."

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)

Continuum of Decision-Making Supports

Supported Decision-Making

- Advance Directive &/ or Power of Attorney
- Representative payee
- Other Substitute or Surrogate Health Care Decision Maker, depending on state law
- Court-appointed Guardian and/or Conservator
  - Temporary or Permanent
  - General/Plenary or Limited

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**.
- It can vary in **scope** — time-limited vs. permanent; general vs. limited.
- Guardianship **laws vary by state**

GUARDIANSHIP

- Guardianship laws **vary by state**.

- 1997 Model Law: Uniform Guardianship and Protection Proceeding Act

  Guardianship is ordered when:

  1) An adult **lacks "capacity"** to make decisions for him or herself; **AND**

  2) The person's identified needs **cannot be met by less restrictive means**

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**.

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

- **Older adults with more self-determination** have improved psychological health, including better adjustment to increased care needs (O'Connor & Vallerand, 1994)

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....

- 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 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?

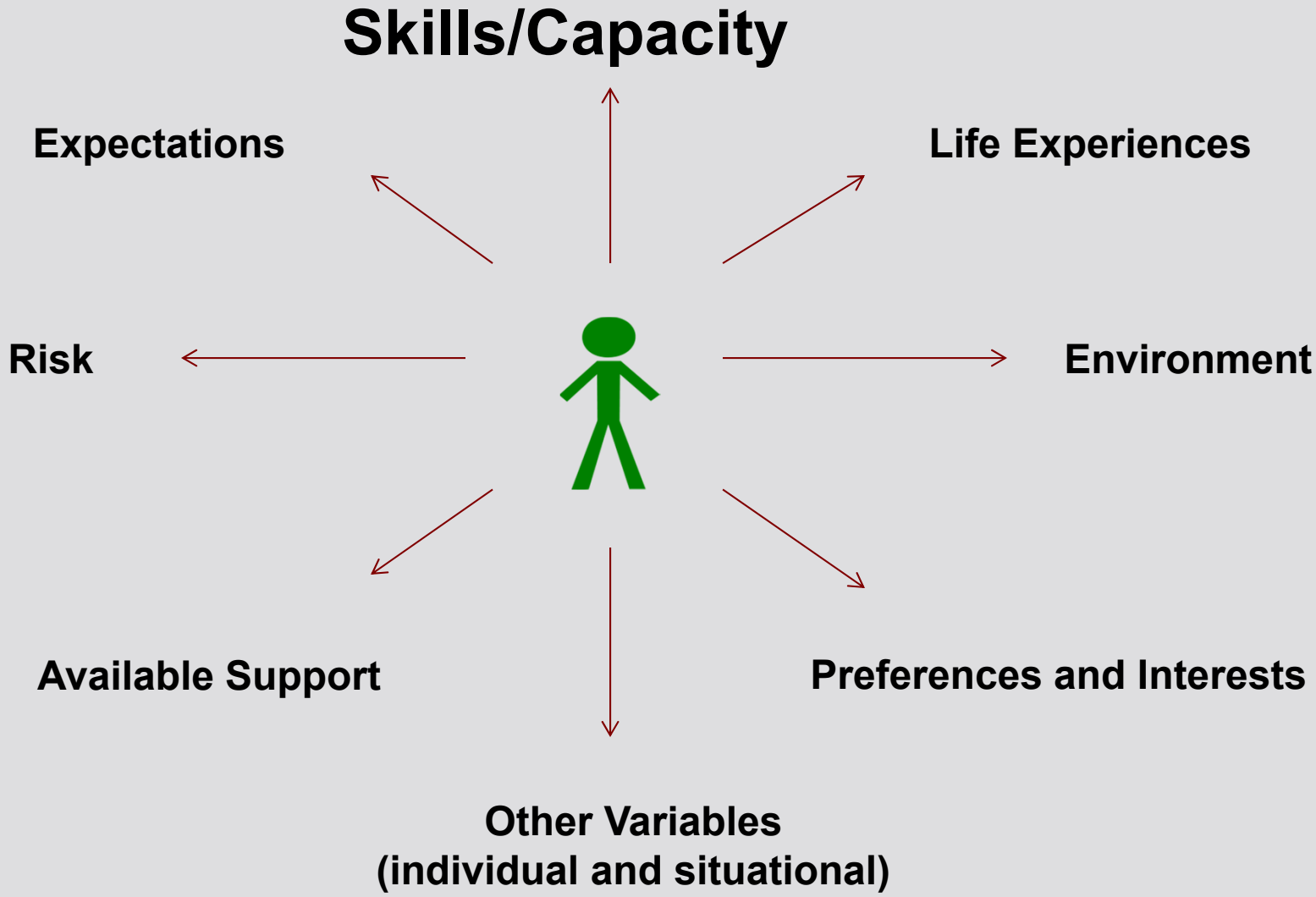
RETHINK "CAPACITY"

- 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"



Rethink "Human Decision-Making"

- **Many decisions** are made every day
  - Some are big, and some are small.
- 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

Indignity =
degradation, debasement, or humiliation

Supported Decision-Making: What?

- An approach to assisting people with making life decisions that **mirrors how everyone makes decisions**.
- Gives people the **help they need and want** to understand the situations and choices they face, so they can **make their own decisions**
- **Supported** Decision-Making **≠ Substitute** Decision-Making

Supported Decision-Making: Why?

- The shift from “surrogacy” to support is consistent with:
  - the Older Americans Act
  - the Americans with Disabilities Act, and
  - Medicaid Home and Community Based Services regulations.

Remember: U.S. Americans with Disabilities Act

- Provides **civil rights protections** for people with disabilities (*e.g.*, dementia and age-related 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.
  - 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)

What we know

- The shift from “surrogacy” to support is consistent with the Older Americans Act, ADA DD Act and other regulatory and legal requirements
- Trusted people may be fewer as we age
- Ageism and disability bias are real
- Risk of undue influence may increase over time
- Institutions are “risk adverse”
- Safeguards linked to “protection” may eliminate control

Relationships

- Support networks can contribute in positive or negative ways
- Family is dynamic
- Paid vs Unpaid
- Higher number of relationships can act as a safeguard

SDM Tools

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

SDM Tools

- **Written Documents**
  - Release of Information forms – “HIPAA”
  - 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
- **Archived Webinars**
  - http://www.supporteddecisionmaking.org/education

What Concerns do We Hear about Older Adults using SDM?

What Concerns do We Hear about Older Adults using SDM?

- Abuse and exploitation
- Undue influence by “supporters”
- The decisions he makes are not in his “best interest.”
- She asks the same question, over and over again.
- He forgets the choice that he made.
- Communicating with her is hard.
- Eventually, SDM won’t work.

SDM and Dementia

- **Declines** in Memory and Cognition
  - Not all dementia affects each person the same way
- **Early Diagnosis**:
  - Improved treatment options (no “cure”)
  - Improved opportunities for **PLANNING** and building a support network
- As dementia progresses:
  - Look at **history of decisions and preferences**
  - A **history of practicing SDM will prepare** supporters

Implementing SDM: How?

- **Example 1: Informed Consent** in Medical Care
- **Example 2: Person Centered Planning** in the Medicaid World
- **Example 3: Within the Guardian/Person Relationship**

Supported Decision-Making in Health Care

Like “Capacity” is to guardianship, **informed consent** is the lynchpin of self-determination in medical care

Three Key Parts:

- **Information** to the person
- **Understanding** by the person
- **Choice** by the person

Example 1: SDM in Health Care

- Remember the **Americans with Disabilities Act!**
  - Doctor must **reasonably accommodate** the person's disability when obtaining his or her informed consent.
    - **Assistance can be provided** to help the person make and participate in medical decisions.
    - **"Explain that to me in English"**
- Remember **not all medical decisions** are the **same**!
  - Flu Shot vs. Surgery

SDM in Health Care

- **Remember "HIPAA" Release Forms!**
  - The person can sign a **release form** to authorize the doctor to **share confidential medical information** with the person's supporters, so they can provide support to the person in making his or her own decisions.

- **Example: Model D.C. Durable Power of Attorney for Health Care** with Special Provisions for Supported Decision-Making
  - http://www.supporteddecisionmaking.org/node/390
  - For informational purposes only. State POA laws vary.

EXAMPLE 2: SDM 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

SDM 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

You Can Use Supported Decision-Making

- To help the person **understand** all components of the plan
- To help the person **prioritize** what is important to him/her
- To help the person **build a network** of supporters for the plan and beyond
- To help the person **communicate and implement** his or her choices

It takes a Network

A Supported Decision-Making Team can include:

- The Person
- The Person's chosen Friends, Family, Professionals
- Case Manager
- Providers
- Advocates
- Anyone Else who Can Contribute!

THINK BROADLY!

TEAMWORK

- **Review!**
  - **Go through each area** of the individual's life.
  - Example: Financial, Medical, Social, Employment
- **Brainstorm!**
  - Does the person need **support** in these areas?
  - If so, talk about what support could help, **who** could provide it, and **how**
- **Write!**
  - As you develop support solutions, create a **written plan or "road map"** for the person and team to use.
- **See Tool**
  - http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf

EXAMPLE 3: SDM 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)

SDM Within Guardianship

- "**Under all circumstances**, efforts should be made to encourage every person under guardianship:
  - to **exercise his/her individual rights** retained and
  - **participate**, to the maximum extent of the person's abilities, in **all decisions** that affect him or her,
  - to **act on his or her own behalf** in all matters in which the person is able to do so, and
  - to **develop or regain his or her own capacity** to the maximum extent possible."

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

SDM: WHERE?

NRC-SDM State Grantees

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

More on U.S. State Trends: Examples

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)
KY (2017)		**ME** (2016) **IN** (2017)	

For specific citations, please email mwhitlatch@dcqualitytrust.org

More SDM Policy & Practice Initiatives

Entity	Resource
Social Security Advisory Board (2016)	**Representative Payees: A Call to Action** • 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** • 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)** • 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** • 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

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.

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.

Join the Conversation

National Resource Center for Supported Decision-Making:

www. SupportedDecisionMaking.Org

jhjp@dcqualitytrust.org

202-448-1448

Morgan K. Whitlatch

MWhitlatch@DCQualityTrust.Org

202-459-4004

About this Project

This project is supported, in part, by grant number HHS-2014-ACL-AIDD-DM-0084, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.