

1500 Union Ave., Suite 2000, Baltimore, MD 21211 www.DisabilityRightsMD.org

## House Judiciary Committee Senate Bill 559 – Supported Decision-Making March 23, 2022 Position: Support

Disability Rights Maryland (DRM), formerly *Maryland Disability Law Center*, is Maryland's federally-designated protection and advocacy organization charged with advancing the rights of people with disabilities for over 40 years. DRM has witnessed how people with disabilities are denied the supports and accommodations they need to make their own decisions and are placed under guardianship as a result. Their stories are harrowing: some have been institutionalized against their will; others have been unable to control their own medical care; and some have been unable marry the person that they love. By recognizing supported decision-making (SDM) as an alternative to guardianship, Senate Bill 559 creates a tool to empower people with and without disabilities to be the architects of their own lives and retain the ability to make their own decisions. As such, DRM strongly supports Senate Bill 559.

## History

Supported decision-making (SDM) is a foundational civil rights issue for people with disabilities. Everyone, regardless of whether they have a disability, relies on the support of people they know and trust to make, communicate, and effectuate their decisions. Whether it is a decision about what car to buy, whether to rent an apartment, or whether to undergo a medical procedure, we all rely on the people closest to us to help us make sense of the situations and decisions we face. Most of us informally choose our own supporters (our close friends, family members, and mentors), to weigh the consequences and pros and cons of our decisions. While we use their support to reach our decision, we remain the decision-maker: that's SDM.

SDM is not a new concept. The first law recognizing SDM passed in British Columbia Canada in 1996.<sup>1</sup> Roughly ten years later in 2006, the United Nations Convention on the Rights of Persons with Disabilities enshrined that people with disabilities have a right to enjoy legal capacity on an equal basis with others and may use SDM to exercise that right.<sup>2</sup> By 2015, Texas became the first state in the US to pass a law formally recognizing SDM agreements, followed by our neighbor Delaware, later in 2015. In fact, in 2015, the Maryland General Assembly passed a narrow law recognizing people with developmental disabilities right to use SDM to access organ transplants.<sup>3</sup> Since then an additional 17 states and DC have passed laws recognizing SDM as an alternative to guardianship and at least an additional 20 have introduced legislation on it. More states pass legislation each year. Senate Bill 559 brings Maryland in line with near majority of states that have broadly recognized SDM as an alternative to guardianship.

<sup>3</sup> Maryland General Assembly, 2015, <u>https://mgaleg.maryland.gov/mgawebsite/legislation/details/sb0792?ys=2015rs</u>

<sup>&</sup>lt;sup>1</sup> British Columbia, Representation Agreement Act, 1996, available at https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96405\_01

<sup>&</sup>lt;sup>2</sup> United Nations Convention on the Rights of Persons With Disabilities, 2006, available at

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html



The momentum to recognize SDM around the country is palpable. SDM has been endorsed by several national organizations, including the National Guardianship Association (2016)<sup>4</sup>, the National Council on Disabilities (2018)<sup>5</sup>, the Social Security Advisory Board (2016)<sup>6</sup>, The American Association of Intellectual and Developmental Disabilities and The Arc of the United States (2016)<sup>7</sup>, The US Department of Education (2017)<sup>8</sup>, the US Senate Special Committee on Aging (2018)<sup>9</sup>, the American Civil Liberties Union<sup>10</sup>, and others. In 2017, the Administration on Community Living established the National Resource Center for Supported Decision-Making,<sup>11</sup> which has become a hub for resources, and best practices surrounding SDM across the country.

Furthermore, SDM has gained acceptance as a best practice among attorneys and courts. In 2016 the American Bar Association (ABA) developed the PRACTICAL Tool, a guide that helps lawyers identify and implement decisions-making options that are less restrictive than guardianship, including SDM.<sup>12</sup> Then in 2017, the ABA passed a resolution advocating for states to pass legislation to recognize SDM and for courts to utilize it to prevent or terminate guardianship.<sup>13</sup> In 2017 the Uniform Law Commission drafted model legislation, the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA), that recognizes SDM and requires its consideration as a less restrictive alternative to guardianship.<sup>14</sup>

SDM is also reasonable accommodation under the Americans with Disabilities Act (ADA). The ADA requires that people with disabilities have equal access to services and programs as those without disabilities. Equal access can include tools to ensure effective communication, which means that whatever is written or spoken must be as clear and understandable to people with disabilities as it is for people without disabilities.<sup>15</sup> Supporters play a critical role in ensuring that people with disabilities have the tools they need to understand and communicate their own decisions. Indeed, the National Guardianship Summit's 2021 recommendations urged the

- <sup>4</sup> National Guardianship Association, Position Statement, <u>https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision Making PositionStatement.pdf</u>
- <sup>5</sup> https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives
- <sup>6</sup> Social Security Advisory Board, Representative Payees: A Call to Action, http://ssab.gov/Portals/0/
- OUR\_WORK/REPORTS/ Rep\_Payees\_Call\_to\_Action\_Brief\_2016.pdf

home/digestviewer/viewthread?MessageKey=62fffa0e-c746-49ea-9d84-

<sup>&</sup>lt;sup>7</sup> AAIDD and The Arc of the United States, Position Statement, <u>https://www.aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship</u>

<sup>&</sup>lt;sup>8</sup> US Department of Education, Transition Guide,

https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-may-2017.pdf

<sup>&</sup>lt;sup>9</sup> US Senate Special Committee on Aging, <u>https://www.aging.senate.gov/download/guardianship-report-2018</u>

<sup>&</sup>lt;sup>10</sup> ACLU, <u>https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making</u>

<sup>&</sup>lt;sup>11</sup> See generally, <u>http://www.supporteddecisionmaking.org/</u>

<sup>&</sup>lt;sup>12</sup> ABA PRACTICAL Tool,

https://www.americanbar.org/groups/law\_aging/resources/guardianship\_law\_practice/practical\_tool/ <sup>13</sup> ABA Resolution, 2017,

https://www.americanbar.org/content/dam/aba/administrative/law\_aging/2017\_SDM\_%20Resolution\_Final.pdf <sup>14</sup> See generally, <u>https://www.uniformlaws.org/committees/community-</u>

<sup>7</sup>d2303788433&CommunityKey=d4b8f588-4c2f-4db1-90e9-48b1184ca39a&tab=digestviewer

<sup>&</sup>lt;sup>15</sup> See ADA toolkit for State & Local Governments, available at <u>https://www.ada.gov/pcatoolkit/chap3toolkit.htm</u>



Department of Justice to issue guidance about SDM's use as a reasonable accommodation under the ADA.<sup>16</sup>

In January 2020, DRM established Maryland's Cross-Disability Supported Decision-Making Coalition, which consists of over 27 partners, including private attorneys, advocacy groups and self-advocacy groups for people with developmental disabilities, mental health conditions, traumatic brain injury, and older adults, as well as partners from state agencies including the Department of Disabilities, the Department of Aging, the Department of Human Services, the Behavioral Health Administration, as well as the Judiciary. With a grant from our Developmental Disabilities (DD) Council, the Coalition received technical assistance from the National Resource Center for Supported Decision-Making to develop an action plan for implementing SDM in Maryland. The Coalition advised action plan goals around education, community outreach, legislation, and data collection and is currently implementing these goals.

Senate Bill 559 reflects the Coalition's collaborative work to create an effective model for Maryland to implement SDM. We have reviewed legislation, initiatives, and pilot projects in other states and spoken with advocates about how it is working in practice. We have crafted a model that is responsive to Maryland's needs and builds upon what others have learned. This bill is the result of a deliberative and comprehensive evaluation of the SDM landscape across the US.

From 2015 to today, the SDM landscape has changed. What was an innovative and new concept seven years ago, is now widely recognized and accepted as a best practice. As the favorable testimony from advocacy organizations, 20 of our partners from the Maryland's Cross-Disability Rights Coalition, the Judiciary, and others show—our state is ready to recognize SDM.

## What does this bill do?

This bill builds best practices from other states who implemented supported decision-making by:

- Creating a framework for how to make a supported decision-making agreement so that third parties are more likely to recognize them
- Allowing courts to terminate or limit guardianship due to the existence of SDM
- Making it clear that a supporter cannot make a decision for a person, rather the person remains the decision-maker
- Limiting who can be a supporter, including excluding people who have been convicted of exploitation of vulnerable adults or people who are the subject of a peace order or protective order against the person
- Limiting liability for those who in good faith rely on the use of SDM agreements
- It does not replace the need for guardianship. Maryland law requires that less restrictive alternatives to guardianship are considered before guardianship is imposed. This bill creates an additional alternative that should be considered and can be a tool to modify or terminate guardianships in certain situations. Guardianship remains available if supported decision-making does not work or is not appropriate.

<sup>&</sup>lt;sup>16</sup> See, <u>https://www.americanbar.org/content/dam/aba/administrative/law\_aging/2021-grd-smmt-recmndtns.pdf</u>



• It does not replace powers of attorney or other legal tools, it instead creates another tool in the toolbox. A supporter does not have the same authority as an agent under a power of attorney. An agent has the authority to make decisions on behalf of an adult and stand in their shoes, a supporter has no authority to make decisions for a person. They merely provide support and accommodation to ensure that a person has the tools they need to communicate their own decisions.

## Why do we need this legislation?

Unfortunately, people with disabilities continue to be denied access to the supports and accommodations they need to have their decisions respected. Bias leads to some people to be found incapable, even though if they had a supporter present to help convey information or even advocate for accommodations, they could make their own decisions. A person's capacities for understanding and decision-making are far more nuanced then their diagnoses. Senate Bill 559 ensures others recognize their obligation to respect the decision a person makes with support.

Senate Bill 559 is also critical because it can prevent the need for guardianship in certain situations and limit and terminate overbroad or unnecessary guardianships. Under guardianship a person loses their ability to make decisions for themselves, which is placed in the hands of their guardian. A person can lose their right to vote, their ability to marry or partner with the person they love, their ability to control what medical care they receive or who can visit them, and other decisions. Once placed under guardianship it is very difficult for a person to have that guardianship terminated. We have seen people remain under unnecessary guardianships and even be abused because they cannot access the medical evaluations or legal resources they need to terminate it. Studies have shown that people in overbroad guardianships experience "a significant negative impact on…physical and mental health, longevity, ability to function."<sup>17</sup> While guardianship still may be the appropriate tool in some cases, it must not be the default. Senate Bill 559 enshrines SDM as an alternative to guardianship. In doing so, it preserves a person's right to make their own choices—fundamentally it is their right to have rights.

This bill provides us all with a tool that can ensure that we can continue to have the dignity to direct our lives and make our own choices. **The Sponsors and advocates of this bill have worked hard and collaboratively to ensure that there is no opposition to it**. Senate 559 ensures that people with disabilities have access to the same fundamental right to make their own decisions as we all do and can chart the course of their own lives. For that right, DRM urges this committee to give SB 559 a favorable report. For additional information, please contact, meganr@disabilityrightsmd.org.

Respectfully submitted, Megan Rusciano Managing Attorney, Disability Rights Maryland

<sup>&</sup>lt;sup>17</sup> Wright, J. (2010). Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA. International Journal of Law and Psychiatry, 33(5-6), 350-368. http://dx.doi.org/10.1016/j.ijlp.2010.09.007.