

# 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?
- **Decisions about you** were made **without you**?

# 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>

# MARGARET “JENNY” HATCH



See <http://www.supporteddecisionmaking.org/impact-stories/jenny-hatch>

# 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](http://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 their 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

# “ENEMIES” OF GOOD DECISIONS

- Addressing the wrong question
- Looking only for information that “confirms” our thinking
- Emotions
- Being too confident
- Lack of engagement
- No creative exploration of options

# MOST LIFE DECISIONS ARE PERSONAL

**YOU CAN'T JUDGE**  
*my choices*  
**WITHOUT KNOWING**  
*my reasons*  
doryoflittlescrets

# 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?



# MR. SMITH

Mr. Smith is 52 years old and has lived in supervised settings all his life. He has finally achieved his goal of living in his own apartment with just drop-in staff. He has many skills, is eager to learn, but has never lived on his own. He does not always identify the things he needs help with. Staff learns about this after things have gone wrong, such as....

- He has been bouncing checks for rent because he has withdrawn money using the ATM card.
- He has been inviting people over to his apartment that staff are worried are taking advantage of him. One young man moved in and had other friends over to party.
- He isn't keeping his apartment clean and has no schedule to follow.

# MRS. JONES

Mrs. Jones resides in a nursing home that is closing and all residents are being moved to alternative placements. She does not speak and requires total assistance from nursing home staff. She was known to have a son, but staff indicated that there has been no recent contact with the son. Reportedly phone calls and letters sent did not receive responses. Staff working with Mrs. Jones consider her incapable of making informed decision regarding her health care and well-being, but there has been no court action on this issue.

# 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

These are examples of less-restrictive alternatives to guardianship.

There are many more! – MOLST forms, joint accounts, ABLE accounts, trusts, technology, etc.

# WHAT IS “GUARDIANSHIP” FOR ADULTS?



# 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.**
- 1997 Model Law: 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 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

## 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 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”

# TOOLS THAT ADVANCE SDM

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



# LEARNING TO LISTEN

- Not being able to talk doesn't mean you don't have anything to say
- Not know how to express yourself should not mean you are ignored
- Everything people do communicates
- Our job as supporters is to move beyond assumptions
- Try many different approaches until one works

# PEER SUPPORT

- Occurs when people provide knowledge, experience, emotional, social or practical help to each other
- Creates relationships where people learn and grow together
- Exposes people to others with relevant experience from people who have experienced similar situations

# LIFE COACHING

- Is NOT therapy, consulting, counseling, or advice.
- Is a process priorities in the person's life
- Helps the person discover barriers, challenges and select a course of action in to make life better
- Involves a relationship between the coach and the person of them, giving all the power to the person.
- Believes that the person knows the answers to questions or problems he or she may be facing in his or her life
- Asks questions to empower people to help them get to the answers already have within

# MEDIATION

- A voluntary, collaborative process that uses a trained, neutral third party to facilitate the negotiation of disputes
- The goal is to reach an agreement that everyone supports
- Each participant has complete decision-making power and a veto over each and every provision of any mediated agreement

# RESOURCES TO USE

- 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>

## CHANGING PRACTICE TO INCORPORATE SDM

- How do people develop and maintain good decision-making skills?
- What role and responsibility do professional “helpers” have to support decision making?
- What about the role of families?
- What should support look like?
- How does guardianship fit in?

# SUPPORTING PEOPLE TO DEVELOP AS DECISION-MAKERS

- Involve youth in decisions early
- Support decision-making skill development
- Use the support approach that imposes the least restriction on rights
- Benchmark to the process and experience of typical young people
- Always plan ahead – documenting and updating plans as the person's preferences develop

# PRACTICAL ASSUMPTIONS

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 need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein 2012)

# FINDING A PATH FORWARD....

- Be proactive
- Assess each person's situation
- Identify opportunities for
  - Learning more about options
  - Getting experience with decision-making
  - Respecting the person as the primary decision-maker
  - Involving family and others as supporters

# SUPPORTED DECISION-MAKING: WHY? RYAN'S STORY



For more on Ryan's story, visit  
<http://www.supporteddecisionmaking.org/>

“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

# 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 ON U.S. STATE TRENDS: EXAMPLES

State Courts	Enacted State Statutes	State Pilots
<b>PA</b> (1999)	<u><b>Agreement</b></u>	<b>TX</b> (2015) <b>DE</b> (2016) <b>TX</b> Volunteer SDM Advocate Pilot (2012)
<b>NY</b> (2012, 2016)		<b>WI</b> (2018) <b>DC</b> (2018) <b>TX</b> SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
<b>VA</b> (2013)	<u><b>Other</b></u>	<b>DC</b> (2015) <b>MA</b> SDM Pilot (CPR and Nonotuck Resources Associates) (2014-2016)
<b>MA</b> (2015)		<b>MD</b> (2015) <b>NY</b> SDM Pilot (2016-2021)
<b>DC</b> (2016)		<b>ME</b> SDM Pilot (2016-2017)
<b>VT</b> (2017)	<u><b>Studies</b></u>	<b>VA</b> (2014) <b>VT</b> SDM Pilot (underway, state taskforce)
<b>KY</b> (2017)		<b>ME</b> (2016) <b>KY</b> My Choice Kentucky
<b>NV</b> (2017)		<b>IN</b> (2017) <b>CA</b> Saks Institute Project

For specific citations, please email [mwhitlatch@dcqualitytrust.org](mailto:mwhitlatch@dcqualitytrust.org)

# MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
<b>Social Security Advisory Board (2016)</b>	<b>Representative Payees: A Call to Action</b> <ul style="list-style-type: none"><li>• States SSA should consider SDM as an alternative to appointing a representative payee</li><li>• <a href="http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf">http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf</a></li></ul>
<b>American Bar Association (2016)</b>	<b>PRACTICAL Tool and Resource Guide</b> <ul style="list-style-type: none"><li>• Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM.</li><li>• Being used by social workers at the Center for Excellence in Supported Decision-Making, led by Volunteers of America of Minnesota</li><li>• <a href="http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html">http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html</a></li></ul>

# MORE SDM POLICY & PRACTICE INITIATIVES

Entity	Resource
<b>Uniform Law Commission (2017)</b>	<b>Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA)</b> <ul style="list-style-type: none"><li>• Model law that, among other things, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship.</li><li>• <a href="http://uniformlaws.org/Committee.aspx?title=Guardianship,Conservatorship,andOtherProtectiveArrangementsAct">http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act</a></li></ul>
<b>American Bar Association (2017)</b>	<b>ABA Resolution 113</b> <ul style="list-style-type: none"><li>• 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.</li><li>• <a href="https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf">https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf</a></li></ul>

# MORE SDM POLICY & PRACTICE INITIATIVES

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

# “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

# 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 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**

# CONTINUUM OF DECISION-MAKING SUPPORTS

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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](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)

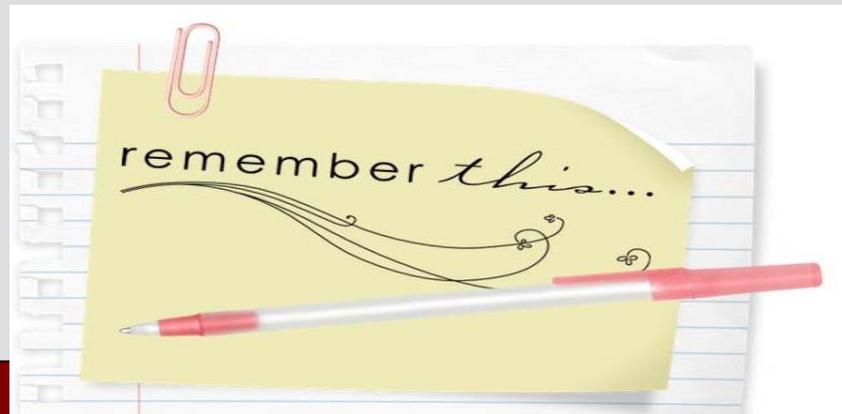
# SDM PRINCIPLES WITHIN GUARDIANSHIP

- **“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](http://www.SupportedDecisionMaking.org)

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