Supported Decision-Making in Action Throughout the Life Span

Tina Campanella
Rhonda White
Morgan Whitlatch

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
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.
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!

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

More evidence

- **When denied self-determination**, people can:
  - 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)

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”

Skills/Capacity

Available Support

Expectations
Life Experiences

Risk
Environment

Preferences and Interests

Culture
Other Variables (individual and situational)

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
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/
- 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

<table>
<thead>
<tr>
<th>Poor decisions often:</th>
<th>Better decisions often:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on limited aspects of a problem or situation</td>
<td>Reflect an understanding of different perspectives</td>
</tr>
<tr>
<td>Consider only immediate benefits</td>
<td>Focus on both short and long range goals</td>
</tr>
<tr>
<td>Oversimplify issues ie., good/bad, right/wrong</td>
<td>Look at multiple potential outcomes</td>
</tr>
<tr>
<td>Are influenced by emotional factors</td>
<td>Include a process for analysis and thinking</td>
</tr>
<tr>
<td>Are reactive</td>
<td>Use tools and resources for making decisions</td>
</tr>
</tbody>
</table>
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](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](http://supporteddecisionmaking.org/node/390)

- Supported Decision-Making Guides
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.
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.”

SDM: Where?
NRC-SDM State Grantees

<table>
<thead>
<tr>
<th>2015 - 2016</th>
<th>2016 - 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>DE – Led by Delaware Developmental Disabilities Council</td>
<td>FL – Led by the Northern Florida Office of Public Guardian</td>
</tr>
<tr>
<td>IN – Led by The Arc of Indiana</td>
<td>GA – Led by the University of Georgia</td>
</tr>
<tr>
<td>ME – Led by Disability Rights Maine</td>
<td>ME – Led by Disability Rights Maine</td>
</tr>
<tr>
<td>NC – Led by First In Families of North Carolina</td>
<td>NV – Led by the Second Judicial District Court, State of Nevada, Washoe County</td>
</tr>
<tr>
<td>WI – Led by Wisconsin Board for People with Developmental Disabilities</td>
<td>NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</td>
</tr>
</tbody>
</table>

For final reports of these NRC-SDM grantees, visit: http://www.supporteddecisionmaking.org/node/425

More on U.S. State Trends: Examples

<table>
<thead>
<tr>
<th>State Courts</th>
<th>Enacted State Statutes</th>
<th>State Pilots</th>
</tr>
</thead>
<tbody>
<tr>
<td>KY (2017)</td>
<td>ME (2016)</td>
<td>KY My Choice Kentucky</td>
</tr>
<tr>
<td>NV (2017)</td>
<td></td>
<td>CA Saks Institute SDM Project</td>
</tr>
</tbody>
</table>

And more states have pending legislation!
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!!!

Quality Trust

www.dcqualitytrust.org
https://www.facebook.com/QualityTrust

www.supporteddecisionmaking.org
https://www.facebook.com/nrcsdm/

Tina Campanella: tcampanella@dcqualitytrust.org
Rhonda White: rwhite@dcqualitytrust.org
Morgan Whitlatch: mwhitlatch@dcqualitytrust.org

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.