

Supported Decision-Making in Action Throughout the Life Span

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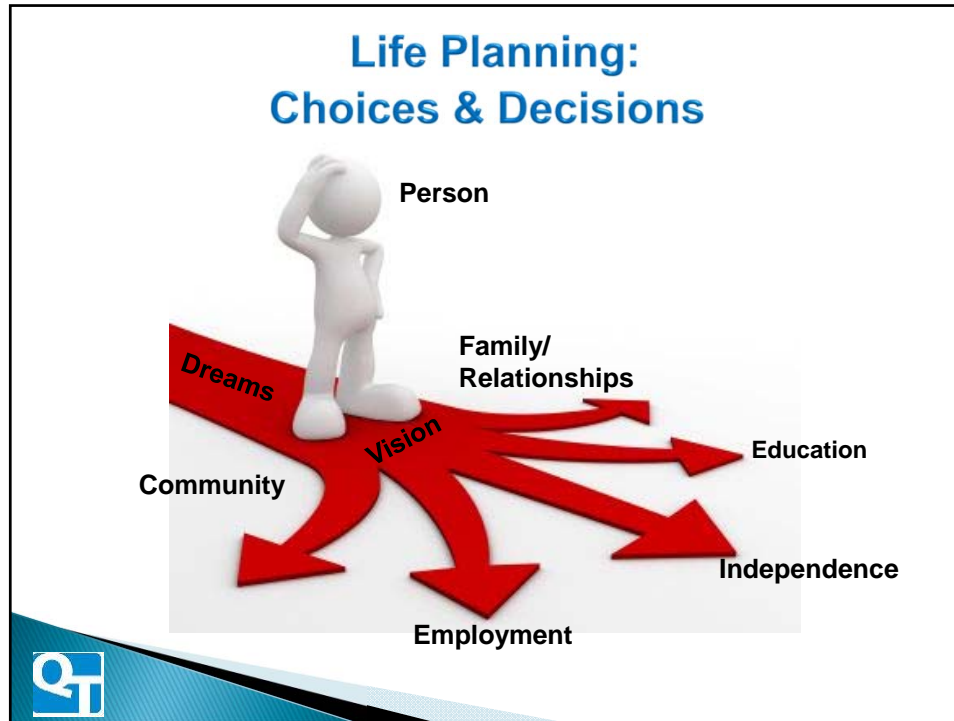
Quality Trust for Individuals with Disabilities
December 2017



Quality Trust

- ▶ Independent advocacy and monitoring
- ▶ Children and adults with disabilities in DC
- ▶ Dignity, respect, and autonomy
- ▶ Rights protection and decision-making supports
- ▶ Partnering with families
- ▶ National Resource Center for Supported Decision-Making (2014)





“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.

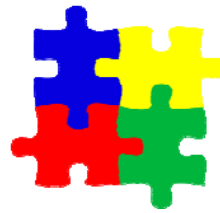
(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

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

These are examples. There are many more – e.g., joint accounts, ABLE accounts, trusts, etc.



“Guardianship” for Adults

- ▶ Guardianship is:
 - A **formal legal step** where a **court removes** some or all decision-making **rights** from an adult and **assigns them** 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**, depending on the state and the court.
 - e.g., time-limited vs. permanent; “guardian” vs. “conservator”; “guardian of the person” vs. “guardian of the property”; general vs. limited.



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 lives going forward.
- ▶ Guardianship can **change relationships**.
- ▶ Guardianship can take **time** and cost **money**.
- ▶ Guardianships are **difficult to modify or terminate**.
- ▶ For many people with disabilities, decision-making is 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, Rifenshark, & Little 2014; Wehmeyer & Schwartz, 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 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)
- ▶ Promoting self-determination is a **special educational “best practice”** (Wehmeyer & Hughes, 1998).
- ▶ Schools should focus on **improving students’ ability to set goals, solve problems, make decisions and advocate for themselves** and, just as importantly, to give students the opportunity to exercise these skills (Wehmeyer & Gragoudas, 2004).



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 is 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).



What are the challenges?

- ▶ Bias towards the use of substituted decision-making as a primary support
- ▶ Concerns for health and safety dominate
- ▶ No support has been given to think through how the parent/child relationship changes in adulthood
- ▶ Family members have gotten a lot of different advice over the years about...
 - the ability of the family member with a disability
 - the options available to support their family member
 - how the law really works



Supported Decision-Making: Why? Ryan's Story



“Don’t judge me before you know me”

– Ryan

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



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.**”

– Ryan's father

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



Supported Decision-Making: How?

- ▶ There is **no “one size fits all” method** of Supported Decision-Making
 - SDM **looks different** for different people and families
- ▶ **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?”**



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 need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.
- (Dinerstein 2012)

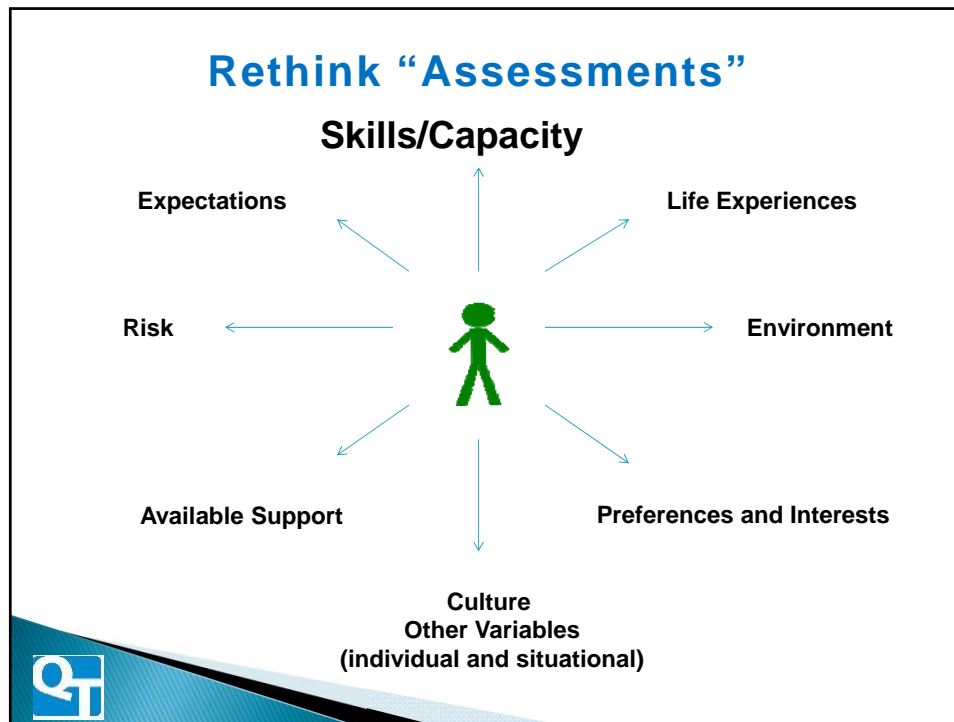


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Rethink "Capacity"

- ▶ 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 “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

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Decision-Making Support Plan

▶ Start with decisions:

- What decisions can I make now?
- What decisions do I want to learn to make?
- What decisions do I need support to make?



▶ Define needed supports:

- What does support look like?
- Who helps with what decisions?



▶ Make agreements:

- What happens if things don't go as planned?
- When will revisit the plan?



Start with Planning!

- ▶ Life Course Toolkit:
<http://www.lifecoursetools.com/planning/>
- ▶ Maps and Paths
<http://www.inclusion.com/bkpcpmapsandpath.html>
- ▶ Essential Lifestyle Plans/Person Centered Thinking -
<http://sdaus.com/resources>
- ▶ The Arc Center for Future Planning
<https://futureplanning.thearc.org/>



Education for People with Disabilities

- ▶ Decision-making skills
- ▶ Rights and responsibilities
- ▶ How to run your own planning meeting
- ▶ Advocacy Skills
- ▶ How to ask for help
- ▶ Opportunities to be in community



Decision-Making Steps

- ▶ Clarifying the issue, problem or choice
- ▶ Assessing the options
- ▶ Evaluating the “goodness” or “fit” of different options.
- ▶ Making a “decision”



Building Healthy Adult Relationships

- ▶ Talk about respect and boundaries
- ▶ Expect differences of opinion and world view
- ▶ Make room for change
- ▶ Focus on the present and future (not the past)
- ▶ Think about how to disagree



Improving Decision Making

Poor decisions often:

- ▶ Focus on limited aspects of a problem or situation
- ▶ Consider only immediate benefits
- ▶ Oversimplify issues ie., good/bad, right/wrong
- ▶ Are influenced by emotional factors
- ▶ Are reactive

Better decisions often:

- ▶ Reflect an understanding of different perspectives
- ▶ Focus on both short and long range goals
- ▶ Look at multiple potential outcomes
- ▶ Include a process for analysis and thinking
- ▶ Use tools and resources for making decisions



SDM Tools


- ▶ **Effective Communication**
 - ASAN with the UCF Office of Developmental Primary Care, "Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations
 - <http://odpc.ucsf.edu/communications-paper>
- ▶ **Informal or Formal Supports**
- ▶ **Peer Support**
- ▶ **Practical Experiences**
- ▶ **Role Play and Practice**
- ▶ **Life Coaching**
- ▶ **Mediation**
- ▶ **Written Agreements**



SDM Tools

- ▶ **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 Form

Adult Student: _____ Cell Phone: _____ Home Phone: _____
 Address: _____ City: **Washington, DC** State: _____ Zip Code: _____

I understand that I may create a network of individuals to help me inform my educational decisions related to my Individualized Education Program (IEP) once I reach the age of majority. I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to the documents listed below.

NAME	RELATIONSHIP	HOME ADDRESS	EMAIL ADDRESS	PHONE NUMBER
1.				
2.				

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENT	ACCESS
IEP meeting invitations, and agendas	
Requests for assessments	
Requests for changes in placement	
Requests for changes in services	
Exit requests	
Progress reports	
Report cards	
Attendance information	
Assessment results	
Other	

It is my understanding that I make the final decisions about my educational future after communicating with members in my network, and can remove a member from my network, or their access to my educational documents at any time.

Adult Student Signature Date

Network Member Signature Date

Network Member Signature Date


Revised 2/2013

▶ **Q: What does this DCPS SDM Form look like?**

▶ **A: A modified FERPA Form!**

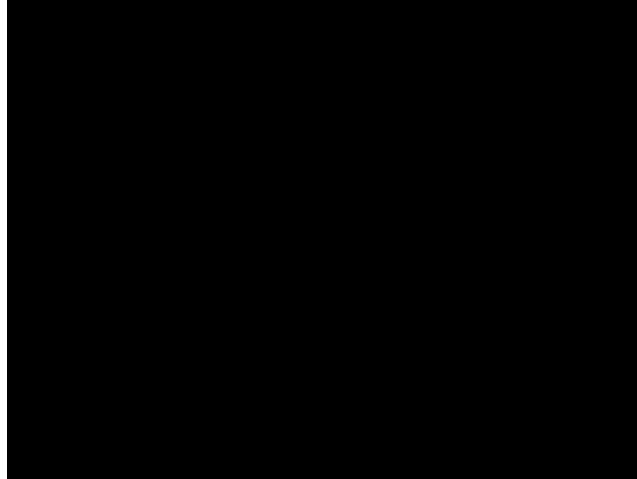
Where is SDM in the Law?

- ▶ **SDM doesn't need to be expressly in state law for you to use it!**
- ▶ Remember the **Americans with Disabilities Act** and **Section 504 of the Rehabilitation Act.**
- ▶ Think of **supports** that a student uses to make his or her own decisions as disability-related **accommodations.**



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SDM in Health Care: Video



“Making Healthcare Choices: Perspectives of People with Disabilities”
Produced by the American Civil Liberties Union



Even Within Guardianship...

- ▶ **Use Supported Decision-Making Principles!**
- ▶ “**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: Where?

NRC-SDM State Grantees


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



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) KY My Choice Kentucky
NV (2017)		CA Saks Institute SDM Project

And more states have pending legislation!



OTHER SDM POLICY & PRACTICE INITIATIVES	WEB SOURCES
ABA (2016 & 2017)	<ul style="list-style-type: none"> • https://www.americanbar.org/content/dam/aba/administrative/cr/sj/supported_decision_making_newspiece.authcheckdam.pdf • http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
SS Advisory Board (2016)	<ul style="list-style-type: none"> • http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
AAIDD & Arc (2016)	<ul style="list-style-type: none"> • http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.V8Xob6PD_nM
NRC-SDM Survey (2016)	<ul style="list-style-type: none"> • http://www.supporteddecisionmaking.org/node/396
U.S. DOE, OSERS (2017)	<ul style="list-style-type: none"> • https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf
Uniform Law Commission UGCOPAA (2017)	<ul style="list-style-type: none"> • http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act

To Reach the SDM Goal:

Every person should be part of decisions 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.



Connect and Stay Tuned!!!



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<https://www.facebook.com/QualityTrust>

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