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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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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 quasisupported 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;



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**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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**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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**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 <u>resolution</u> 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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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