

WHAT TOOLS TO USE?

DECISION-MAKING SUPPORTS FOR PEOPLE WITH DISABILITIES AND OLDER ADULTS

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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



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 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

HUMAN DECISION-MAKING



- Typical decision-making is flawed
- No standard process or measure of “goodness”
- Culture and personal values are important
- History, experience and relationships often reflect personal preference and identity
- “Good” decision making seems part science and part art
- Brain and decision making science are deepening our understanding of ways to help

MOST LIFE DECISIONS ARE PERSONAL

YOU CAN'T JUDGE
my choices
WITHOUT KNOWING
my reasons
diaryoflittlesecrets

CRITICAL QUESTIONS

- How do you assess capacity for decision-making?
- How do you determine which supports will help?
- What practical steps can you take to help?



CAPACITY....



- People may have “capacity” to make some decisions but not others.
- Or be able to make decisions some times but not others.
- Or be unable to make decisions unless they get help understanding the decision to be made.
- Lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity. (Salzman, 2010)

DIGNITY...

- Our inherent value and worth as a human beings
- Honors person's unique identity
- Preserves any existing capacity
- Ensures access to accommodation as needed

Indignity = *degradation, debasement or humiliation*



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



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

- Guardianship **laws vary by state.**
- Uniform Guardianship & 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?

Parents, family members, support teams may:

- Have been told by the person's **doctor or health/home care provider** 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 SHOULD YOU 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!

RIGHTS THAT MAY BE LOST OR AFFECTED BY GUARDIANSHIP

- Voting
- Marriage and reproductive rights
- Residence and travel
- Association
- Health care and medical decisions
- Access to own money
- Right to contract

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 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)

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?

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”

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.**”

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

– Herbert King

SDM TOOLS

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



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 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

DE – Led by Delaware Developmental Disabilities Council

IN -- Led by The Arc of Indiana

ME -- Led by Disability Rights Maine

NC -- Led by First In Families of North Carolina

WI – Led by Wisconsin Board for People with Developmental Disabilities

For **final reports** and links to related **SDM resources**, visit:
<http://www.supporteddecisionmaking.org/node/425>

2016 - 2017

FL – Led by the Northern Florida Office of Public Guardian

GA – Led by the University of Georgia

ME – Led by Disability Rights Maine

NV – Led by the Second Judicial District Court, State of Nevada, Washoe County

NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)

TN – Led by The Arc Tennessee

MORE SDM TRENDS IN U.S.

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)	

OTHER POLICY AND PRACTICE INITIATIVES

Other Initiatives	Web Sources
NGA (2015)	http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
SS Advisory Board (2016)	http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
AAIDD & Arc (2016)	http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
ABA (2016)	http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
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., UGPPA (Draft 2017)	http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act

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“POWER OF ATTORNEY” OR “POA”

■ What is a POA?

- A legal paper where an adult (“principal”) agrees that someone else (an “agent” or “attorney-in-fact”) will make decisions for him/her under certain circumstances and in certain areas of his/her life.

■ How’s a POA different from guardianship?

- The principal decides what power to give away and who gets it, not a court.
- The principal can cancel or change the POA.

COMPARE . .

Health Decision

- Deciding to have open heart surgery

Health Care Power of Attorney

- Deciding who you would trust to make that decision for and with you.

“POWER OF ATTORNEY”: HOW?

- Forms and Requirements **Vary by State**
 - **May be broad or narrow** in scope (financial, educational, health care, etc.)
 - **May be limited** in time or purpose
 - Without a special provision (“**durability clause**”), the POA authority generally ends if the principal becomes unable to make decisions.
- **A POA may go into effect:**
 - Immediately
 - At a later specified date
 - At a specified future event

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WHAT ARE OPTIONS THAT CAN BE USED FOR DECISIONS ABOUT FINANCES?

- **Supported Decision-Making**
- **Direct deposit and payment**
- **Joint bank accounts**
- **Financial power of attorney**
- **Representative payee**
 - **Manages a person's social security benefits and is appointed by the Social Security Administration, not a court.**
- **Trusts**

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STATE HEALTH CARE DECISIONS ACTS

- Varies from state to state
- See ABA Commission on Law and Aging, “Default Surrogate Consent Statutes” by State (Sept. 2016)
 - Available at: http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.authcheckdam.pdf

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SDM – BEFORE & 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)

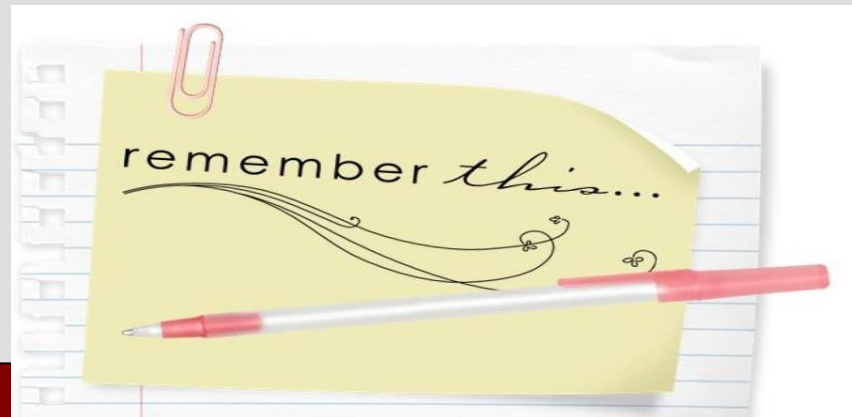
SDM PRINCIPLES WITHIN GUARDIANSHIP

- **“Under all circumstances**, efforts should be made to encourage every person:
 - 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)

IN CLOSING....

- One strategy won't fit all situations
- Decision-making requires learning and adaptation throughout life
- We all need support sometimes
- The right to make choices is a fundamental human right!!!!



JOIN THE CONVERSATION

National Resource Center for Supported Decision-Making

www.SupportedDecisionMaking.org

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