Off the Guardianship Path: Utilizing Supported Decision-Making as a Road to Self-Determination

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Learning Objectives

• Understand the Supported Decision-Making (SDM) concept: fundamental principles, key participants, proper design, implementation and evaluation.

• Understand the distinction between forms of legal guardianship (Limited Guardianship and Full Guardianship) and Supported Decision-Making.

• Learn the barriers that currently prevent Arizona from embracing SDM as a viable model for independent living for persons with I/DD, as well as means for overcoming these obstacles through collaboration with stakeholders in the government, legal, health, advocacy, and provider communities.
Self-Determination

“People with intellectual and/or developmental disabilities (I/DD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They must have opportunities, respectful support, and the authority to exert control in their lives, to self-direct their services to the extent they choose, and to advocate on their own behalf.”

Including:
- The right to take risks
- The right to choose their own allies
- The right to lead in decision-making about all aspects of their lives

(excerpts from The Arc’s Position Statement on Self-Determination)
Conflicting Points of View

There are two gifts we should give our children. One is roots and the other is wings.
What are Decision-Making Supports?

Formal and informal ways people can have others help them make decisions:

• Advice and Guidance
• Representative Payee
• Powers of Attorney for Financial Matters and Health Care Matters
• Supported Decision-Making
What is Supported Decision-Making?

- Supported Decision-Making (SDM) can be used by anyone, including people with I/DD, people with mental health issues, seniors
- SDM can be informal or formal
- Person using SDM chooses a team of people to help him/her make decisions
  - Supporters agree to be available for advice and assistance
  - Supporters do not make decisions for person using SDM, except in specific circumstances
What is Supported Decision-Making?

- Increasingly, around the world, there is legal recognition of SDM agreements.
- Texas was first US state to pass a law recognizing SDM agreements.
- 8 states plus DC currently recognize, with 6 more pending.
Supported Decision-Making - We All Do It!!

Think about everyday choices you make:

- Changing jobs
- Moving
- What to have for dinner
- ...and the list goes on
Why Supported Decision-Making Matters

• Moving away from paternalistic and medical model of disability
• Empowerment vs. Substitution
• Natural way to grow a circle of support
Presuming Competence

To presume competence is to acknowledge that all individuals have the ability to learn, to communicate, to participate in their own way. It means that we provide opportunities by creating accessible & inclusive spaces.

To presume competence is to respect the value of human diversity.

Not presuming competence is to actively harm.
Consequences of NOT Presuming Competence

• Not enough focus on building skills, assuming people belong on a single “track”

• Individuals with disabilities may be left out of decisions around their services and every day life

• Ignorance about medical care

• Difficulties entering into contracts
Dignity of Risk

• The concept that acknowledges risk is a natural part of life that helps all people learn and develop

• The freedom to make mistakes, to make decisions for ourselves, even if others believe that those choices could be in error.
Dignity of Risk

- What if you never got to make a decision?
- What if you never got to make a mistake?
- What if your money was always kept in an envelope where you couldn’t get it?
- What if you were never given the chance to do well at something?
- What if you took the wrong bus once and now you can’t take another one?
- What if the job you did was not useful?
- What if you had no privacy?
- What if the only risky thing you could do was to act out?
- What if you grew old and never knew adulthood?
- What if you never got a chance?
Right to Risk

“Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure. Life is either a daring adventure or it is nothing.”

- Helen Keller
## Differentiating SDM from PCP

<table>
<thead>
<tr>
<th>Supported Decision-Making</th>
<th>Person-Centered Planning</th>
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<tbody>
<tr>
<td>- Focuses on creating a process</td>
<td>- Focuses on setting goals</td>
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<tr>
<td>- Affects interactions with the world</td>
<td>- Affects interactions with agencies</td>
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<tr>
<td>- Covers the universe of decisions</td>
<td>- Covers activities within agencies’ purview</td>
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Basic Components

• Gathering necessary information
• Educating individuals about that information
• Identifying possibilities and alternatives
• Aiding the individual in weighing choices and understanding consequences
• Helping communicate decisions to others
• Assisting in the implementation of decisions
SDM Alternatives to Guardianship

- Third-party financial management
- Specified case management/support coordination
- Advance directives
- Limited or standby guardianship - when properly applied
What “Systems Change” is Needed to Make Supported Decision-Making a Reality?

• Work together to gain recognition of SDM:
  ◦ Public
  ◦ Financial & Educational Institutions
  ◦ Health Care System
  ◦ Judicial System

• Build Decision-Making Skills
  ◦ For adults
  ◦ For children
Conflicts of Interest

• Retaining capacity provides protections from many forms of abuse or exploitation

• Power dynamic shifts

• Conflict of interest provisions should restrict who may serve as supporter:
  ◦ Doctors
  ◦ Those with major financial interest
  ◦ Provider staff
Conflicts of Interest

Others with potential conflicts:

• Parents
• Spouses
• Friends
• Personal support workers
Where It Works

Effective SDM Laws:

• Recognize right of person with disability to:
  ◦ Voluntarily enter into SDM agreement with supporter(s)
  ◦ Determine scope of agreement
  ◦ Terminate agreement

• Specify protections against abuse, neglect, exploitation

• Provide templates of required content

• Mandate reporting
Outside U.S., notable nations with Co-Decision Making acts include:

- Australia
- Canada
- Ireland
- Israel
- Sweden
- United Kingdom
Barriers to Acceptance

- Limited experience
  - Few examples from which to learn
  - Brief history of U.S. laws
- Lack of conceptual understanding
  - Policymakers
  - Support providers
  - Individuals & family members
- Concerns about coercion & abuse
- History of third-party authority
Barriers to Acceptance

- Individual & institutional attitudes
  - Fear
  - Uncertainty of political climate
  - Equity

- Individualized approach
  - Not cookie-cutter solution
  - Investment of time, expertise, money

- Funding

- Institutional inertia: Power of the Status Quo
Overcoming Barriers

Overcoming barriers to Supported Decision-Making requires more than simply changing Guardianship laws.
Overcoming Barriers - Education & Advocacy

- Individuals with disabilities
- Communities
  - Grassroots - families & support networks
  - Advocacy & service organizations
- Legal professionals
- Healthcare providers
- Financial institutions
- Education entities
Overcoming Barriers - Education & Advocacy

- Housing providers
- I/DD Service Providers
- State & Federal Governments
  - Agency leadership
  - Legislators
  - Courts
Overcoming Barriers - Systems Change

- Focus on individual rather than preservation of system
- SDM options first consideration; full guardianship a last resort
- Safeguards built into SDM structure
- Understanding & acceptance of risk
  - Trial & error
  - Ongoing training, revision, reinforcement
- Collective action - *It Takes a Village*
Change Offers Opportunities

• Put public face on ability, not disability
• Transform attitudes about competence
• Meet unique needs of each individual
• Maximize self-determination
• Increase community integration & inclusion
• Drive improvements in guardianship & conservatorship
• Increase efficiency & cost-effectiveness of support systems
Supported Decision-Making Pilot Project
Arizona’s Developmental Disabilities Planning Council

Each state and territory of the United States has a council on developmental disabilities focused on advocacy, inclusion and improving access and services, as outlined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000.
Grant Partners

Southwest Institute for Families and Children supports people with disabilities through empowerment, advocacy, and knowledge.

ACDL is a non-profit law firm that assists Arizonans with disabilities to promote and protect their legal rights to independence, justice, and equality.

The Arc of Arizona advocates for the rights and full community participation of all people with intellectual and developmental disabilities by improving systems of supports and services, connecting families, inspiring communication, and influencing public policy.
Project Goal

Increase the use of Supported Decision-Making among individuals with intellectual and developmental disabilities as an alternative to legal guardianship.
How We Will Reach Our Goal

• Teach family members and caregivers, individuals with IDD, and all relevant stakeholders about Supported Decision-Making.

• Pass legislation recognizing Supported Decision-Making as a less restrictive alternative to legal guardianship.
White Paper

• Forums conducted in northern, central, and southern Arizona
  ◦ Parents and caregivers
  ◦ Young adults with IDD
• Interviews with relevant stakeholders
  ◦ Medical providers
  ◦ Education professionals
  ◦ legal professionals
  ◦ Social service providers
Curriculum
People with IDD, families, and caregivers

• Learn how to advocate for themselves
• Learn the history and philosophy of the self advocacy and independent living movements
People with IDD, families, and caregivers

- Learn the differences between Supported Decision-Making and legal guardianship
- Learn how to create a supported decision-making agreement
Legal & Judicial Community

• Learn about intellectual and developmental disabilities
• Learn the differences between Supported Decision-Making and legal guardianship
• Learn the proper role and responsibilities of trusted advisors within a Supported Decision-Making relationship
Social Service Providers, Medical and Education professionals

- Learn about Supported Decision-Making and its benefits
- Learn how to develop a Supported Decision-Making relationship with a client or patient
- Learn how to best work with a client or patient who uses Supported Decision-Making
Legislation

- Collaborate with disability partners to develop legislation
- Introduce in the 2020 AZ legislative session
- Educate lawmakers and state agency leaders
- Encourage advocacy for proposed legislation among various stakeholder communities
Years Two and Three

- Create and implement a Strategic Plan to increase the use of Supported Decision-Making
- Teach the curriculum throughout the state of Arizona
- Push legislation forward that recognizes Supported Decision-Making
Our Findings

• Widespread misunderstanding about legal guardianship - necessity, process, responsibilities, implications, limitations

• Misinformation is rampant
  ◦ Spread by institutional as well as informal sources
  ◦ Rural areas, in particular, have few reliable resources

• Continues to be seen as default option
Our Findings

• Very little familiarity with concept of Supported Decision-Making
  ◦ Families/caregivers
  ◦ Individuals with IDD
  ◦ Professionals
• Resistance likely from some stakeholder communities
• *But*, eagerness to learn more
Questions?

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