

Disability
Rights
Maryland

Empowerment. Integration. Equality.

Alternatives to Guardianship in Maryland
Howard County Autism Society
October 27, 2022

Introductions

- Megan Rusciano, Esq
 - Disability Rights Maryland
- This presentation provides basic information for Maryland residents, it does not contain legal advice.

Disability Rights Maryland

- Maryland's federally-designated Protection & Advocacy (P&A) agency, mandated to advance the rights of people across disabilities wherever they reside
- Provide free legal services to people with disabilities on a wide range of issues
- Engage in systemic litigation and advocacy on alongside people with disabilities

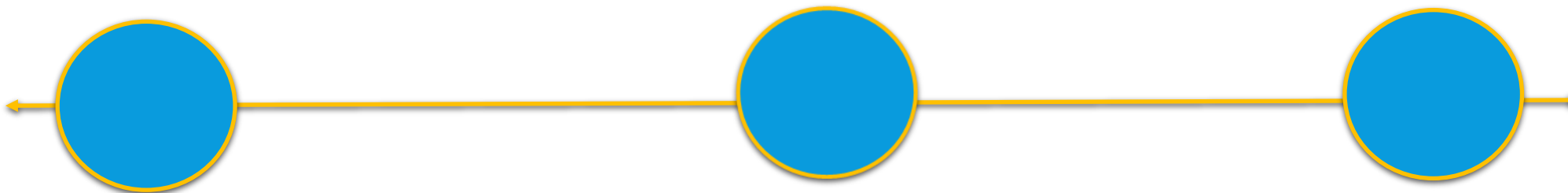
Overview

- **I.** Understanding Guardianship and Its Alternatives
- **II.** Supported decision-making in Maryland
- **III.** Why is consideration of alternatives to guardianship, like supported decision-making important?
- **IV.** Resources

I. Understanding Guardianship and its Alternatives

Capacity

- In this context, refers to a person's ability to understand, make, and communicate a decision. Effectively, it is a person's **decision-making ability**.
 - An ability to indicate will or a preference and act on it
- It exists on a spectrum that can vary depending on the person's context and the nature of the decision
- It is usually exercised through support.



Needs less support

Needs more support



Legal Capacity

- Is a legal principle that determines what decisions a person can make under law. Examples include:
 - Providing consent
 - Making a contract
- Everyone is presumed to have legal capacity.
- If a person has legal capacity, their decisions are recognized under law.
- A person may lack legal capacity to make certain decisions, but not others.

Guardianship

- If a person lacks LEGAL capacity to make a decision they are susceptible to guardianship.
- In Maryland
 - Guardian of the person
 - Guardian of the property
- If a person is under guardianship they lose the legal authority to make certain decisions by themselves. This is called substitute decision-making.
 - The guardian acts for the person.
 - The court oversees the guardianship.
 - Adult guardianship is different than a parent's guardianship of their child
 - Guardianship is an adversarial judicial process that requires the involvement of attorney

Guardianship

- Standards:

- Guardian of the person

- A person must lack sufficient understanding or capacity to make or communicate responsible decisions concerning his or her person, including provisions for health care, food, clothing or shelter

- Must be due to disability

- **Must be no less restrictive alternatives available**

- Guardian of the property

- Due to disability...

- A person must be unable to manage his or her property and affairs effectively and they must be entitled to property or benefits that require proper management

What are some alternatives to guardianship:

- **General**

- Consent to exchange information (HIPAA; FERPA)
- Person-centered planning
- Supported decision-making

- **Financial**

- ABLÉ Accounts
- Powers of Attorney
- Special Needs Trust
- Representative Payees

- **Medical**

- Advanced Medical Directive
- Advanced Directive for Mental Health Treatment
- Surrogate Decision-Making

What is Supported Decision-Making?

- Alternative to guardianship that allows a person to **keep** their decision-making authority without appointing a substitute decision-maker.
 - Sometimes framed as a reasonable accommodation under the ADA
- **How?** *“People use trusted friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions – it is a means for increasing self-determination by encouraging and empowering people to make their own decisions about their lives to the maximum extent possible.”* National Resource Center on Supported Decision-Making

II. Supported decision-making in Maryland

Background

- In 2020, through a small grant from our Developmental Disabilities (DD) Council, Disability Rights Maryland founded the Maryland Cross-Disability Supported-Decision Making Coalition.
- The Coalition is comprised of stakeholders from across the state, representing a diverse group of advocates and organizations in the aging and disability community.
- The Coalition received technical assistance from the National Resource Center for Supported Decision-Making to create an action plan for implementing SDM in Maryland.
- Action plan items included passing legislation, developing pilot projects, and creating robust educational and outreach resources.
- As a result of the Coalition's efforts, SB 559, a bill recognizing supported decision-making, passed Maryland's legislature in 2022.

Background

- Senate Bill 559 requires that supported decision-making be considered as a less restrictive alternative before guardianship can be imposed
- It can be used as a tool to prevent, limit, or end the use of a guardianship
- People can use supported decision-making informally or they can make supported decision-making agreements
- Having a supported decision-making doesn't prevent someone from acting independently of it
- Supporters do not have access to an adult's personal information, unless the adult separately gives them permission
- The manner in which a person communicates is not grounds for saying that they cannot make a supported decision-making agreement
- A supported decision-making agreement does not impact a power of attorney or an advanced medical directive

Supported Decision-Making (SDM)

- In Maryland:
 - A person may select a person or a team to help them think through, decide, and communicate decisions of their choosing.
 - The person chooses BOTH the types of decisions they want support with and the type of support they want
 - Supporters ask, listen, provide advice, translate, and respect the person's decision.
 - It can occur with or without an agreement, but there are rules if someone makes an agreement.
 - **The person retains their right to make decisions.**

SDM Agreements in Maryland

- A person under guardianship can enter into a SDM agreement if it does not impact the guardian's authority. A supporter must provide a copy to a guardian.
- In an agreement a person can select a supporter to help them:
 - Gather information
 - Understand and interpreting information
 - Weigh options
 - Understand consequences
 - Participate in conversations (with permission)
 - Provide support and advocacy in implementing a decision

SDM Agreements in Maryland

- It cannot be required as participation in a program, activity, or service
- A supporter needs to maintain records about their actions and how the adult communicates and expresses opinions
- Unless the person objects, the supporter should provide a copy of the agreement to the person's existing power of attorney, advance directive, or trustee.
- A supporter cannot enforce decisions make the adult
- A person can choose anyone to be their supporter, except: a minor, a person against whom they have a peace or protective order, or a person who has been convicted of financial exploitation

SDM Agreements in Maryland

- Needs to be documented in writing and be dated
- Describe the decision-making assistance that each supporter may provide, how supporters may work together, how any perceived or actual conflict of interest should be mitigated, and how the adult choose the supporter
- State that the supporters cannot make decisions for the adult and that it doesn't supplant the authority of a power of attorney or advance directive
- Be signed and witnessed by two adults who are not the supporter(s) or employees or agents of the supporter
- A person can revoke or modify an agreement at any time and may receive support to do so

What makes a good supporter?

- Understands their role and that they do not influence or make decisions for the adult
- Knows how the person communicates and redirects others who try to speak with them (the supporter) instead of the adult
- Consults with the person about how they want to be supported
- Acknowledges when they might not be the right person to help with a decisions
- Talks to the person about what is important to them
- Doesn't make value judgments on the person's decisions
- Checks in to make sure the adult feels in control of the process

What are some tools a supporter might use?

- Provide plain language materials or information in visual or audio form
- Advocate for a person to have extra time in discussing and deciding on choices
- Help a person create a list of pros and cons of a decision
- Role-play activities to help a person understand choices
- Take notes at appointments and in conversations (if given permission), to help the person remember and discuss their options.
- Using person-centered and driven tools
 - Relationship maps
 - One-page profiles

III. Why are alternatives to guardianship, like supported decision-making important?

Supported Decision-Making

Supported Decision-Making

- **25+ states** have passed or are working on legislation to recognize supported decision-making
- Various state courts have terminated guardianships in favor of supported decision-making
- The US Department of Health and Human Services' Administration on Community Living funds the National Resource Center for Supported Decision-Making that has, in turn, funded pilot projects on SDM across the country.

Supported Decision-Making

- It has been endorsed by many organizations, including but not limited to:
 - American Bar Association
 - National Guardianship Association
 - National Council on Disability
 - American Civil Liberties Union
 - The Arc of the United States
 - The Uniform Law Commission

Supported Decision-Making (SDM)

- See Ben's story:

<https://www.youtube.com/watch?v=8mwF7-zp9aQ&t=176s>

Why are alternatives to guardianship important?

- Historically we have denied people with disabilities the ability to make their own decisions
 - Fundamental rights are still at stake in the disability rights movement
- People with disabilities are regularly subject to unnecessary, overbroad guardianships often based on bias
- It respects people's voices and choices, regardless of how they communicate or what their diagnosis is
- It helps a person develop advocacy, self-determination, and decision-making skills
- It keeps the person in the driver's seat and allow them to keep their rights.
- Consideration of alternatives to guardianship is an ongoing analysis

Why is SDM important?

- **Studies show that people who are denied self-determination experience worse life outcomes:**
 - Overbroad guardianship has a “significant negative impact on...physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010).
 - Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency” (Winick, 1995)

Studies show that people who exercise greater self determination have improved life outcomes, including:

- Living Independently
- Working in the community at higher paying jobs and making greater advances in employment.
- Being “more likely to identify situations where they could be abused and less likely to suffer abuse.”
- Having greater financial independence
- Having greater community integration
 - Peter Blank and Jonathan Martinis, “The Right to Make Choices”: National Resource Center for Supported Decision-Making, Inclusion 3:1 (2015). See also Bradley et. al., National Core Indicator Data Brief, 2019.

Ask yourself, how important is it for me to make my own decision about:

- What I have for breakfast
- How I style my hair
- What clothing I wear
- Where I live
- Who I love
- Who I spend time with
- Who I live with
- Where I work
- What TV shows I watch or stream?
- What music I listen to
- What books I read
- What exercise I do (or don't do)?
- What kinds of snacks I eat—Oreos or carrot sticks?

IV. Resources

On SDM:

Disability Rights Maryland: <https://disabilityrightsmd.org/resources/>

National Resource Center for Supported Decision-Making:

<http://supporteddecisionmaking.org/>

American Civil Liberties Union Disability Rights Program:

- <https://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library>

Autistic Self-Advocacy Network (ASAN): <https://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>

- *Center for Public Representation (CPR):* <https://supporteddecisions.org/resources-on-sdm/>

- *The Arc of Northern Virginia:* <https://thearcofnova.org/programs-services/sdm-resource-library/>

- *SDMNY Pilot:* <https://sdmny.org/>

- *Maryland SDM bill text:* <https://mgaleg.maryland.gov/2022RS/bills/sb/sb0559t.pdf>

Videos:

National Disability Rights Network, Supported Decision-Making & Health Care Video:

https://www.youtube.com/watch?v=Qi07_WriG60&t=391s

Disability Rights Texas Supported Decision-Making Video, Dawn & Belinda's story:

<https://www.youtube.com/watch?v=iZ7jhgay-r8&t=1>

Maryland Judiciary's Alternative to Guardianship Videos, including SDM:

<https://mdcourts.gov/reference/alternativesvideolibrary>



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