

HB 529 Testimony.pdf

Uploaded by: Alle Andresen

Position: FAV



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March 7, 2022

The Honorable Luke H. Clippinger
Chair, House Judiciary Committee
House Office Building, Room 101
Annapolis, MD 21401

Re: Support for House Bill 529: Estates and Trusts – Supported Decision Making

Dear Mr. Chairman and Members of the Committee:

Thank you for the opportunity to testify in support of HB 529. This Bill creates a process to establish Supported Decision-Making agreements (SDM) in Maryland. SDM creates a statutory tool that enables disabled persons to retain the right to make personal decisions. It is a less restrictive alternative to guardianship, which is a well-recognized statutory process but which completely strips a person of their decision-making rights. Alle Andresen, Esq. will testify in support of HB 529 at the request of Delegate Peña-Melnyk.

Maryland Legal Aid (MLA) is a non-profit law firm that provides free legal services to the State's low-income and vulnerable residents, including abused and neglected children, nursing home residents, and veterans. Maryland Legal Aid frequently represents and advocates for older adults and people with disabilities in matters pertaining to accessing long-term care, Medicaid services in the community, and their rights concerning nursing homes and assisted living facilities.

HB 529 will provide assistance and support to adults with disabilities while they make, communicate and effectuate their decisions. It can prevent the need for a substitute decision-maker such as a guardian and give self-determination to adults with disabilities.

Individual decision-making is a human right.¹ Every adult has the right to make life choices and to have those choices respected.² The right to personal decision-making applies to older adults with declining cognition and persons with disabilities.³ Adults make choices about where they live, what they eat, what they do, and how they spend

¹ Convention on the Rights of Persons with Disabilities (CRPD):

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

²<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#preamble>

³ Id.

money. SDM provides a statutory tool for disabled people to retain their right to make personal decisions, yet have assistance with the decision-making process.

MLA represents persons with diminished capacity and those who may be otherwise disabled. MLA is an active member of the Cross-Disability Supported Decision Making Coalition, comprised of more than 27 partner organizations, including non-profit advocates and Maryland government agencies. One purpose of the Coalition is to promote the self-determination of older adults and people with intellectual and developmental disabilities.

For example, MLA was recently contacted by a county Ombudsman regarding an assisted living resident assigned a court-appointed Guardian. The Ombudsman wanted to know how they could help the resident if she had a guardian who would not talk to her ward because she no longer had the right to decide where she lived. The Guardian moved the resident from one assisted living home to another every few months. The Guardian would not communicate about decisions, did not explain options, or ask for the resident's preference about her residency. No court-appointed attorney was available. With the assistance of the Ombudsman, the resident was referred to the Guardianship Attorney for the Circuit Court to have her case reviewed by a Magistrate. This entire proceeding may have been avoided if the supported decision-making process had been considered or included in the original guardianship process.

Maryland Legal Aid supports HB 529 for several reasons. The Bill would codify the concept that adults have the right to make life choices but sometimes need support. It will formalize SDM agreements to ensure acceptance and provide clear guidelines and protections in creating these agreements.

Thank you for considering this written testimony. For the reasons stated above, **MLA urges a favorable report on HB 529.**

Sincerely,

/s/Alle Andresen

Alle Andresen

Long-Term Care Assistance Project Attorney

/s/Mary Aquino

Mary Aquino

Senior Attorney for Elder Law

HB 529_PJC_Support.pdf

Uploaded by: Ashley Black

Position: FAV



Ashley Black, Staff Attorney
Public Justice Center
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HB 529
Estates & Trusts – Supported Decision Making
Hearing of the House Judiciary Committee
March 9, 2022
1:00 PM

SUPPORT

The Public Justice Center (PJC) is a not-for-profit civil rights and anti-poverty legal services organization which seeks to advance social justice, economic and racial equity, and fundamental human rights in Maryland. Our Health Rights Project supports policies and practices that promote the overall health of Marylanders struggling to make ends meet, with the explicit goal of promoting strategies that work to eliminate racial and ethnic disparities in health outcomes. **The PJC stands in strong support of HB 529**, which would authorize the use of supported decision-making agreements to assist an adult in making, communicating or effectuating certain decisions without the need for a court to appoint a substitute decision maker.

Guardianship has the impact of stripping away the rights that adults naturally have to make certain decisions for themselves. Though there are times where guardianship may be the appropriate course, courts tend to place adults with disabilities, primarily those with intellectual, developmental or mental health disabilities, under guardianship that is more broad than necessary.¹ At risk for individuals proposed for guardianship is the ability to make decisions that impact their quality of life, like the right to marry, who to communicate with, how to spend money, receiving healthcare and voting. Further, individuals who are appointed a public guardian are at risk of neglect, abuse from others and being unnecessarily institutionalized.²

Supported decision making is a person-centered tool that empowers adults with disabilities to make decisions for themselves with limited support from someone they trust. By not recognizing supported decision making as a less restrictive alternative to guardianship, Maryland is actually behind more than 20 other states that have enacted laws allowing adults to utilize supported decision-making agreements. HB 529, if passed, would prevent the appointment of a guardian where the adult can make decisions with assistance from a support person. It

¹ Teaster, Pamela B., et al. *Wards of the State: A National Study of Public Guardianship* (2007), http://www.supporteddecisionmaking.org/sites/default/files/wards_of_the_state.pdf.

² *Id.*

would also allow for a court to terminate or limit guardianship where a supported decision-making agreement exists.

It is time for Maryland to join other states in recognizing supported decision making as a tool to preserving the self-determination of adults with disabilities. For these reasons, the Public Justice Center urges the committee to issue a **FAVORABLE** report for **HB 529**. If you have any questions about this testimony, please contact Ashley Black at 410-625-9409 x 224 or blacka@publicjustice.org.

Audrey Sellers SDM Favorable Testimony HB 529 3.9.

Uploaded by: Audrey Sellers

Position: FAV

**House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support**

**Submitted by:
Audrey Sellers
2523 Wentworth Road
Parkville, MD 21234**

Hello, I'm Audrey Sellers, an individual with disabilities and Advocate with Disability Rights Maryland. Thank you for considering my testimony in support of House Bill 529.

At this time, formal supported decision-making (SDM) agreements are used mostly by individuals with intellectual and developmental disabilities. But SDM can also be positively utilized by people with serious mental illness (SMI). Since symptoms typically fluctuate over time, SDM can be used by persons with SMI when planning ahead for future times of impairment.

Many individuals with SMI cherish their independence, distancing themselves from support systems as needed to defend against unwelcome interventions. This isolation worsens symptoms, raising the likelihood that serious consequences – such as substance use, incarceration, or suicide – will ensue from this period of heightened impairment. The good news is that a person with SMI can preemptively mitigate the life impacts of recurring impairment through use of SDM.

SDM could, in fact, help me as I navigate life with Bipolar 1 Disorder. Fall of 2020 presented me with the most significant manic episode of my life, and I didn't see it coming. During this period, I slept about 2 hours per night; for the rest of the night I'd walk the streets of South Baltimore, or zip around on scooters, or dance, or make friends from strangers. Suffice to say my behavior was resolutely risky. My well-meaning family pushed for hospitalization. I refused and, fearing involuntary admission, soon stopped communicating with my entire family. Despite having 17 years of experience navigating behavioral health services, I knew that, if given the power, my family wouldn't honor my own preferences for treatment. The risk of institutionalization was too high for me to stay in contact with my family support system. I would just have to get by on my own.

Having since learned about SDM, now I hope to utilize a formal, legally recognized SDM agreement to authorize a trusted friend to help me manage my SMI. This agreement would enable my friend to act on my behalf while protecting my rights, including the right to consent to medical care. I truly believe that my life can be happy, productive, and fulfilling, assuming that I effectively manage my SMI. In summary, a formal, legally recognized SDM agreement would help me make good decisions even in times of impairment, so I will reach my full potential.

By supporting HB 529, you will help individuals with varied disabilities to lead self-determined and fulfilling lives. You will help people like me. I urge you to support this bill. Thank you very much for your time and attention.

Brenna Lester - FAV

Uploaded by: Brennan Lester

Position: FAV

**House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support**

**Submitted by:
Brennan Lester
5518 Thomas Avenue
Arbutus, MD 21227**

Hello, I'm Brennan Lester from Arbutus, MD. Thank you for allowing me to testify today in support of House Bill 529. When I learned about this bill, I knew I had to speak up.

Six years ago, I was in a car accident that put me in a coma for months. When I woke up the doctors told me that I had experienced a severe traumatic brain injury, or TBI. Things would be different, people said. The doctors told my parents that it would be easier to help me recover if they were my legal guardians.

Since I was injured as an adult, I already had all my due rights as a citizen of this republic. I was 22 years old, and in charge of my life – as I should be. When guardianship was granted, I lost agency.

If you haven't lost your rights to guardianship, you probably won't understand the day-to-day impacts. Allow me to explain. At doctor's appointments, nine times out of ten my providers talk only with my guardian. I'm left guessing the appointment's purpose because I've been left out of the entire process, from scheduling through treatment. Because my guardian is uncomfortable with telehealth, I haven't received mental health treatment for 2 years.

Now, imagine if my doctors had told my parents about supported decision-making, and how this tool could help me make good decisions and get any services I may need. Imagine if I had the power to choose who I want to support me. I could actually vote.

What I'm trying to show you is how supported decision-making protects individual agency while establishing a kind of human safety net. Self-determination is fundamentally important, and it's time for the law to reflect that. Thank you for listening. I hope you will support House Bill 529.

H 529_BIAMD_fav - (2).pdf

Uploaded by: Catherine Mello

Position: FAV



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Delegate Luke Clippinger, Chair
Delegate David Moon, Vice Chair
House Judiciary Committee
Room 101
House Office Building
Annapolis, Maryland 21401

Re: Favorable-HB 529 Estates and Trust-Supported Decision Making

Dear Delegate Clippinger, Delegate Moon and Members of the Judiciary Committee,

I am writing on behalf of the Brain Injury Association of Maryland (BIAMD) in support of HB 529. Through advocacy, education, and research partnerships, BIAMD has sought to improve the lives of Marylanders affected by brain injury. We are part of the no wrong door system for access to long-term care services and regularly responds to over 300 phone calls a month from individuals living with brain injury, family members, and professionals seeking information and assistance on how best to help. Our organization regularly provides information on supported decision making and other alternatives to guardianship when individuals and family members navigating the changes after a brain injury that impact decision making.

A brain injury can cause physical, cognitive, and emotional changes that may last a few days or weeks but can be life-long. The ongoing symptoms of brain injury can impact all domains of a person's life, resulting changes in roles and relationships, employment, and finances in addition to physical and mental health. The ripple effects can alter a person's sense of self as they navigate changes in their roles and routines. Maintaining self-determination, control, and autonomy through supported decision-making allows the individual to define how they want to move forward after a life altering injury.

During the acute phase of recovery from a moderate to severe brain injury, rehabilitation providers utilize the surrogate decision maker law because the person may be in a coma or have limited ability to participate in decision making but family and health providers cannot project the person's needs in the coming days, weeks, or months as they are trying to navigate a very traumatic situation for all involved. The expectation, according to the Attorney General's office, is that while a surrogate decision maker is in place, decisions should be consistent with the person's wishes¹. Currently there is no clear, gradual process for shifting decision making back to the person as they regain capacity during recovery. Implementing supported decision making can allow the process of shifting decision making back to the individual gradually with updates to supported decision-making agreements as the individual regains capacity to make increasing complex decisions with supports. Using this process allows them to avoid guardianship, which in our organization's experience, is difficult to terminate. We are aware of several situations where there was evidence that person wanted to make decisions using the same values and process as they did prior to their injury, yet they were still under guardianship, without support from their guardian in terminating the guardianship.

A person's frontal lobe that controls executive functions that critical to decision making. Due to its position in the front of the skull and anatomy of the skull itself it makes it the lobe that is most likely to be injured. Injury to the frontal lobe can impact attention, memory, understanding and processing information and self-awareness. A person may need the assistance of supporters to gather information, understand or interpret information, understand the consequences of making their decision and implement their decisions.

Putting a person centered, structured framework for considering important decisions may lead to better clinical outcomes for individuals. This can include compensatory strategies that address long-term symptoms of brain injury and help the individuals "practice" using the strategies and supports in the same way which can lead to increasing independence. Using supported decision making can improve self-awareness, which is associated with better rehabilitation outcomesⁱⁱ. One of the tenants of supported decision making is for supporter to give feedback about concerns or potential negative consequence of a decision.

We request that the Committee give a favorable report to HB529 and give Marylanders living with brain injury and other disabilities a legally recognized tool to maintain control over their choices.

Thank you for your consideration of our position.

Sincerely,
Catherine Rinehart Mello
Brain Injury Association of Maryland
2200 Kernan Dr.
Baltimore, MD 21207
443-364-9856

ⁱ <https://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/HCDASummary.pdf>

ⁱⁱ Robertson K, Schmitter-Edgecombe M. Self-awareness and traumatic brain injury outcome. *Brain Inj.* 2015;29(7-8):848-58. doi: 10.3109/02699052.2015.1005135. Epub 2015 Apr 27. PMID: 25915097; PMCID: PMC4769700.

SDM Favorable Testimony HB 529 for Ellen Callegary

Uploaded by: Ellen Callegary

Position: FAV

Ellen A. Callegary
The Law Offices of Ellen A. Callegary, P.A.
House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support

The attorneys in The Law Offices of Ellen A. Callegary, P.A. represent individuals with disabilities throughout Maryland. For over forty years, I have worked to protect the most vulnerable members of our community --- children and adults with disabilities. Beginning with my time as an Assistant Attorney General in Maryland in 1979 and continuing through today as a private attorney working on their behalf. Because of my desire to promote greater independence in decision-making for all Maryland adults including adults with disabilities, I submit this testimony in support of House Bill 529.

- Supported decision-making is a nationally and internationally recognized best practice that helps preserve a person’s right to make their own decisions by recognizing that just like people without disabilities, people with disabilities rely on “supporters” - the people who they trust to help them make, communicate, and effectuate their decisions.
- This law would help formalize supported decision-making (SDM) agreements, to ensure that these agreements are accepted and that there are clear guidelines and protections in making these agreements.
- Passing supported decision-making in Maryland would not be a ground-breaking act. In 2015 the legislature passed a narrow bill recognizing supported decision-making in the context of organ transplants. As of today, 20 jurisdictions in the US have passed laws formally recognizing SDM and over 40 states have introduced legislation. The Administration on Community Living has funded SDM projects in over 18 states and created a National Resource Center for Supported Decision-Making, which is a hub for best practices across the country.
- Maryland’s Developmental Disabilities (DD) Council provided a small grant to help propel the creation of the Cross-Disability SDM Coalition, which consists of over 27 partners, including representation from various state agencies, the Administrative Office of the Courts, advocacy groups, self-advocates and family members, and others across the disability and aging communities to help draft a plan to implement SDM in Maryland. The Coalition received technical assistance from the National Resource Center for Supported Decision-Making to draft its action plan, which included an action plan item around passing legislation. I have the honor of being a member of this Coalition.

I am also Co-Editor of “Guardianship and Its Alternatives: A Handbook on Maryland Law”, a joint publication of The University of Maryland Francis King Carey School of Law and the Maryland State Bar Association. SB 559 would provide one more valuable alternative to guardianship for all Maryland adults and their families. Personally, SDM would help my family members with disabilities to receive the support they need throughout their lives. I urge you to give SB 559 a favorable report.

HB529_Supported Decision Making_KennedyKrieger_Sup

Uploaded by: Emily Arneson

Position: FAV



DATE: March 9, 2022 **COMMITTEE:** House Judiciary
BILL NO: House Bill 529
BILL TITLE: Supported Decision-Making
POSITION: Support

Kennedy Krieger Institute supports House Bill 529 – Supported Decision Making

Bill Summary:

House Bill 529 would formalize supported decision-making agreements. Supported Decision-Making is a tool where individuals with disabilities can make their own choices, with support.

Background:

Kennedy Krieger Institute provides specialized services to patients nationally and internationally. Kennedy Krieger Institute is dedicated to improving the lives of children and young adults with developmental, behavioral, cognitive and physical challenges. Kennedy Krieger's services include inpatient, outpatient, school-based and community-based programs.

The Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute is proud to be Maryland's University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and a member of the national Association of University Centers on Disabilities (AUCD).

MCDD links the community to vital services, research and information to improve the lives of people with disabilities. Our mission is to provide leadership that advances the inclusion of people with intellectual, developmental and other disabilities through preservice preparation and training; research and evaluation; community service and technical assistance; and information dissemination.

Rationale:

Supported Decision-making is a process of supporting and accommodating a person so that they can make, communicate, and effectuate life decisions in accordance with their preferences and right to self-determination. This tool allows anyone, but especially a person with disabilities, to retain their decision-making capacity by selecting people who they trust to assist them with making and communicating their will, choices, and opinions.

Supported Decision-Making respects individuals with disabilities voices and choices. This process establishes independence, so that individuals with disabilities have a support system when making informed decisions about their life. In addition, individuals with disabilities develop self-advocacy and decision making skills.

Supported Decision-making is a nationally-recognized best practice that preserves the civil rights of people with disabilities by providing an alternative for guardianship and is endorsed by the American Bar Association, The American Civil Liberties Union, the Uniform Law Commission, and the United Nation's Committee on the Rights of Persons with Disabilities.

Kennedy Krieger Institute requests a favorable report on House Bill 529.

HB529_FAV_AlzheimersAssociationMD.pdf

Uploaded by: Eric Colchamiro

Position: FAV

Testimony of the Alzheimer's Association Greater Maryland and National Capital Area Chapters
HB 529 – Estates and Trusts - Supported Decision Making
Position: Favorable

Chair Pendergrass and Vice-Chair Pena-Melnyk,

My name is Eric Colchamiro, and I am Director of Government Affairs for the Alzheimer's Association in Maryland. Thank you for the opportunity to submit testimony on House Bill 529, which authorizes the use of supported decision making to assist an adult through the provision of certain support for the adult in making, communicating, or effectuating certain decisions and preventing the need for the appointment of certain substitute decision makers for the adult; authorizes an adult to enter into a supported decision-making agreement with one or more supporters under certain circumstances; and provides immunity from civil or criminal liability under certain circumstances.

Alzheimer's and other forms of dementia is a complicated disease, and over time, those who have this chronic disease lose their ability to communicate. According to the Penn Memory Center, "Supported decision making provides a space for people living with dementia and their care partners to safely navigate challenges associated with decision making and dementia. With the support of a care partner, people with dementia can continue to make decisions independently."ⁱ

More than 110,000 Marylanders currently live with this cruel disease, and they need help. They need an infrastructure for care, in so many different ways. This legislation empowers individuals with dementia, and their loved ones, and gives them a structure to make life-altering and life planning decisions.

Thank you again for the opportunity to submit testimony, and we ask for a favorable report on House Bill 529.

ⁱ <https://pennmemorycenter.org/supported-decision-making/#:~:text=Supported%20decision%20making%20provides%20a,continue%20to%20make%20decisions%20independently.>

Estates and Trusts - Supported Decision Making Gai

Uploaded by: Gail Godwin

Position: FAV



HOUSE Judicial Proceedings Committee

March 9, 2022

HB 529: Estates and Trusts – Supported Decision Making
Position: FAVORABLE

Good afternoon, Delegate Pena-Melnyk and members of the Committee. My name is Gail Godwin, I live in Baltimore City, and I am the Founder of Shared Support Maryland, Inc. (SSMD). SSMD stands in strong support of House Bill 529 which, if passed, would authorize the use of supported decision-making contracts to assist people to make, communicate or effectuate decisions without the need for a court appointed substitute decision maker. Thank you for this important session to hear from Marylanders on this civil right. Support to make decisions is already an established freedom and passing this bill will allow recognition to the formal processes of SDM agreements.

SSMD is a non-profit providing Support Brokerage to over 135 people in Maryland who use Self Directed Services, Individual Support Services, Department of Rehabilitation Services and privately pay. SSMD is a proud member of the Maryland's Cross Disability Rights Coalition who has entered testimony in favor. Our objective is not to run the lives of people with disabilities but to support people to run their own. We work in collaboration with people and other organizations to move the resources and information closest to the person so that what defines people as vulnerable has less of a chance of doing so. People live in their own homes, alone, or with people whom they choose. People hire, are the employer of record and are in charge of their own support staff and contractors, hold jobs that pay a living wage, and spend their time in activities of their choosing. We are one of fewer than 75 agencies in the country that provides this kind of person-directed, customized support and services to people with any level or multiplicity of disability, without exception. In everything SSMD does, the intent is to support people to make decisions for themselves. Supported Decision Making, the fact that everyone communicates and presuming capacity are 3 of SSMD's basic operating principles. SSMD does not hire anyone to work here without them, if we make a mistake, we move them along ~ that keeps our customers off of that learning curve.

Shared Support Maryland, Inc.

www.sharedsupportmd.org ~ Baltimore, MD 21229

Shared Support Maryland, Inc.

For 16 years SSMD has worked for hundreds of people who have chosen to leave nursing facilities and institutions, who use up to 24 hours a day of support, people with co-occurring mental illness, co-occurring addictions, acquired injuries, children, people who are aging.. With people's own determination and/or support, ***these are the same people*** with disabilities who who have made major life decisions about:

- What, if and how to receive their services, sometimes decisions not to use a service when others disagree
- Leaving an institute, nursing facility or family home and all of the key decisions that go along with that, like deciding where to live, with whom and how
- Having children and how many,
- Changing gender identity,
- Finding and landing jobs that pay a living wage,
- Saving and spending money,
- Learning to read or going back to school for an advanced degree
- Recruiting, employing, managing/retaining, terminating employees and all of the Human Resources decision making that goes along with that, like approving their time for payroll, providing feedback and giving raises,
- Making determinations to press criminal charges for medicaid fraud, which goes beyond the initial report to our system which, while important, is ineffective in putting an end to it,
- Receiving serious mental health treatment, even when highly recommended or potentially dangerous.
- Futures planning so that when their support system is no longer available or available in the way that it is now, that the person does not acquire a guardian, undecidedly go to a group home for living or segregated services otherwise.

Supported Decision Making is a tool that uncomplicates information and the general public uses it. Routinely, people obtain free and paid advice in order to make decisions. They use accountants to break the numbers down, engineers/builders and architects to show them why their version of a dream home won't be possible, fertility clinics to help weigh options about how to start a family, doctor's second, and third opinions, a therapist to help a couple choose divorce, expert witnesses support lawyers through difficult cases, friends help you decide on the paint for



your room or how to wear your hair. No one is necessarily asked to demonstrate the support that they receive and the support people use is rarely up for debate.

The tools of SDM are endless. Assuming people do understand or that they can understand is first and then making it clear that supporters do not have the authority to make a decision for a person, rather the person remains the decision maker. Then, relying on the capacity of direct supporters to help someone learn; adapting material and information into plain language, graphics, pictures, use of color and pie charts; reading something out loud when a person does not read; calling someone with information from electronic communication every time an email is sent about them when they don't use email; understanding someone who uses a facial expression to state their dissatisfaction about something; bringing in others who know more about a topic; uses coaching and mentoring tools; supporting people through their communication; waiting minutes, hours, days or years for someone to weigh risks and benefits of making certain decisions; using the time that Medicaid pays us for in order to support decision making (Medicaid pays for people to spend time with people); and educating and expecting the same from other supporters including families who are helping their children with decision making for the first time even as adults.

Person directed planning is another SDM tool. SSMD holds a major grant through the Maryland Developmental Disabilities Council that pays people with disabilities and family members to decide on and develop curriculum about Person Centered Planning since they are subject matter experts because of their experience. Trainers, who have disabilities and family members train and mentor others with disabilities and family members on person centered planning. A main takeaway of the training is to stay in charge, expect accountability from teams to do what they say and *for people to take the time that they need to make decisions* (not 1 hour, once a year). Planning time is an ideal place for decision making and determining structure on how decisions are made.

Guardianship and guardians are not the only people that make decisions for people. Currently, our system allows others, who are not appointed guardians, like providers, family members and others to make major decisions for people on a regular basis about service provision, where to live and with whom, what services they will get, and who provides them. In the general public, families can make



decisions about their family members' living situation and care who experience a decline in health and/or ability that is easily acted on by service providers (including institutions and nursing facilities) as if the person were asking for the service themselves. Many of these decisions result in more segregation and isolation, creating an opportunity for abuse that can go unnoticed.

People with disabilities who use a system of support, may inherently see authority in that system and not a place where they can make decisions and be in charge of their lives. The system is designed on the premise that people need something because they have a disability. We are well aware of what can happen when someone has a sphere of influence in someone's life significantly impacting their decision making, rather than supporting it. *This is not Supported Decision Making.* People may be well meaning, they may not consider or are aware of options and information available to support people in their decisions. Some common examples are 1) decisions made by others for someone about behavior services and interventions when people are expressing their need for change and to have control over their lives, 2) a person making a decision to work less because they have been told not to work more than 20 hours a week or they will lose their benefits and services (misinformation), and 3) guiding a person to make a decision to move to a group home because they may be facing difficulty making ends meet or homelessness. When people are in vulnerable positions, they may be more influenced to make decisions they otherwise would not. *This is the danger*, common and essentially acceptable practice. *This is not Supported Decision Making.* Supported decision-making is about ensuring that the person remains the decision-maker, and that they get the support they need to do that.

SDM legislation is not intended to replace power of attorney agreements and guardianship, it is an additional tool. As an additional tool, SDM legislation may give way to reconsideration of current appointments, agreements and other similar contracts if this tool is also and ultimately change a system that is built on people making decisions for other people about what's best because of their diagnosis.

Shared Support Maryland, Inc. and I urge you to vote in favor of House Bill 529/Senate Bill 559 and join the increasing number of states in the US who have passed SDM legislation and the United Nations who mandates SDM.



Thank you for believing in the capacity of all Marylanders and allowing us to join our colleagues and partners in this movement and testimony.

HFAM Testimony HB 529.pdf

Uploaded by: Joseph DeMattos

Position: FAV



**TESTIMONY BEFORE THE
HOUSE JUDICIARY COMMITTEE**

House Bill 529: Estates and Trusts - Supported Decision Making

March 9, 2022

Written Testimony Only

POSITION: FAVORABLE

On behalf of the members of the Health Facilities Association of Maryland (HFAM), we appreciate the opportunity to express our support for House Bill 529. HFAM represents over 170 skilled nursing centers and assisted living communities in Maryland, as well as nearly 80 associate businesses that offer products and services to healthcare providers. Our skilled nursing members provide the majority of long-term and post-acute care to Marylanders in need.

We are pleased to support House Bill 529, with the understanding that the House bill will be amended to match the text of Senate Bill 559 as passed by the Senate, reflecting important clarifications to this proposed legislation.

HFAM endorses this legislation because it helps adults with decision making capacity to obtain the assistance of supporters who will help give effect to directions from the decision makers. This will help caregivers, including the dedicated staff of healthcare facilities such as those HFAM represents.

We offer this support with the understanding of the following legislative intent in adopting this bill.

- Because the authority of supporters is derived from the ability of adults to identify supporters and make their own decisions, supporters will not have the authority to act for an adult who lacks decision making capacity.
- Supporters will not make independent decisions for others; their authority is derived from and is only to act at the direction of a competent adult.
- Adults who wish to appoint decision makers who have authority that survives incapacity can still use durable powers of attorney and healthcare advance directives to appoint agents with such authority. Also, guardianships of person or property and surrogate decision makers under the Health Care Decisions Act will still have authority to act for adults who lack capacity and have not appointed an agent.
- The legislation authorizes the designation of more than one supporter. The potential for disagreements among supporters is mitigated because the supported decision making agreement can give direction. Moreover, if there is any uncertainty over the action of a supporter or the supporter that is inconsistent with direction an agent under a power of attorney or healthcare advance directive, the appointing adult still has capacity and decision making control and can always be consulted to give the final say over what should be done.

For these reasons, we respectfully request a favorable report from the Committee on House Bill 529.

Submitted by:

Joseph DeMattos, Jr.

President and CEO

(410) 290-5132

HB0529 Estates and Trusts_Supported Decision Makin

Uploaded by: Margo Quinlan

Position: FAV

House Bill 529 Estates and Trusts - Supported Decision Making

House Judiciary Committee

March 9, 2022

Position: SUPPORT

The Mental Health Association of Maryland is a nonprofit education and advocacy organization that brings together consumers, families, clinicians, advocates and concerned citizens for unified action in all aspects of mental health, mental illness and substance use. MHAMD, and the Policy Committee of the Maryland Coalition on Mental Health and Aging, appreciate this opportunity to present testimony in support of House Bill 529.

HB 529 would authorize the use of supported decision making to assist an adult through the provision of certain support in making, communicating, or effectuating certain decisions and preventing the need for the appointment of certain substitute decision makers for the adult. It would authorize an adult to enter into a supported decision-making agreement with one or more supporters, thus protecting the dignity and autonomy of the individual by centering their capacity for choice, care, and appropriate community supports.

Maryland's public guardianship program guides the care of hundreds of vulnerable older adults, many with dementia, mental illness and substance use disorders. Individuals with behavioral health disorders represent a disproportionate number of those in the overall program and they tend to be in the program for many years. Alternatively, supported decision-making agreements prioritize an individual's ability to make decisions with appropriate supports if and as needed. It has been demonstrated as an effective intervention to public guardianship when an individual retains the legal capacity to make decisions for themselves. Through supported decision-making, an older adult may rely on trusted friends, family members, and professionals to help them understand the choices they face, thus supporting their own autonomy and independence without state intervention.

While MHAMD appreciates the necessity of public guardianship in certain situations, it must be viewed as a last resort. The legislature must pass legislation that would recognize supported decision-making as a pre-requisite to the public guardianship program. For these reasons, we urge a favorable report on HB 529.

For more information contact:

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HB0529 Testimony.pdf

Uploaded by: Maryland Legislative Latino Caucus

Position: FAV



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TO: Delegate Luke Clippinger, Chair
Delegate David Moon, Vice Chair
Judiciary Committee Members
FROM: Maryland Legislative Latino Caucus (MLLC)
DATE: March 7, 2022
RE: HB0529 Estates and Trusts-Supported Decision Making

The MLLC supports HB0529 Estates and Trusts-Supported Decision Making

The MLLC is a bipartisan group of Senators and Delegates committed to supporting legislation that improves the lives of Latinos throughout our state. The MLLC is a crucial voice in the development of public policy that uplifts the Latino community and benefits the state of Maryland. Thank you for allowing us the opportunity to express our support of HB0529.

In 2018, the prevalence of disability among persons of all ages of Hispanic or Latino origin in the US was 8.9 percent.¹ Although, some people with disabilities may need assistance making a whole range of life decisions, they do not necessarily need a guardian to make those decisions for them. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making. It is important for organizations to recognize the needs of the culturally and linguistically diverse populations they serve.² This bill would allow the individual to choose representatives that understand their language and other culturally specific values who would then be able to communicate effectively to all entities. The supporter can assist in helping the person with a disability understand the nature of a decision and help communicate their wishes. The agreement does not replace an appointed guardianship and does not shift legal liability to a supporter or supporting organization.

Supported Decision-making is an alternative to guardianship. Currently, Maryland does not have an effective alternative to guardianship. This bill would legitimize the supported decision-making process, protecting everyone involved. This bill is essential in allowing Maryland Latinos living with a disability to make their own decisions while promoting self-determination and independence.

For these reasons, the Maryland Legislative Latino Caucus respectfully requests a favorable report on HB0529.

1. "2018 Disability Status Report" (Yang-Tan Institute on Employment and Disability at the Cornell University ILR School, 2020), https://www.disabilitystatistics.org/StatusReports/2018-PDF/2018-StatusReport_US.pdf.

2. Michael López, Erin Bumgarner, and Djaniele Taylor, "Cultural Competence Guide - Hispanic Research Center" (National Research Center on Hispanic Children & Families, May 2017), <https://www.hispanicresearchcenter.org/wp-content/uploads/2019/08/Cultural-Competence-Guide-V21.pdf>

testimony in support of house Bill 529 supported d

Uploaded by: Mathew Rice

Position: FAV



Figure 1 The Arc Maryland Logo



Figure 2: The National Federation of the Blind of Maryland Logo

**House Judiciary committee
HB 529 - Supported Decision-Making
March 9, 2022**

Position: Support

The Arc Maryland is the largest statewide advocacy organization dedicated to protecting and advancing the rights of people with intellectual and developmental disabilities. The National Federation of the Blind of Maryland is the Maryland state affiliate of the [National Federation of the Blind](#). The National Federation of the Blind is the oldest and largest nationwide organization of blind Americans. Founded in 1940 and currently headquartered in Baltimore, the NFB consists of affiliates, chapters, and divisions in all fifty states, Washington, DC, and Puerto Rico. We are in support of SB 559 as it will require the legal recognition of supported decision-making as a foundational civil rights issue for people with disabilities.

Everyone relies on the support of people they know and trust to help them to make, communicate, and effectuate important decisions in their lives. Unfortunately, many people with disabilities, due to historic stereotypes and perceptions about capacity, have been placed in overboard and unnecessary guardianships. Under guardianship, a person loses their ability to make even the most basic decisions for themselves. A person loses the ability to control their medical care, make decisions on their friends/who can visit them and with whom they may have a relationship. They are not allowed to vote or make other decisions that those not under guardianship often take for granted. Also, once a person is placed under guardianship or conservatorship, it is very difficult for a person to have that arrangement terminated.

While guardianship is an important tool in our toolbox, and may be appropriate for some cases, **it must not be the default for people with disabilities. This is why recognition of Supported Decision-Making is so important.**

Supported Decision-Making preserves a person's right to make their own choices—fundamentally it is their right to have rights. Support Decision-Making has been recognized as a reasonable accommodation under the Americans with Disabilities Act. Nineteen states and Washington DC have passed laws similar to this legislation, recognizing supported decision-making agreements.

This bill has the opportunity to prevent unnecessary guardianship for many Marylanders with disabilities. The significance of this legislation cannot be overstated. For all of these reasons, The Arc Maryland and National Federation of the Blind of Maryland support

Contact:

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Ronza Othman, President, National Federation of the Blind of Maryland, ph: 443-426-4110

email: President@nfbmd.org

SDM HB 529 Favorable Testimony__DRM.pdf

Uploaded by: Megan Rusciano

Position: FAV

House Judiciary Committee
House Bill 529 – Supported Decision-Making
March 9, 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, House Bill 529 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 House Bill 529.

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 1996.¹ 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.² 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.³ 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. House Bill 529 brings Maryland in line with near majority of states that have broadly recognized SDM as an alternative to guardianship.

¹ British Columbia, Representation Agreement Act, 1996, available at https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96405_01

² 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>

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

The momentum to recognize SDM around the country is palpable. SDM has been endorsed by several national organizations, including the National Guardianship Association (2016)⁴, the National Council on Disabilities (2018)⁵, the Social Security Advisory Board (2016)⁶, The American Association of Intellectual and Developmental Disabilities and The Arc of the United States (2016)⁷, The US Department of Education (2017)⁸, the US Senate Special Committee on Aging (2018)⁹, the American Civil Liberties Union¹⁰, and others. In 2017, the Administration on Community Living established the National Resource Center for Supported Decision-Making,¹¹ 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.¹² 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.¹³ 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.¹⁴

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.¹⁵ 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

⁴ National Guardianship Association, Position Statement, https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf

⁵ <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

⁶ 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

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

⁸ US Department of Education, Transition Guide, <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-may-2017.pdf>

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

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

¹¹ See generally, <http://www.supporteddecisionmaking.org/>

¹² ABA PRACTICAL Tool, https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/

¹³ ABA Resolution, 2017, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.pdf

¹⁴ See generally, <https://www.uniformlaws.org/committees/community-home/digestviewer/viewthread?MessageKey=62fffa0e-c746-49ea-9d84-7d2303788433&CommunityKey=d4b8f588-4c2f-4db1-90e9-48b1184ca39a&tab=digestviewer>

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

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

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 devised action plan goals around education, community outreach, legislation, and data collection and is currently implementing these goals.

House Bill 529 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.

¹⁶ See, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2021-grd-smmmt-recmndtns.pdf

- 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 than their diagnoses. House Bill 529 ensures others recognize their obligation to respect the decision a person makes with support.

House Bill 529 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."¹⁷ While guardianship still may be the appropriate tool in some cases, it must not be the default. House Bill 529 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. House Bill 529 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 HB 529 a favorable report. For additional information, please contact, meganr@disabilityrightsmd.org.

Respectfully submitted,
Megan Rusciano
Managing Attorney
Disability Rights Maryland

¹⁷ 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>.

HB529_Mid-Shore Pro Bono Written Testimony.pdf

Uploaded by: Meredith Lathbury Girard

Position: FAV



*Supporting and assisting people
on the Eastern Shore with limited
financial means to legal
representation and connections
to community services*

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March 7, 2022

BILL NO: HB529– Estates and Trusts Supported Decision Making
COMMITTEE: Judiciary
FROM: Mid-Shore Pro Bono, Inc.
POSITION: SUPPORT

Mid-Shore Pro Bono (MSPB) recommends a favorable report for HB529. This bill creates an effective solution for people who would benefit from having support in decision making. Allowing people to maintain control over decisions with support ensures higher levels of self-determination and provides a positive alternative to guardianship.

Mid-Shore Pro Bono, Inc. is a Maryland nonprofit that connects people on the Eastern Shore with limited financial means to legal representation and essential community resources. Each year, MSPB helps over 3,000 people in our community access the legal system in times of need. Our network of volunteer lawyers provides free legal services for elder law, family law, landlord/tenant, mortgage foreclosure, and consumer debt. These services help families gain financial and housing stability and create safe, secure home environments for children, which is especially important in times of crisis.

MSPB assists about 500 clients a year with elder law and guardianship issues. Many of our clients are seeking solutions to make sure that their loved ones are properly cared for, or are seeking to plan for their own future to make sure people caring for them can help. Supported decision making provides far greater flexibility and opportunity for self-determination than existing legal frameworks. Our clients need an alternative legal option that empowers people to direct their own lives. Too often, families are forced into a more restrictive legal tool, such as guardianship, than is necessary. As a result, people lose their rights, their voice, and the ability to make their own decisions. For example, one of MSPB's clients was under a guardianship arrangement that prevented her from having a say over her finances. Under this arrangement, she was unable to ensure that some of her limited funds could be used to help with needed personal care items or for transportation to visit her family. In another example, one of MSPB's clients was advised by the child's school to seek guardianship of her young adult son with intellectual disabilities, with no consideration of the impact that a guardianship would have on his legal rights to make decisions about his own life.

HB529 formalizes the nationally and globally recognized best practice of preserving a person's rights to make their own decisions with recognition that people with disabilities, just like those without disabilities, rely on people they trust to help them make, communicate, and implement decisions.

For these reasons, Mid-Shore Pro Bono urges the Committee's support for HB529. If you have any questions regarding our position on this bill, please contact Meredith Lathbury Girard, Esq., executive director, at 410-690-8128 or mgirard@midshoreprobono.org.

MSBA Testimony-HB529.pdf

Uploaded by: Morris Klein

Position: FAV



Planning for Life, Planning for Legacies

Stephen R. Elville, Principal, J.D., LL.M. (Tax)
Lindsay V.R. Moss, J.D.
Duncan Scott Keir, J.D.
Shannon F. Werbeck, J.D.
Shannon K. Mumaw, J.D.
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Gary Greenwald, J.D., LL.M. (Tax) †
Charles A. ("Chuck") Borek, J.D., MBA, CPA ††
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**House Judiciary Committee
Honorable Delegate Luke Clippinger, Chair
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support**

**Testimony of Stephen R. Elville, J.D., LL.M.
and Statement on behalf of the Elder Law and Disability Rights Section Council**

My name is Stephen R. Elville. I am the principal and lead attorney of Elville & Associates, P.C. a mid-size estate planning, elder law, and special-needs planning law firm located in Columbia, Maryland. I am the former Chair of the Elder Law and Disability Rights Section Council of the Maryland State Bar Association, and I currently serve as a continuing member of the Council and chair its Pro Bono Subcommittee. I am also the Elder Law and Disability Rights Section Council liaison to the Estates & Trust Section Council of the Maryland State Bar Association. I have been a practicing attorney in the areas of estate planning, elder law, special needs planning, and taxation for over twenty-one years.

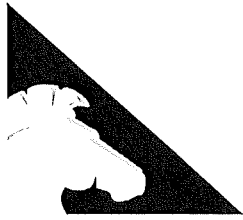
Approximately seven ago I met the acquaintance of Megan Rusciano, an attorney and disability rights advocate, and the main proponent of supported decision-making legislation in Maryland. I met Megan while presenting at the ARC of Frederick on the topic of guardianship while she co-presented on the subject of supported decision-making. At that time, I had never heard of the concept of supportive decision-making and went about my business of presenting to the large audience of special needs parents during which I expounded on the concepts and mechanics of guardianship. Megan presented on supported decision-making as an alternative and tool in guardianship. In the weeks and months following the presentation, I continued to stay in touch with Megan as a new awareness of supportive decision-making permeated my thinking during the daily ins and outs of our firm's very busy special needs and guardianship practice. Over time, I began to understand that supported decision-making was something parents of children with disabilities, older adults with disabilities, and the aging population strongly desired and wished to see passed into law. As I continued to gain more insight into the idea that persons with disabilities (and their advocates) want to be able to make their own decisions to whatever degree possible, I began to understand that the traditional paradigm of guardianship limits our ability to think in terms of persons with disabilities being able to take risks. I gradually realized that supported decision-making is a powerful tool that attorneys and courts need to ensure that all alternatives to guardianship are explored prior to the implementation of a guardianship.

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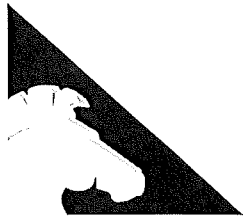
Planning for Life, Planning for Legacies

House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support
Page 2

But beyond that, I concluded that supported decision-making was an essential tool for persons with disabilities to be able to reach their fullest capacity, something that is one of the foundational principles of special needs planning. Along these lines, I undertook to educate myself about the supported decision-making laws in various states such as Indiana, Alaska, Texas, Delaware, the District of Columbia, and Wisconsin. I then decided that it would be a worthy goal to dedicate the use of my production studio (Elville Studios, LLC) for the purpose of producing a documentary film to educate the citizenry of Maryland and its thought leaders and decision makers about the need for supported decision-making; and further to educate the public about the uses and applications for supportive decision-making on a practical level so that the idea not be passed into law and then pigeonholed in a one or two dimensional approach. As part of the production of the documentary (still underway), I have interviewed and filmed top Maryland guardianship attorneys, persons with disabilities, and their advocates. I have concluded that the leading guardianship attorneys in Maryland agree that supportive decision-making is not only an idea whose time has come, but that courts are already improvising by way of consent orders and in essence creating quasi-supported decision-making agreements (largely by necessity). It is also clear from my research that persons with disabilities who have advocates and supporters who can help them effectuate their own wishes and desires to whatever extent they are capable of making such wishes and desires known have a very high quality of life compared to persons with disabilities who live in and labor under the conditions of the traditional paradigm of guardianship.

Having provided the foregoing narrative summary, I submit the following further points:

Supported Decision-Making (SDM) is about support - supported decision-making is about providing support. It is about this concept: people with disabilities can make their own decisions to a very large degree provided that they have the support to do so. Again, supported decision-making is about whether persons with disabilities can make their own decisions. It is a question of whether we are willing to provide enough support so that they can do so;



ELVILLE
AND ASSOCIATES

Planning for Life, Planning for Legacies

House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support
Page 3

People with disabilities can make their own decisions to a very large degree provided they have the support to do so - - persons with disabilities do not want to live under the paradigm of protection such as exists under the old regime of guardianship. Rather, persons with disabilities want to be able to take risks; and only by being able to take risks can they live as persons with the same rights and opportunities as those without disabilities. Persons with disabilities have to be given the right to take risks and to make mistakes - and only by doing so can they be free. This is the theme of the documentary film in progress and again I submit it as the core concept that, once accepted, leads to a greater understanding of what supported decision-making is all about and that *it is to be embraced rather than feared*;

Supported decision-making recognizes everyone - regardless of whether they have a disability, and relies on the support of people that they know and trust to help them understand, make, and effectuate decisions. A person may rely on their supporter to help them understand a medical situation that they face, but they remain the ultimate decision-maker. This is a critical feature of SDM and one that distinguishes it from other less restrictive alternatives: the supporter does not have any authority to make decisions for a person, instead the supporter merely provides feedback and helps the person understand the nature and consequences of the decision.

A tool for the individuals – Supported decision-making can be a stand-alone document and legal mechanism for a person with disabilities to appoint a supporter to help them make their own decisions – and that supporter could be the same person who is named as the attorney-in-fact in a power of attorney document, or as health care agent in an advance directive; or it could be a different person than these agents who are named as fiduciaries;

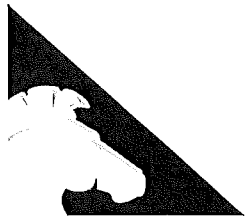
Can be used as a tool for the legal community (and as part of guardianship) – as discussed herein, supported decision-making is another tool in the toolbox for attorneys and for courts. If supported decision-making were part of Maryland Law, courts could truly say they are examining *all lesser restrictive alternatives* to guardianship and also implement guardianships where necessary while including the right of the ward to have a supported decision-maker. Thus, the concepts of guardianship and supported decision-making do not have to be mutually exclusive. Rather, they can live together in a framework for achieving the highest and best outcomes for persons with disabilities;

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ELVILLE
AND ASSOCIATES

Planning for Life, Planning for Legacies

House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support
Page 4

Does Not replace guardianship Supported decision-making does not replace the need for guardianship. Maryland law requires that less restrictive alternatives to guardianship are considered before guardianship is imposed. Supported decision-making creates an additional alternative that should be considered and can be a tool to terminate guardianships in certain situations. Guardianship remains available if supported decision-making does not work or is not appropriate.

Does not replace powers of attorney or advance medical directives - as mentioned and implied above, a supported decision-making agreement *does not replace* a power of attorney or advance medical directive document. It does *not* provide the supporter with any decision-making power over the disabled person's decisions. Rather, the supported decision-making agreement can be an adjunct to these important incapacity documents. At the risk of redundancy, it's important to understand that a supporter under a supported decision-making agreement does not have the authority to make decisions for the person with disabilities. Rather, the supporter is only there to provide *support* and to *accommodate* the person with disabilities so they can make their own decisions to the extent possible. The supporter has *no legal access or control* over the funds of the disabled person;

The concept is simple, not complex - Supported decision-making is a *simple* concept. It is not a complex concept. It becomes complex only if misunderstood. The supporter *accommodates and supports* the person with disabilities. The supporter *does not make decisions* for or *control* the person with disabilities;

SDM is mandated by the United Nations - if Maryland passes supported decision-making into law, it will be fulfilling the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (Article 12);

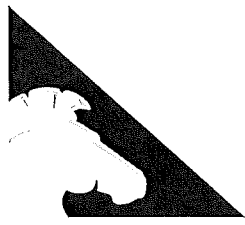
SDM-type agreements are already happening now in guardianships - as mentioned above, Maryland's top guardianship attorneys will tell us that attorneys and courts are already accommodating and facilitating agreements short of guardianship in an attempt to address the customize needs of each individual who is faced with the prospect of guardianship. Supported decision-making would simply bring to light in a simpler fashion what is already going on under the traditional paradigm of guardianship;

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House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support
Page 5

SDM is eagerly anticipated by most parents, grandparents, and other relatives of disabled children, along with their providers and advocates too - all eagerly anticipate the passage of supported decision-making into law as an expansion of human rights and dignity for persons with disabilities. It is my hope that the Maryland General Assembly will hear these voices and provide the legal mechanism necessary to effectuate this path to self-determination; and

Equally powerful for the Aging Community - supported decision-making is not just for young persons with disabilities or those with intellectual disabilities - it is an equally powerful and necessary tool for the aging population who oftentimes are not accommodated to continue to make their own decisions for as long as possible or given the opportunity to avoid guardianship. With the proper understanding that a supporter only exists to provide support and to accommodate the person with disabilities, young or old, it becomes clear that the concerns or risks associated with allowing a person with disabilities to appoint a supporter are outweighed by the benefits and the enhanced rights of the self-determination experienced by the aging or disabled person.

Other points:

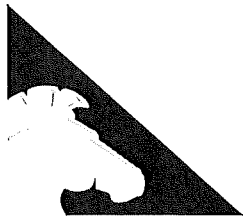
- Several national organizations, including the National Guardianship Association, the National Council on Disabilities, the US Administration on Community Living, the American Civil Liberties Union, and others, have endorsed supported decision-making as an alternative to guardianship.
- SDM has been endorsed by the American Bar Association, which passed a resolution in 2017 advocating for states to pass legislation to recognize SDM and for courts to utilize it as a tool to prevent or terminate guardianship.
- SDM is a reasonable accommodation under the Americans with Disabilities Act. Indeed, the National Guardianship Summit's 2021 recommendations recognize it as such and urge the Department of Justice to issue guidance about SDM's use as a reasonable accommodation. The recommendations also reiterate the need for courts to consider SDM and for states to make explicit in their laws that it must be considered as a less restrictive alternative. Those recommendations are available here.

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House Judiciary Committee
HB 529 – Supported Decision-Making
March 9, 2022
Position: Support
Page 6

In closing, the great state of Maryland is situated between the District of Columbia and Delaware, both states having already passed supported decision-making legislation into law several years ago. Maryland is therefore behind its neighbors and must consider a more progressive view of the rights of its many citizens with disabilities. Furthermore, Maryland must continue to shift away from the traditional notion and paradigm of guardianship while always walking towards the bright and shining path of human rights and dignity for all. Based on my foregoing testimony, I ask the Maryland General assembly to pass HB 529 – Supported Decision-Making - into law this legislative session. By doing so you will be enhancing the lives of those persons who seek a voice, who seek to direct their own lives, and who do not wish to live under the auspices of protectionism.

Thank you,

Stephen R. Elville, J.D., LL.M

NAbouraya - Supported Decision Making.pdf

Uploaded by: Nadia Abouraya

Position: FAV

Nadia Abouraya
Montgomery County, Maryland
Self-advocate
SUPPORTING House Bill 529
tennisnadia@gmail.com

I am more independent now that I work for the Montgomery County Government, and I can walk to work/drive anywhere close to my home. It is good for me to be independent now if something happens to my parents. I believe young people with disabilities should be able to make some of their own decisions even if it's hard. They can have another relative or friend/service provider to count on if they have a hard time, and sometimes they can make their own decisions for themselves without difficulties. Decisions and choices are hard for me, but I have learned how to solve problems like creating and cooking my own menus and speaking up when I have issues in my apartment. I can do this myself but I always have people to ask if I need help. More young people like me should be able to do this.

HB529.DD Council.Support.pdf

Uploaded by: Rachel London

Position: FAV



Maryland Developmental Disabilities Council

CREATING CHANGE • IMPROVING LIVES

House Judiciary Committee

March 9, 2022

HB 529: Estates and Trusts – Supported Decision Making

Position: Support

The Maryland Developmental Disabilities Council (DD Council) is a statewide public policy organization that creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. The DD Council is led by people with developmental disabilities and their families. From that perspective, the DD Council strongly supports SB 559.

In fact, the DD Council's support of supported decision making (SDM) began years ago when we provided a grant to help create the Cross-Disability SDM Coalition – a group of over 27 partners, including representation from various state agencies, the Judiciary, advocacy groups, self-advocates and family members, and others across the disability and aging communities. Our funding provided technical assistance to the Coalition from the National Resource Center for SDM to draft an action plan.

WHY is this legislation important to people with disabilities and their families?

- **Supported decision making is a critical civil rights issue for people with disabilities—it is about the right to have rights and use them to direct your own life.** Too often people with disabilities have been placed in overbroad and unnecessary guardianships based on stereotypes about their capabilities. **Guardianship is incredibly restrictive—it takes away a person's basic rights to direct their life.** 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.
- **Supported decision-making is a nationally and internationally recognized best practice that helps preserve a person's right to make their own decision.** It recognizes that just like people without disabilities, people with disabilities rely on "supporters" - the people who they trust to help them make, communicate, and effectuate their decisions.
- **This law would help formalize supported decision-making agreements, to ensure that people accept it and that there are clear guidelines and protections in making these agreements.** Passing supported decision-making in Maryland would not be a ground-breaking act. In 2015, the legislature passed a narrow bill recognizing supported decision-making in the context of organ transplants. **As of today, 20 jurisdictions in the US have passed laws formally recognizing SDM and over 40 states have introduced legislation.**

WHAT does this legislation do?

This bill ensures people with disabilities have access to the same fundamental rights and decisions that we all do. It does this by:

- Creating a framework for how to make a supported decision making agreement so that third parties are more likely to recognize them.

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Kalani Brown, *Chairperson* • Rachel London, Esq., *Executive Director*

- Providing an alternative that courts must consider before placing someone under guardianship, and allowing courts to terminate or limit guardianship due to the existence of a supported decision making agreement.
- Ensuring that the manner in which a person communicates is not grounds for determining that a person is incapable of making a supported decision making agreement.
- Making it clear that a supporter does not have the authority to make a decision for a person, rather the person remains the decision maker.
- Limiting liability for those who in good faith rely on the use of supported decision making agreement.

Supported decision making and allows a person to continue to make their own decisions—just recognizing that they use support to do so. It preserves a person’s right to make their own choices—fundamentally it is their right to have rights.

For these reasons, the Maryland Developmental Disabilities Council supports HB 529.

Contact: Rachel London, Executive Director: RLondon@md-council.org

MDCDRC SDM Favorable Testimony HB 529 3.7.22.pdf

Uploaded by: Rodney Coster

Position: FAV

House Judiciary Committee
HB 529 – Supported Decision-Making
March 7, 2022
By the Maryland Cross Disability Rights Coalition
Position: Support

The Maryland Cross-Disability Rights Coalition (CDRC) is a network of advocacy organizations that advocate for people across disabilities—including people with developmental disabilities, mental health concerns, and older adults. As such, the CDRC supports HB 529.

Why is this bill important?

Recognition of supported decision-making 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. However, for people with disabilities simply recognizing this support can ensure that they can continue to direct their lives and make their own decisions.

Too often people with disabilities have been placed in overbroad and unnecessary guardianships based on stereotypes about their capabilities. 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. Too often, we have seen people with disabilities remain under unnecessary guardianships and even experience abuse and neglect, 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.”¹ While guardianship still may be the appropriate tool in some cases, it must not be the default for people with disabilities.

This is why recognition of supported decision-making is so critical. Supported decision-making provides an alternative that courts must consider before placing someone under guardianship and allows a person to continue to make their own decisions—just recognizing that they use support to do so. It preserves a person’s right to make their own choices—fundamentally it is their right to have rights.

Supported decision-making is not a new concept. It has been recognized as a reasonable accommodation under the Americans with Disabilities Act and over 20 states have passed laws similar to this legislation recognizing supported decision-making agreements. Several national organizations, including the National Guardianship Association, the National Council on

¹ 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>.

Disabilities, the US Administration on Community Living, the American Civil Liberties Union, and others, have endorsed supported decision-making as an alternative to guardianship. It is time that Maryland joins the ranks of those that more broadly recognize supported decision-making and an alternative to guardianship.

What does this bill do?

This bill that builds on and incorporates best practices from others who passed and implemented supported decision-making in other states, including by:

- Helping to prevent abuse and neglect of people with disabilities by bolstering their self-determination and control of their own lives
- Creating a framework for how to make a supported decision-making agreement so that third parties are more likely to recognize them
- Ensuring that the manner in which a person communicates is not grounds for determining that a person is incapable of making a supported decision-making agreement
- Allowing courts to terminate or limit guardianship due to the existence of a supported decision-making agreement
- Making it clear that a supporter does not have the authority to make a decision for a person, rather the person remains the decision-maker
- Limiting liability for those who in good faith rely on the use of supported decision-making agreement

This bill has the opportunity to immediately restore a person's rights who is subject to guardianship and to prevent the need for guardianship for many Marylanders with disabilities. The significance of this legislation cannot be overstated. The CDRC supports HB 529 and its critical efforts to ensure that people with disabilities have access to the same fundamental rights and decisions that we all do and can chart the course of their own lives.

Sincerely,

Accessible Resources for Independence

American Council of the Blind of Maryland

The Arc Baltimore

The Arc of Maryland

B'More Clubhouse

Consumers for Accessible Ride Services (CARS)

The Coordinating Center

Disability Rights Maryland

The Freedom Center

IMAGE Center for People with Disabilities

Independence Now

The League for People with Disabilities

Maryland Association of Community Services

Maryland Center for Developmental Disabilities at Kennedy Krieger Institute

Maryland Developmental Disabilities Council

Mental Health Association of Maryland

National Federation of the Blind of Maryland

On Our Own of Maryland

Patient Providers

Peer Wellness and Recovery Services, Inc. (PWRS Inc)

People Encouraging People

People On the Go of Maryland

Shared Support Maryland, Inc.

NASW HB 529 House Side.pdf

Uploaded by: Scott Tiffin

Position: FAV

Testimony Before the House Judiciary Committee

House Bill 529 Estates and Trusts - Supported Decision Making

On behalf of the National Association of Social Workers, Maryland Chapter (NASW-MD) Committee on Aging, we would like to express our support for House Bill 529 Estates and Trusts - Supported Decision Making.

As social workers, we are in favor of this bill because it supports the autonomy and self-determination of individuals with disabilities. The bill authorizes the use of supported decision making (SDM), an important tool that enables people with cognitive or intellectual limitations to maintain control of the most important decisions that shape their lives, such as where to live or how to spend their funds, while receiving vital input from people they trust. SDM in Maryland would reduce the number of people who lose the right to have a voice in these matters through the appointment of a guardian or other substitute decision maker.

In our experience, most people with intellectual and cognitive disabilities want to receive help to make, communicate, or carry out decisions that affect their lives, while retaining the ability to make the final decision. This is the process of SDM. It is important to remember that many of us engage in SDM when we buy a car, look for a new home or invest in the stock market; when we rely on expert advice but retain the final decision-making power.

Currently, Marylanders with disabilities often lose the right to make these basic decisions because a substitute decision maker has been appointed. The appointment of a guardian, the most restrictive step, occurs when the court determines that the individual lacks the capacity to make decisions regarding their finances, their personal affairs, or both. People under guardianship often lose all ability to make important personal choices in their lives, choices that many of them could have made with appropriate supports.

According to the Council on Quality and Leadership in their White Paper on SDM in the U.S., nine other states have supported decision making laws. The White Paper concludes that, while more work is needed to collect data and develop best practices, SDM appears to offer a viable alternative to more restrictive guardianship laws.

Critics of SDM say that this process may leave individuals with disabilities open to exploitation. This bill includes important guidelines and requirements to ensure that individuals with disabilities are not coerced or unduly influenced by their supporters.

People with intellectual and cognitive disabilities deserve to be treated with respect and dignity, and they should have a voice in important decisions that affect their lives. For these reasons, we ask for a favorable report on HB 529.

Respectfully,

Mary Beth DeMartino, LCSW

Executive Director, NASW-MD

NMSS Support Testimony HB 529 Wood .pdf

Uploaded by: Shannon Wood

Position: FAV

National Multiple Sclerosis Society

Testimony in Support of HB 529 – Supported Decision Making

March 9, 2022

The National Multiple Sclerosis Society strongly supports HB 529 regarding supported decision-making for people with disabilities in Maryland. We thank Delegate Pena-Melnyk for bringing forward this important legislation.

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information with the brain, and between the brain and the body. Symptoms vary from person to person and range from numbness and tingling to walking difficulties, fatigue, dizziness, pain, depression, blindness, and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. The cause is unknown and there is no cure. Most people with MS are diagnosed between the ages of 20 and 50 and it is the leading cause of disability in young adults. While it is much rarer, MS is sometimes diagnosed in children. There are an estimated 1 million Americans living with MS.

As you consider our support of this bill, please reflect on the mission of the National MS Society, which is “We will cure MS while empowering people affected by MS to live their best lives.” Our mission is congruent with HB 529.

Recognition of supported decision-making is a foundational civil rights issue for people with disabilities. Too often, people with disabilities have been placed in overbroad and unnecessary guardianships based on stereotypes about their capabilities. Under guardianship, a person living with MS 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 receive a termination of guardianship. We have seen people with disabilities remain under unnecessary guardianships and even experience abuse and neglect, because they cannot access the medical evaluations or legal resources needed 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.” While guardianship still may be the appropriate tool in some cases, it must not be the default for people with disabilities. Guardianship should be a tool of last resort.

Supported Decision-Making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose resulting in a structured agreement. Legal recognition of supported decision-making in Maryland will reduce the need for guardianship rulings. Supported decision-making provides an alternative that courts must consider before placing someone under guardianship and allows a person to continue to make their own decisions—just recognizing that they use support to do so. It preserves a person’s right to make their own choices—fundamentally it is their right to have rights.

Supported decision-making is not a new concept. It has been recognized as a reasonable accommodation under the Americans with Disabilities Act and over 20 states have passed similar laws recognizing supported decision-making agreements. Several national organizations, including the National Guardianship Association, the National Council on Disabilities, the US Administration on Community Living, the American Civil Liberties Union, and others, have endorsed supported decision-making as an alternative to guardianship. It is time that Maryland joins the ranks of those that more broadly recognize supported decision-making and an alternative to guardianship.

This bill that builds on and incorporates best practices from others who passed and implemented supported decision-making in other states, including by:

- Helping to prevent abuse and neglect of people with disabilities by bolstering their self-determination and control of their own lives
- Creating a framework for how to make a supported decision-making agreement so that third parties are more likely to recognize them
- Ensuring that the manner of an individual's communication is not grounds for determining that a person is incapable of making a supported decision-making agreement
- Allowing courts to terminate or limit guardianship due to the existence of a supported decision-making agreement
- Making it clear that a supporter does not have the authority to decide for a person, rather the person remains the decision-maker
- Limiting liability for those who in good faith rely on the use of supported decision-making agreement

Thank you for the opportunity to provide comment on this legislation. The Society strongly urges Committee members to support this bill. If you have any questions regarding the Society's position, please contact Shannon Wood, Director of Advocacy and Policy, at shannon.wood@nmss.org.

HB529 supported decision making.pdf

Uploaded by: Tami Goldsmith

Position: FAV



Testimony in Support
HB 529 Estates and Trusts-
Supported Decision Making
Judiciary
March 9, 2022
By Ken Capone

Hello committee members my name is Ken Capone. I am the Director of People On the Go of Maryland which is Maryland's statewide self advocacy organization. We are here to testify in support of HB 529 Estates and Trusts - Supported Decision Making.

Supported decision making is a tool that allows people with disabilities to retain their decision- making capacity by choosing supporters to help them make choices instead of the alternative of having someone appointed as a certain substitute decision maker.

With the introduction of supported decision-making, people with disabilities have the opportunity to do really what people without disabilities have done when it comes to having input in life choices; if you think about it if you don't have a disability you still are using supported decision-making. We all ask our friends, family and others how we should handle certain choices in a given situation. In a sense the policy of supported decision-making helps level the playing field between those with disabilities and those without, because this policy presumes competence and that anybody is capable of making choices for them they just might want and need some support.

A person using supported decision making chooses trusted advisors; such as friends, family members, or professionals to serve as supporters. The supporters agree to support the person with a disability to understand, consider, and communicate decisions. This gives the person with a disability the tools to make his or her own, informed decisions.

With Supported decision making I was able to get advice, information and communicate decisions with supporters and retained my ability to make my own decisions on important issues like purchasing a house, Trust and Estate documents for my deceased mother and purchasing a modified van. With supported decision making your supporters do not make decisions for you like a certain substitute decision maker may decide if appointed to do so.

We feel supported decision-making is important for people with disabilities and their families as an alternative to guardianship. This method of assistance allows for people with disabilities to have the input from their family, and other key supporters recognized without taking away the person's legal rights to make the decisions. Historically we have not presumed competence when it comes to people with disabilities being able to make appropriate life choices, some examples include the area of finance, and managing one's own money, choosing where and with whom to live and even whether or not you can refuse or accept medical treatment. Some families have turned to guardianship to make some of these life decisions for their love ones even though guardianship was not necessary.

In conclusion supported decision making give options for those seeking to retain independence with supports and the dignity of presuming competence. We ask for a favorable report

HB 529 Supported Decision Making 03.09.2022.pdf

Uploaded by: Tammy Bresnahan

Position: FAV



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HB 529 Estates and Trusts - Supported Decision Making
House Judiciary Committee
FAVORABLE
March 9, 2022

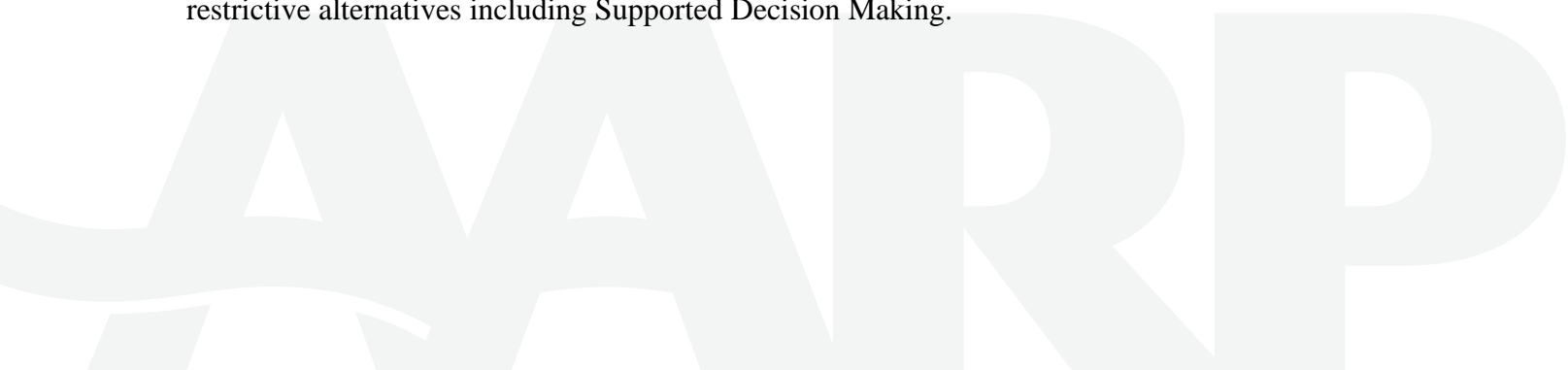
Good afternoon Chair Clippinger and members of the House Judiciary Committee. I am Tammy Bresnahan. I am the Director of Advocacy for AARP Maryland. AARP Maryland is one of the largest membership-based organizations in the Free State, encompassing almost 870,000 members. **AARP MD overwhelmingly supports HB 529 Estates and Trusts – Supported Decision Making.** We thank Delegate Peña-Melnyk for championing this issue.

AARP is a nonpartisan, nonprofit, nationwide organization that fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse.

HB 529 authorizes the use of Supported Decision Making. Supported Decision Making allows adults to retain their decision-making capacity by choosing supporters to help them make choices. A person using Supported Decision Making selects trusted advisors, such as friends, family members, or professionals, to serve as supporters. HB 529 codifies Supported Decision Making in Maryland law and outlines the guidelines and protections for both the individual and the individual's supporter.

Supported Decision Making has emerged as a cutting-edge alternative to guardianship, placing the individual at the center of the decision-making process. Supported Decision Making describes the process by which most individuals make decisions - by consulting with friends, family, social services, community organizations, and and/or other sources of support to weigh the pros and cons of a decision, review potential outcomes, and finally make a choice. Supported Decision Making promotes self-determination, control, and autonomy. It fosters independence. We all engage in Supported Decision Making. We all consult with family or friends, colleagues or classmates, mechanics or mentors before we make decisions.

AARP for nearly a decade has advocated for and has led to reforms that include establishing standards and training for guardians, safeguarding the rights of those under guardianship, combating abuse and strengthening court oversight of guardians and conservators. Other reforms encourage judges to make guardianships a last resort and to explore, when appropriate, less restrictive alternatives including Supported Decision Making.



AARP shares the provisions of Supported Decision Making, which align perfectly with our bedrock principles: empowering people to choose how they live as they age and to lead their best lives possible.

For these reasons, AARP supports HB 529. AARP MD respectfully ask the Committee for a favorable report. For questions or follow up, please contact Tammy Bresnahan tbresnahan@aarps.org or by calling 410-302-8451.

MSBA Estate Trust Law Sec. Testimony HB529 Favors

Uploaded by: Christine Hubbard

Position: FWA

To: Members of House Health and Government Operations Committee

From: MSBA Estate & Trust Law Section

Date: March 9, 2022

Subject: **HB529** – Estates and Trusts - Supported Decision Making

Position: **Support With Amendments**

The Estate and Trust Law Section of the Maryland State Bar Association (MSBA) **supports with amendments House Bill 529 – Estates and Trusts - Supported Decision Making.**

House Bill 529 seeks to implement a process by which any adult (an “Adult”) may enter into a Supported Decision-Making Agreement (a “SDM Agreement”) with another adult (a “Supporter”) who may assist the Adult with any life decisions specified by the Adult in the SDM Agreement. For example, these decisions may relate to healthcare issues, medical insurance, personal finances, personal relationships, cell phone plans, changing beneficiaries under the Adult’s will or IRAs, arranging for transportation to doctor’s appointments, or other similar life experiences.

One of the purposes of a SDM Agreement is to help prevent the need for the appointment of a guardian when a person may be compromised but still capable of making their own decisions. We recognize and deeply respect the importance of personal dignity and self-pride that comes with appropriate self-determination. We had a number of concerns with the original language of HB529; however, the amendments to the bill that are now being proposed by the sponsors fully address these concerns. With these amendments, the purposes of HB529 are being met but without unnecessary opportunities for abuse and potential conflicts with an Adult’s power of attorney, advance healthcare directive or revocable trust. For example, the amendments require greater accountability of the Supporter to certain interested parties, not just the Adult, and that the SDM Agreement be in writing and signed by the Adult and Supporter in front of two credible witnesses.

More specifically, the most notable amendments to HB529 include the following:

1. Neither the existence of a SDM Agreement, nor any provision contained therein, shall (i) authorize the Supporter to act on behalf of the Adult, (ii) supplant the authority of an agent under a validly executed power of attorney or valid advance directive, or (iii) supplant or grant authority or agency powers contemplated to be

provided by a power of attorney under the Maryland Power of Attorney Act or a valid advance directive;

2. If the Adult has a fully executed power of attorney, advance directive, or revocable trust agreement, and the Adult does not expressly object, the Supporter shall deliver a copy of the fully executed SDM Agreement to any agent designated under a power of attorney or advance directive, or trustee under a revocable trust. if one is found to exist;
3. The SDM Agreement shall state that the Supporter may not (i) make decisions for the Adult, (ii) effectuate transactions on behalf of the Adult, or (iii) enforce the Adult's decisions;
4. The SDM Agreement is to be signed by the Adult and the Supporter or Supporters with each signature to be witnessed by two adults who are not a Supporter or the Adult, or an employee or agent of the Supporter; and
5. A third party may decline to honor a SDM Agreement if they have a reasonable good faith belief that the SDM Agreement was invalid, revoked or abrogated, or the Supporter was coercing or unduly influencing the Adult or otherwise acting outside the scope of the SDM Agreement.

We believe that HB 529, with these amendments, will allow for meaningful and effective SDM Agreements that help adults maintain their independence while still protecting their interests.

For the reasons stated above, the Estate and Trust Law Section of the MSBA **urges a committee report on HB529 that is favorable with amendments. For Further Information, Please Contact:**

Michaela C. Muffoletto (410) 332-8534 mcm@nqgrg.com	Christine W. Hubbard (410) 798-4533 christine@chubbardlaw.com	Jonathan G. Lasley (410) 263-4876 jlasley@frankebeckett.com	Todd Bornstein (301)634-3104 tbornstein@sgrwlaw.com
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HB 529 Supported Decision Making SPONSOR PenaMeln

Uploaded by: Joseline Peña-Meln

Position: FWA

JOSELINE A. PEÑA-MELNYK

Legislative District 21
Prince George's and
Anne Arundel Counties

Vice Chair

Health and Government
Operations Committee

Subcommittees

Insurance and Pharmaceuticals

Chair, Public Health and
Minority Health Disparities



The Maryland House of Delegates

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March 9, 2022

HB 529 Estates and Trusts - Supported Decision Making Testimony of Delegate Joseline A. Peña-Melnyk (FWA)

Chair Clippinger, Vice Chair Moon, and members of the Judiciary Committee, I am pleased to present House Bill (HB) 529. This bill allows a person with a disability to voluntarily enter into a supported decision making agreement to assist in making, communicating, and executing life decisions.

One in five people in Maryland are living with a disability.¹ Some of these individuals may struggle with making big decisions about their life in areas of medical care, relationships, and finance. Individuals living with a disability are often able to make these decisions with support from friends, relatives, and other trusted people.

While people with disabilities may need assistance making a whole range of life decisions, they do not necessarily need a guardian to make those decisions for them. Currently, Maryland does not have an effective alternative to guardianship. The solution of guardianship would not be right for these individuals. It would strip them of their hard-earned independence and would offend their sense of dignity as a person. Supported decision making would provide our residents a less restrictive option while prioritizing their independence. It allows people with

¹ <https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/maryland.html>

disabilities to have trusted adults assist them in making important life decisions including decisions related to medical care, housing, marriage, and legal contracts.

This bill would provide individuals with a disability an accommodation for the decision making process. An accommodation for people with disabilities is essential so they are not forced to make decisions wholly on their own or to abide by decisions completely made by others. Those who can voluntarily participate in their own guidance must be allowed to do so.

Adults, regardless of their ability, are entitled to receive support in making decisions that correspond to their will, preferences, and choices. Making decisions about your own life is a human right. It is inherent to all people, regardless of ability or diagnosis. Human rights include the right to life, liberty, and the freedom of opinion and expression.² Everyone is entitled to these rights, without discrimination. This bill would preserve the human rights of a whole population of Marylanders by allowing individuals living with a disability the opportunity to make their own decisions, promoting self-determination, control, and autonomy.

This accommodation is not new or novel. 19 states have passed laws allowing for supported decision making, including Texas, D.C., and Delaware. All residents of our great state deserve the opportunity to be in the driver's seat of their own life. Supported decision making is a human rights issue that we need to take action on.

Thank you for the opportunity to present House Bill 529. I respectfully request a favorable report.

² <https://www.un.org/en/global-issues/human-rights>

HB 529 Supported Decision Making- Letter of Inform

Uploaded by: Erin Dorrien

Position: INFO



Maryland
Hospital Association

March 9, 2022

To: The Honorable Luke Clippinger, Chair, House Judiciary Committee

Re: Letter of Information - House Bill 529 - Estates and Trust - Supported Decision Making

Dear Chair Clippinger:

On behalf of the Maryland Hospital Association's (MHA) 60 member hospitals and health systems, we appreciate the opportunity to comment on House Bill 529. The hospital field supports the intent of HB 529, to provide an alternative to guardianship, when possible, particularly for people with disabilities.

The guardianship process in Maryland can often be cumbersome and lengthy. Patients in acute care hospitals who require a surrogate decision maker may languish in the facility beyond medical necessity as they wait for judicial action on their guardianship petitions. The judiciary is studying ways to improve Maryland's guardianship process.

MHA supports attempts to improve the guardianship process and create alternatives when appropriate. For supported decision-making agreements to be effective, health care professionals and staff will need to understand their promise, limitations, and restrictions. Given this is a new concept in Maryland, the hospital field is prepared to work with stakeholders to ensure that an already unwieldy guardianship process is not further complicated.

We hope you find this information useful as you deliberate on HB 529.

For more information, please contact:
Erin Dorrien, Vice President, Policy
Edorrien@mhaonline.org

HB529 - SDM - LOI.pdf

Uploaded by: Jennifer Eastman

Position: INFO



March 7, 2022

The Honorable Luke Clippinger, Chair
House Judiciary Committee
House Office Building, Room 101
6 Bladen St., Annapolis, MD 21401

Dear Chair Clippinger:

The Maryland Commission on Caregiving is pleased to submit this **letter of information for HB529 “Estates and Trusts - Supported Decision Making.”** This bill would authorize the use of supported decision-making and establish a process for entering a supported decision-making agreement for the purpose of assisting adults to obtain support in making, communicating, or effectuating decisions that correspond to their will, preferences, and choices. It would also prevent the need for the appointment of a substitute decision maker, including a guardian of the person or property, which is a restrictive alternative that infringes upon the rights of the person.

Serving as “the voice of the Maryland caregiver,” the Maryland Commission on Caregiving (MCC) is a Governor-appointed body composed of caregivers, community-based organizations supporting caregivers, and representatives from the Departments of Health, Disabilities, Human Services and Aging. MCC is charged with recommending policies that positively impact family caregivers, soliciting and responding to their concerns and acknowledging their contributions. Family caregivers provide the majority of care and financial support for their loved ones who are unable to care for themselves due to an illness, injury or disability.

Supported decision-making is a nationally and internationally recognized best practice that helps preserve a person’s right to make their own decision by recognizing that just like people without disabilities, people with disabilities rely on “supporters”, the people whom they trust to help them make an array of decisions - decisions that pertain to their healthcare, supports they receive, and how they wish to live their lives. It allows family and informal caregivers to maintain meaningful involvement in their loved ones’ lives by formally recognizing the relationship they have with the person. It also curtails the costly process of guardianship, one that some caregivers resort to because they believe they have no other option.

The Maryland Commission on Caregiving works to ensure that caregivers across the lifespan are equipped with the resources needed to provide safe care to their loved ones across the state of Maryland. Supported decision making is another tool that caregivers can utilize to ensure that happens.



Sincerely,

Jennifer Eastman, Chair
Maryland Commission on Caregiving

HB 529_cpr_info.pdf

Uploaded by: Morgan Whitlatch

Position: INFO



Center for Public
Representation

WRITTEN TESTIMONY OF THE CENTER FOR PUBLIC REPRESENTATION

Informational Only

2022 Regular Session, HOUSE BILL 529 “Estates and Trusts - Supported Decision Making”

Submitted by Morgan K. Whitlatch, Director of Supported Decision-Making Initiatives

House Judiciary Committee
Maryland General Assembly

March 7, 2022

Dear Chair Luke Clippinger, Vice Chair David Moon, and the Honorable Members of the House Judiciary Committee:

My name is Morgan K. Whitlatch, and I am the Director of Supported-Making Initiatives at the Center for Public Representation (CPR). I am submitting this informational testimony to provide a national perspective on Supported Decision-Making (SDM) across the United States.

CPR is a nationally recognized legal advocacy center that is committed to protecting and advancing the rights of people with disabilities by using legal strategies, systemic reform initiatives, and policy advocacy. We have offices in Massachusetts, New York, and Washington, D.C. Working on state, national, and international levels, CPR is committed to equality, diversity, and social justice in all its activities. CPR is also a national leader in advancing SDM. We lead the State Team Community of Practice for the Center on Youth Voice, Youth Choice,¹ a national resource center that works to increase access to alternatives to guardianship for youth with intellectual and developmental disabilities. We also regularly provide training, consultation, and technical assistance on SDM to people with disabilities, family members, and other advocates around the country. We have established and maintain an SDM virtual library of resources at <https://supporteddecisions.org/>.

Under the SDM model, people can turn to a network of supporters – family members, friends, colleagues, and others they trust – to help them make their own decisions regarding healthcare, finances, jobs, and other personal matters. It is a model that allows people, including adults with disabilities, to exercise their autonomy and promotes self-determination. Based on what we have

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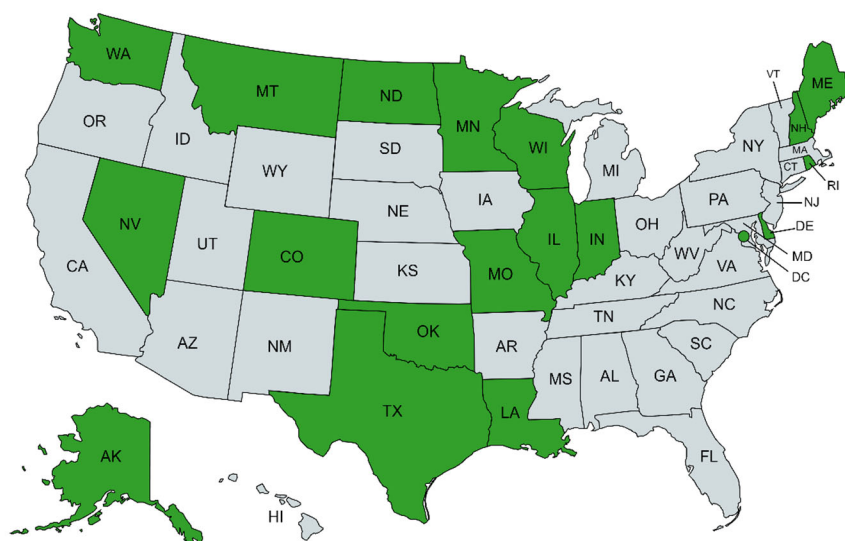
22 Green Street
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learned from our work nationally and in individual states, too many people are unnecessarily placed under restrictive guardianships, even when they would be able to make their own decisions with individualized assistance from people they trust. Widespread recognition of their right to use SDM as an alternative would allow them to retain their legal rights and dignity.

CPR launched the nation's first SDM pilot in 2014 and has since overseen five other pilots in Massachusetts.² From our pilots, which have been independently evaluated, we know that the SDM model works, strengthens support networks, and can transform lives. To see evidence of this, you have only to read some of the powerful stories shared by our pilot participants.³ CPR has expanded our SDM pilot work to Georgia, and we know that other states are also piloting SDM with great success.⁴

Through our national work, we have seen formal recognition of SDM gain momentum across the United States. At least 18 states and the District of Columbia have already passed statutes that formally recognize SDM agreements and/or specifically require courts to rule out SDM as a less-restrictive option before appointing a guardian. These include Texas (2015), Delaware (2016), Wisconsin (2018), Maine (2018), the District of Columbia (2018), Missouri (2018), Alaska (2018), North Dakota (2019), Indiana (2019), Nevada (2019), Rhode Island (2019), Washington (2020), Minnesota (2020), Louisiana (2020), Montana (2021), Colorado (2021), Illinois (2021), Oklahoma (2021), and New Hampshire (2021).⁵



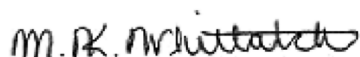
We have heard from partners in a number of these states that implementing these SDM statutes has resulted in people with disabilities improving their decision-making skills and experiencing greater self-esteem and better family relationships. In addition, there has been an apparent decrease in the need for guardianship. For example, since Wisconsin's SDM law was introduced, the annual number of guardianship requests in that state has decreased by 20 percent.⁶ This suggests that formal recognition of SDM not only benefits people with disabilities

and their supporters by making it easier for them to access and enforce their use of the SDM model. It also benefits the state courts by reducing the financial and administrative burden of having to address guardianship petitions for people who do not need them. That said, SDM does not replace guardianship for those who do need it. Rather, SDM is an additional and less restrictive option -- another legal tool in the decision-making toolbox that people with disabilities and their families can consider using.

SDM has been recommended and endorsed by a number of respected national organizations and federal agencies, including the American Bar Association, the National Guardianship Association, The Arc of the United States, the U.S. Department of Education, the U.S. Department of Health and Human Services, the American Association on Intellectual and Developmental Disabilities, United States Senate Special Committee on Aging, and the National Council on Disability.⁷ SDM is also recognized as a less restrictive alternative in the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA),⁸ a 2017 update to the model guardianship law. Further, at the recent Fourth National Guardianship Summit, leaders in the field of guardianship law and reform from around the country recommended states adopt practices, policies, and laws that promote SDM.⁹

In short, CPR's experience with SDM has shown that it is a viable and beneficial alternative to guardianship that is a nationally and internationally recognized best practice. Formal recognition of Supported Decision-Making would enable many more individuals and families to access and enforce this innovative model.

Sincerely,



Morgan K. Whitlatch
Director of Supported Decision-Making Initiatives
Center for Public Representation
mwhitlatch@cpr-ma.org

¹ See Center on Youth Voice, Youth Choice website, <https://youth-voice.org/>.

² See Supported Decision-Making Pilots, <https://supporteddecisions.org/supported-decision-making-pilots/>.

³ See Supported Decision-Making Stories, <https://supporteddecisions.org/stories-of-supported-decision-making/>.

⁴ See Cathy Costanzo, Hon. Kris Glen, & Anna Krieger, *Supported Decision-Making: Lessons Learned from Pilot Projects*, draft available at <http://law.syr.edu/uploads/docs/academics/constanzo-glen-krieger.pdf> (background paper prepared for the Fourth National Guardianship Summit held in May 2021; pending publication in Syracuse Law Review).

⁵ See TEX. EST. CODE ANN. §§ 1357.001 - 1357.102 (2015 & 2017); DEL. CODE ANN. tit. 16, §§ 9401A-9410A (2016); WIS. STAT. ANN. §§ 52.01-52.32 (2018); ME. STAT. tit. 18-C, §§ 5-102, -301, -304, -317, -401, -405, -502, -503, -506 (2018); D.C. CODE ANN. §§ 7-2131 - 7-2134 (2018); MO. REV. STAT. § 475.075(13) (2018); ALASKA STAT. ANN. §§ 13.56.010-13.56.195 (2018); N.D. CENT. CODE ANN. §§ 30.1-36-01 - 30.1-36-08 (2019); IND. CODE ANN. §§ 29-3-14-1 - 29-3-14-13 (2019); NEV. REV. STAT. ANN. §§ 162C.010 - 162C.330 (2019); 42 R.I. GEN. LAWS

ANN. §§ 42-66.13-1 - 42-66.13- 10 (2019); WASH. REV. CODE ANN. §§ 11.130.700 – 11.130.755 (2020, eff. 2022); MINN. STAT. §§ 524.5-102, -310, -409 (2020); LA. STAT. ANN. § 13:4261.101- 13:4261.302 (2020); MONT. CODE ANN. §§ 72-5-305(3), -319, -316 (2021); COLO. REV. STAT. ANN. Sec. 15-14-801 - 15-14-806 (2021); H. Bill 3849, 102nd Gen. Assem., Act 102-0614 (Ill. 2021); N.H. REV. STAT. § 464-D:1 (2021); Sen. Bill 198, 58th Leg., 1st Reg. Sess. (Okla. 2021).

⁶ See WSAW-TV, *Guardianship requests decline as knowledge of alternative legal option grows* (Aug. 9, 2021), available at <https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-option-grows/> (stating that, in Wisconsin, “since the [SDM] law was introduced, guardianship requests have declined each year from 5,147 in 2017 to 4,146 by 2020”).

⁷ See Organizations Endorsing Supported Decision-Making, <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making/>; Tina Campanella & Morgan Whitlatch, *Supported Decision-Making: U.S. Status and Trends*, 32 IMPACT 1 (2019), available at <https://publications.ici.umn.edu/impact/32-1/supported-decision-making-us-status-and-trends>.

⁸ See NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS, *Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act* (2017), available at <https://tinyurl.com/b6uzh43k>. UGCOPAA is an update of Article V of the Uniform Probate Code, which is the basis of Massachusetts guardianship law in the Massachusetts Uniform Probate Code, G.L. c. 190B.

⁹ See FOURTH NATIONAL GUARDIANSHIP SUMMIT, *Recommendations Adopted by Summit Delegates (May 2021)*, at p. 1 and Recommendations 2.1, 2.2, 2.3, 2.4, 3.3, 3.4, and 5.2, available at: <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability>.