

Power to the Person

Supported Decision-Making and Self-Determination in Arizona

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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

We Use Decision-Making Supports Every Day...

Think about common choices you make:

- Changing jobs
- Moving
- What to have for dinner
- ...and the list goes on

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
- 10 states plus DC currently recognize, with several more pending

Three Pillars of SDM

- Self-Determination
- Presumed Competence
- Dignity of Risk

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)

Presumed Competence

pre·sume com·pe·tence

pri'zoōm/ 'kämpetəns/

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.

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 that choices could be in error.

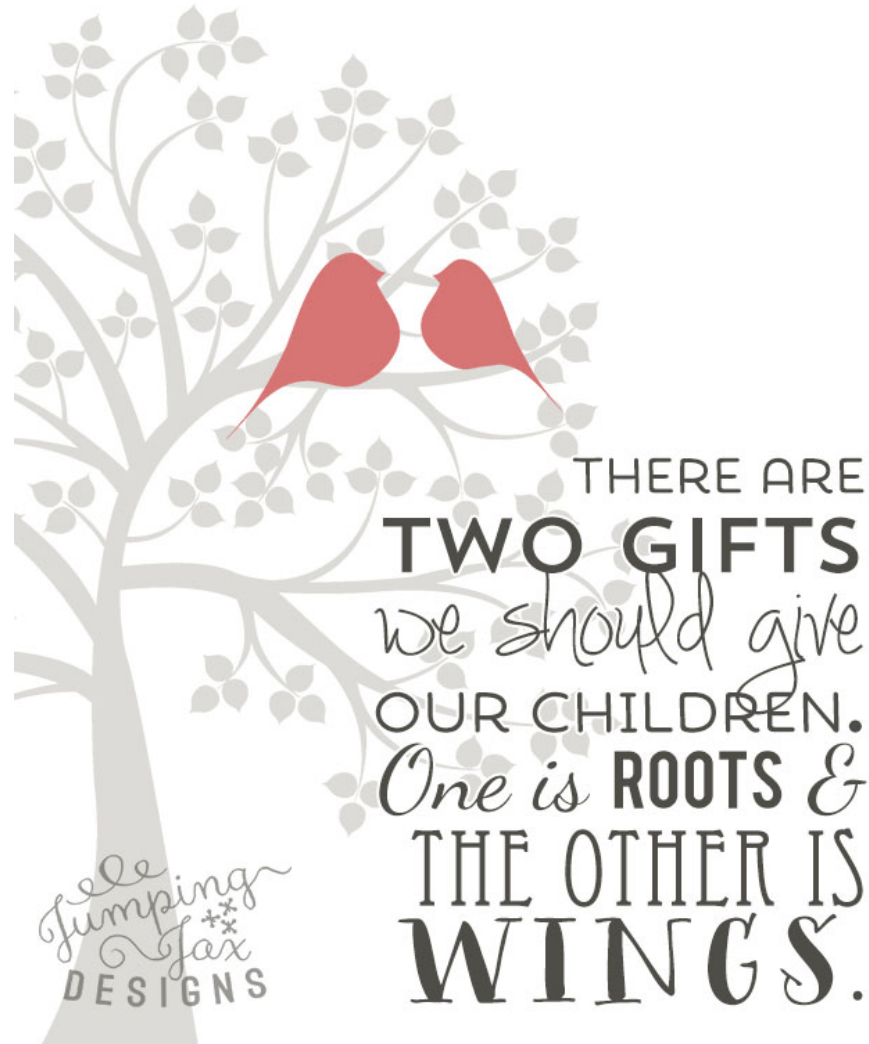
Right to Risk

“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

Conflicting Points of View



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

Differentiating SDM from PCP

Supported Decision-Making

- *Focuses on creating a process*
- *Affects interactions with the world*
- *Covers the universe of decisions*

Person-Centered Planning

- *Focuses on setting goals*
- *Affects interactions with agencies*
- *Covers activities within agencies' purview*

Basic Components

- Gathering necessary information
- Educating individual about that information
- Identifying possibilities and alternatives
- Aiding individual in weighing choices and understanding consequences
- Helping communicate decisions to others
- Assisting in 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*

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

Where It Works

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

- Australia
- Canada
- Ireland
- Israel
- Sweden
- United Kingdom

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

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

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*

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.

Understanding the Landscape

- Forums conducted in northern, central, and southern Arizona
 - Parents and caregivers
 - Young adults with I/DD
- Interviews with relevant stakeholders
 - Medical providers
 - Education professionals
 - legal professionals
 - Social service providers

White Paper: 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 (cont.)

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

How We Will Reach Our Goal

- Teach family members and caregivers, individuals with I/DD, and all relevant stakeholders about Supported Decision-Making.
- Pass legislation recognizing Supported Decision-Making as a less restrictive alternative to legal guardianship.
- Continually advocate for acceptance of SDM in concept and in practice

Curriculum

People with I/DD, families, and caregivers

- Learn the differences between Supported Decision-Making and legal guardianship
- Learn how to identify and select trustworthy supporters
- 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

Legislation

- Collaborated with disability partners to develop legislation
- Introduced in the AZ legislative session
- Educated lawmakers and state agency leaders
- Encouraged advocacy for proposed legislation among various stakeholder communities

Creating A Supported Decision-Making Reality in Arizona - Together

- House Bill 2538 (2021)
 - Rep. Jennifer Longdon (D-24) - Prime sponsor
 - Co-sponsors: Reps. Tim Dunn (R-13), Becky Nutt (R-14), Diego Rodriguez (D-27), Athena Salman (D-26), Judy Schwiebert (D-10), Lorenzo Sierra (D-19)
- Passed House of Representatives 59-0; failed in Senate 15-14
- Will be re-introduced in 2022 session

Resources

Southwest Institute for Families & Children

<http://swifamilies.org/supported-decision-making-pilot-project/>

National Resource Center for Supported Decision-Making

<http://supporteddecisionmaking.org/>

Center for Public Representation

<https://supporteddecisions.org/>

The Arc Wisconsin - Learn about Supported Decision-Making in Wisconsin

<https://arcwi.org/2018/04/13/supported-decision-making/>

The Arc's Center for Future Planning

<https://futureplanning.thearc.org/>

Questions?

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