

# Supported Decision Making

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## An Emerging Model



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[www.c-q-l.org](http://www.c-q-l.org)



# Today's Agenda

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- What is Supported Decision Making (SDM)?
- History of SDM
- Why SDM is Important?
- Linking SDM with Personal Outcome Measures<sup>®</sup> and Basic Assurances<sup>®</sup>
- Personal & Systems Advocacy
- Commitment Challenge
- Wrap Up

# CQL's Mission of Quality

- Self determination
- Person directed thinking & planning
- Personal autonomy
- Dignity & respect



# A Quick Poll

Have you personally or professionally been involved in using the SDM process with a person supported?



Yes

No



When making a decision, do you typically:

- Talk to a trusted friend or family member?
- Make a list of pros and cons? or
- Get advice from a professional or someone who has more experience than you?

# A Quick Poll

Select the one answer that best defines SDM



- A paradigm in which people with disabilities make their own choices with the assistance of family members and others they trust.
- A tool used to help people with disabilities exercise their right to self-determination
- A way of empowering people with disabilities to make their own decisions, rather than appointing someone else to make decisions for them
- A fancy way of saying how we all make choices
- All of the above



# Supported Decision Making International Backdrop

## 2006 – 2008: Convention on the Rights of Persons with Disabilities, Article 12

- <http://www.un.org/disabilities/convention/>
- 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.”
- Requires State parties to:
  - “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 In the United States

- National Resource Center for Supported Decision-Making
  - [www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)
  - “In Your State”: <http://www.supporteddecisionmaking.org/States>
- At least 17 states (AK, CA, DE, IN, ME, MD, MA, MO, NM, NC, OH, RI, TN, TX, VA, WA, WI) and DC have introduced legislation or resolutions referring to Supported Decision-Making in various ways
  - Of these, 11 have enacted legislation or resolutions referring to Supported Decision-Making (TX, DE, WI, DC, MO, NM, ME, KS, MD, VA, IN)
  - At least 2 states (AK and RI) have legislation pending



# Supported Decision Making In the United States

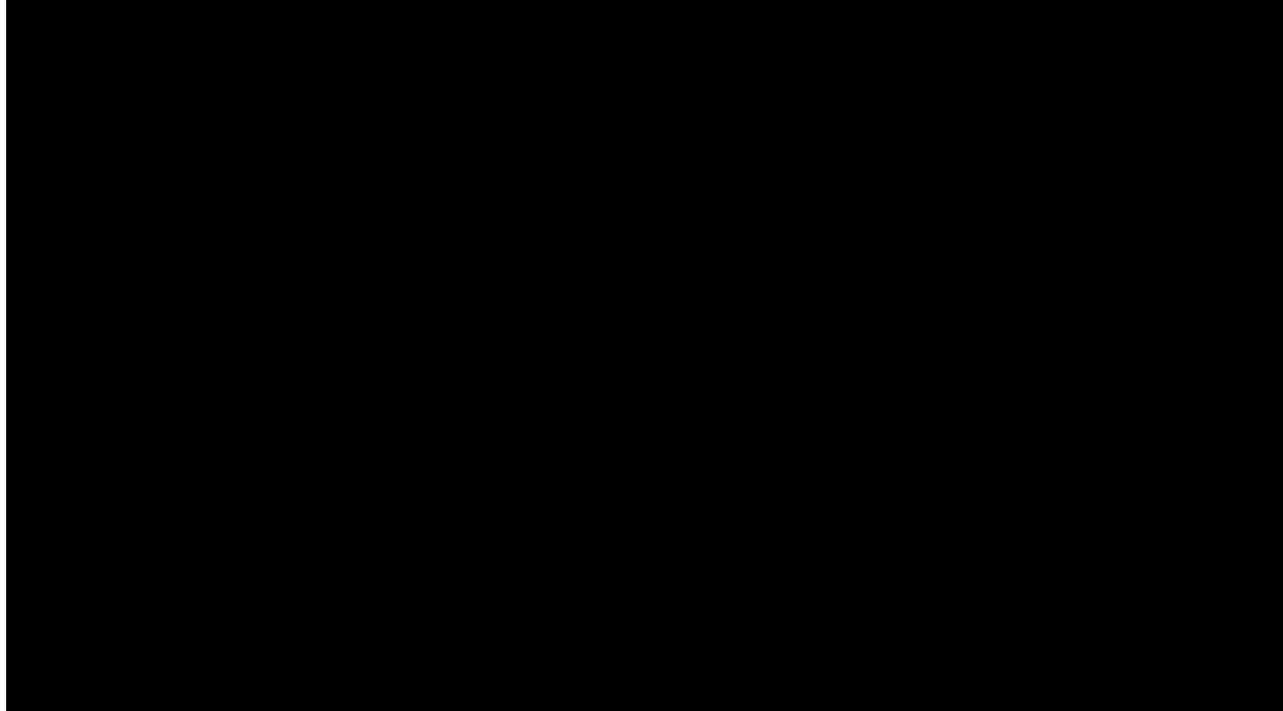
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- Court orders recognizing Supported Decision-Making in NY, VA, MA, DC, FL, VT, KY, and NV
- Projects in SC, TN, NY, KY, CA, NV, NC, ME, MA, FL, GA, AK, and other states focused on increasing access to Supported Decision-Making
- Endorsed by U.S. Department on Health and Human Services, American Bar Association, National Guardianship Association, Uniform Law Commission, Autistic Self-Advocacy Network, AAIDD, The Arc, and NAMI



# NRC-SDM Delaware Grantee Video

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# Supported Decision Making

## Why is it important?

- Driven in part by The United Nations: The Convention on the Rights of Persons with Disabilities
- The presumption of competence in the United States of America: one's right to liberty, self-determination, and personal autonomy is fundamental to the American culture, democracy and economy (National Council on Disability) to increase person's access to preferred environments and activities
- Dignity and respect for people: The Jenny Hatch story



# Supported Decision Making The Benefits

- As recognized by the National Council on Disability:
  - “SDM has the potential to provide people with disabilities the supported needed to understand their options while ensuring that they still retain ultimate legal decision making authority . . .”
  - Studies have shown people with intellectual and developmental disabilities who exercise greater self-determination have better life outcomes and quality of life.
  - As one interviewee explained, “It’s not about protecting someone. It’s about teaching them how to best protect themselves.”
- See <https://www.ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

# In the Absence of SDM

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- When denied self-determination, people can feel:
  - Helpless
  - Hopeless and
  - Self Critical
- When denied self-determination, people experience:
  - Low self-esteem
  - Passivity and
  - Feelings of inadequacy and incompetency
- A decrease in their ability to function



# UN Convention on the Rights of Persons with Disabilities (entered into force May 2008)

- Movement FROM viewing people with disabilities as objects of charity, medical treatment and social protection
- Movement TO viewing people with disabilities as “subjects” with rights and capable of claiming those rights and,
- Making decisions based on free and informed consent, as well as being active members of society
- (CQL Webinar on Ableism)



# The Convention's Approach to People with Disabilities

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- Intended as a human rights instrument with an explicit social development dimension,
- Reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms,
- Specifies that all categories of rights apply to persons with disabilities, and
- Areas where their rights have been violated, and where protection of rights must be reinforced



# Suzanne Heck (prefers Suzie)

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- At age 18, became a ward of the State of Kentucky
- She and her team contacted KY Protection & Advocacy to request its help with restoring her rights
- Initially, county attorney not comfortable with request for restoration
- Court appointed attorney & Dream Board



## Suzanne Heck *(continued)*

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- Finally, the judge, with agreement of county attorney who better understood SDM, fully restored Heck's rights
- Heck is a sort of Jackie Robinson for restored rights
- First person on record in KY to have rights fully restored with SDM as alternative
- <http://www.supporteddecisionmaking.org/node/444>

## A Quick Poll

Does SDM apply ONLY on an individual level, and not to guide an organization's approach to supporting people?



Yes

No

## People Exercise Rights

- Representative Payee
- Guardianship
- Free movement
- Access to personal possessions, including money (CQL Capstone August 30, 2018)

## People are Treated Fairly

- Any rights restriction viewed as temporary
- Due process procedures applied
- Promote system change with practices that restrict or limit





# SDM, Rights & Fair Treatment Outcomes

## Potential Information-Gathering, Leading to Rich & Informed Decision Making:

- How is the person informed about right of lesser restrictive decision making supports, including SDM?
- What information or support is needed to exercise that option?
- Who does the person include in her/his network when have concerns or questions regarding the exercise of rights?
- How does the organization inform people about rights, along with learning about SDM?
- How is the person exposed to and supported to access and use an independent review of any personal freedom limitations?
- What assistance, training, orientation and/or supports does the organization provide to people to recognize and understand personal freedoms, including SDM?
- How does the organization provide the person with training or support so that limitations can be reversed or removed?

## People Choose Where and With Whom to Live

- Placements/openings/slots

## People Choose Services

- Choice of banking/financial services





# SDM, Choice of Living & Services Outcomes

## Potential Information-Gathering, Leading to Rich & Informed Decision Making:

- How is the person and her/his team informed about options, including generic, non-disability community settings and/or services?
- What information or support is needed to learn about those options (EEE)?
- Who does the person include in her/his network when learning about and being exposed to new, potentially overwhelming services/settings?
- If the person has limited experience in decision making, how is she/he supported to overcome barriers?
- What organizational practices provide the framework for supporting to learn about options and make choices?



## Factor 1: Rights Protection and Promotion

- Indicator A: Policy and procedures promote people's rights
  - Probe 1: Commitment to protect and promote people's rights
  - Probe 4 : Procedures describe how individual rights and documentation are reviewed
- Indicator E: Decision-making supports are provided to people as needed
  - Probe 2: Assess the need for advocacy, guardianship, representative payee and alternatives to guardianship or payee
  - Probe 3: Determine the scope of advocacy, guardianship, representative payee and alternatives to guardianship or payee
  - Probes 4: Person-centered plan to document the need for and scope of



# SDM & Basic Assurances<sup>®</sup> Factor 1

## Potential Information-Gathering, Leading to Rich & Informed Validation:

- What rights are restricted?
- How did the person consent to this?
- What would it take for these rights to be restored?
- How are staff trained to learn about supporting people to exercise their rights?
- What are the measures in place to restore rights if people have rights restrictions?
- How does the Human Rights Committee function in the restoration of people's rights?



# SDM & Basic Assurances®

## Factor 2: Dignity and Respect

- Indicator A: People are treated as people first
  - Probe 2: Refrain from referring to people by labels or conditions
  - Probe 5 : Support staff trained to promote dignity and respect and to recognize each person as an individual
- Indicator E: Supports and services enhance dignity and respect
  - Probe 4: Supports provided only to the extent needed by the person
  - Probe 6: Supports provided so that people can access community services similar to others in community at large



## SDM & Basic Assurances<sup>®</sup> Factor 2

### Potential Information-Gathering, Leading to Rich & Informed Validation:

- Do others treat you the same as other adults?
- Whom does person talk to with a concern or complaint? And, what is done about it?
- What is staff's role in assisting person to feel and be respected?
- What are organizational efforts to ensure that services/supports are person-centered??

# The Role of Advocacy Personal & Systems

- Dignity for people
- Peer support & consumer control
- Civil rights
- Activism
- Advocacy support





# The Role of Advocacy

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- Promote independence and social/economic participation
- Promote choice and control
- Maximize independent lifestyles
- Maximize full inclusion in communities



# The Role of Advocacy in Educational System

- NCD Report refers to the School-to-Guardianship “Pipeline” for Youth with ID/DD
  - “[A]ll parents have fears about whether their teenager will be ready for the responsibilities of adulthood when they turn 18, but it is only the parents of teenagers with disabilities who are regularly advised that they have the option of preventing the child from becoming legally an adult in the eyes of the world.”
- Often, guardianship is the family’s first choice rather than the last resort
- Regardless of who made first recommendation, plenary guardianship and power of attorney most often recommended

# Advocacy in Educational System: Alternatives to the Pipeline

- Workforce Innovation and Opportunity Act (WIOA)
- Some State efforts
  - Developmental Disabilities Councils
  - Virginia, Wisconsin, Florida examples
- Cost of “justice”
- Public funding
- Professional guardianship





# The Role of Advocacy in Restoration of Rights

- States DO provide means to terminate guardianship and restore rights (varies from state to state)
- Limited data and information on the frequency or circumstances for restoration
- Panel of experts identified issues for person subject to guardianship:
  - Awareness of restoration option
  - Access to courts
  - Right to counsel
  - Role of counsel as zealot advocate, not purely guardian ad litem
  - Focus on supports and alternatives to guardianship
  - Role of guardian



# Example: State of Delaware

[https://www.dhss.delaware.gov/dsaapd/supported\\_decision\\_making.html](https://www.dhss.delaware.gov/dsaapd/supported_decision_making.html)

***“Supported Decision Making is different from these options. Supported Decision Making allows YOU to continue to make your own decisions by enabling others to help you. They may help you by gathering information for you, or by sitting with you at your doctor’s appointment and taking notes, or listening with you to what the doctor is saying, so that they can explain it to you again.*”**

***Supported Decision Making was created by Senate Bill 230 in 2016, and is found in the Delaware Code at Title 16, section 94A. Governor Jack Markell signed the bill into law on September 15, 2016. The Bill was sponsored by then Senator (now 2 Lieutenant Governor) Bethany Hall-Long and Representatives Debra Heffernan and David Bentz. Delaware was the second state in the nation to adopt this option of decision making. “***

**And**

**Supported Decision Making Agreement Form**



## Advocacy:

# Restoration in Developing Skills & Alternatives

National Council on Disability statements:

- The vehicle of guardianship is a violation of basic rights unless no less restrictive alternative found
- When people reach out, clearly indicates awareness
- States and court systems should welcome ready review of guardianship

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- SDM laws: Texas, Maine, Wisconsin, District of Columbia, Tennessee, Missouri and Alaska

(source: Indiana Disability Rights)



# Advocacy: ABA PRACTICAL Steps in Supporting Decision-Making

## National Council on Disability Steps to Lesser Restrictive

- Presume guardianship is unnecessary
- Reason
- Ask
- Community
- Team
- Identify abilities
- Challenges
- Appoint
- Limit

[https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/practical\\_tool.html](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)

# Benefits of SDM

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- Improved quality of life
- Organizations structured around person centeredness: dignity and respect for people
  - Personal Outcome Measures®
  - Basic Assurances®
  - Shared Values®
- Continued opportunities to enhance self-determination
- Improved systems and practices in support of achieving SDM

# A Quick Poll

Is pursuing and restoring rights through SDM easily achieved and clearly defined in all states?



Yes

No

# Ryan's Story

- “Don’t judge me before you know me.”  
-- Ryan
- “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, Ryan’s father
- Visit <http://www.supporteddecisionmaking.org/impact-stories/ryan-king-updated>



## Ryan's Story *(continued)*

- When Ryan turned 18, his parents were told they had to become his guardian in order for him to receive services in DC.
- In 2007, Ryan and his parents went back to court to try and get the guardianship terminated. The judge said no.
- In 2016, with the help of Quality Trust and the Burton Blatt Institute, Ryan and his parents tried again, presenting evidence to the court of Ryan's history of making decisions and directing his life using SDM. This time, the judge agreed and restored Ryan's rights.
- Ryan's case was the first in D.C. where guardianship was terminated in favor of SDM.
- Visit <http://www.supporteddecisionmaking.org/impact-stories/freedom-ryan-king>



# SDM Challenge to Participants

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When guardianship discussions take place within your organization

- **FOR PEOPLE and/or**
- **FOR ORGANIZATIONAL PRACTICES/PRINCIPLES**

Please attempt to at least begin dialogue around and raise awareness of ...

## **SUPPORTED DECISION MAKING**

How do you rank the quality of this webinar?



- Excellent
- Good
- Adequate
- Needs Improvement

# A Quick Poll

Will you do something different in your organization or in supporting people with disabilities?



Yes

No



# Supported Decision Making Resources

## SDM Tools

- <https://www.ncd.gov/about>
- <http://supporteddecisionmaking.org/>
- [www.sdaus.com](http://www.sdaus.com)
- [www.learningcommunity.us](http://www.learningcommunity.us)



# Supported Decision Making Resources

## SDM Tools

### Personal Outcome Measures®

- [www.c-q-l.org](http://www.c-q-l.org)

### CMS HCBS Rules

- <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>



# Supported Decision Making Resource

## SDM Tools

### NRC-SDM 2016 “From Theory to Practice” Webinars

- Archived webinar topics including implementing SDM in education, community based supports, and financial decisions.
- <http://www.supporteddecisionmaking.org/events>

### SDM 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 Resources

## SDM Tools

CQL Training Options - [www.c-q-l.org/Training](http://www.c-q-l.org/Training)

- 1-Day Supported Decision Making Training



A **huge thank you** to our guest speaker:  
Morgan Whitlatch | DC Quality Trust





**CQQL**<sup>SM</sup> | The Council on  
Quality and Leadership  
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