“I learned that I have a voice in my future”

Summary, Findings, and Recommendations

of

The Virginia Supported Decision-Making Pilot Project

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INTRODUCTION

The Arc of Northern Virginia (The Arc) and **The Burton Blatt Institute at Syracuse University** (BBI) are pleased and proud to present this report on the work, findings, and recommendations of the **Virginia Supported Decision-Making Pilot Project** (the Pilot Project).

This report will first provide background information and foundational research on **Supported Decision-Making** (SDM) as an alternative to guardianship[1] and a way to increase self-determination and enhance quality of life for people with disabilities.

Next, we summarize the Pilot Project, including how we: (1) Provided education and outreach on SDM to over 2,000 people with disabilities, families, and professionals; (2) Educated and empowered 10 people with intellectual and developmental disabilities (IDD) to develop and implement individualized SDM plans; and (3) Documented how using SDM positively impacted project participants' quality of life.

Third, we discuss in detail the results of our study, which found that project participants who used SDM showed improved independence and decision-making skills, made better decisions, and had enhanced quality of life.

Finally, we provide recommendations for ways the Commonwealth of Virginia can increase knowledge, access to and use of SDM for people with disabilities through policy and legislative activities and advocacy.

[1] In this Report, we are using the word "guardian" to refer to a person appointed by a court to make decisions and exercise rights for another and "guardianship" to refer to the legal process where that person is appointed. In general, Virginia law refers to a "guardian" as a person appointed to make *life* decisions for another and a "conservator" as a person appointed to make *financial* decisions for another. For the sake of simplicity, we use "guardians" and "guardianship" to refer to the people and processes Virginia law calls "guardians," "guardianship, "conservators," and "conservatorship."

EXECUTIVE SUMMARY

- SDM is a less restrictive alternative to guardianship and a way to increase independence and self-determination for people with disabilities. SDM has been recognized by courts, legislatures, and policymakers across the United States.
- When people with disabilities use SDM, they work with friends, family members, and professionals they choose, who help them understand the situations and choices they face, so they can make their own decisions to the maximum extent possible. In that way, SDM mirrors how *everyone*, with and without disabilities, makes informed decisions.
- SDM is based on decades of research showing that people with disabilities who have more control over their lives and make more decisions have a better quality of life. Therefore, SDM can empower people with disabilities to avoid guardianship when it is unnecessary and improve their quality of life whether or not they are in guardianship.
- In the Pilot Project, we worked with 10 people with IDD and their supporters to create individualized SDM plans. We then studied the impact of SDM on their quality of life.
- Our study found that project participants who used SDM improved their independence and decision-making skills, made better decisions, and had enhanced quality of life.
- Based on our findings and research, we recommend that the Commonwealth of Virginia increase knowledge, access to, and use of SDM by: (1) Increasing education and research on SDM as an alternative to guardianship and a way to improve independence and quality of life for people with disabilities; (2) Encouraging the use of SDM in Special Education, Vocational Rehabilitation, and Medicaid Waiver programs, consistent with existing law and best practices; and (3) Exploring legislation formally recognizing SDM as an alternative to guardianship, as other states and the District of Columbia have done.

SUPPORTED DECISION-MAKING: HISTORY AND RESEARCH

A. Supported Decision-Making Theory and Practice

Supported Decision-Making is a less restrictive alternative to guardianship and a way to increase self-determination and independence for people with disabilities that has been recognized by state courts and legislatures across the United States.[2]

SDM empowers people with disabilities to make their own decisions and direct their lives to the maximum extent possible.[3] While there is no "one-size-fits-all" model of SDM, it generally occurs when people choose and work with friends, family members, and professionals who help them understand the situations and choices they face, so they can make their own decisions.[4] In this way, SDM mirrors "what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents and consent to medical procedures: they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices."[5]

While SDM relationships may be "of more or less formality and intensity" - ranging from informal support by people who "speak with, rather than for, the individual with a disability"[6] to

[2] *e.g.* Blanck, P., and Martinis, J. (2015). "The right to make choices:" The national resource center for supported decision-making. *Inclusion, 3*(1), 24; Martinis, J., et al. (in press). State guardianship laws and supported decision-making in the United States after Ross and Ross v. Hatch: Analysis and implications for future research, education, and advocacy. *Journal on Disability Policy Studies*.

[3] *e.g.*, Martinis, J. (2015). Supported decision-making: Protecting rights, ensuring choices. *Bifocal: The Journal of the American Bar Association Commission on Law and Aging, 36*(5), 107-110.

[4] Dinerstein, R. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficulty road from guardianship to supported decision-making. *Human Rights Brief, 19*, 8-9. .

[5] Quality Trust for Individuals with Disabilities. (2014). Supported decision-making: An agenda for action. *Retrieved from:* http://jennyhatchjusticeproject.org/node/264

[6] Dinerstein, 2012.

more formalized "micro-board[s]" and "circles of support"[7] - they share three common elements:

> (1) They recognize that people have the right to make decisions to the maximum of their abilities;
>
> (2) They understand that people can use support to make decisions without needing a guardian to make decisions for them; and,
>
> (3) They acknowledge that there are many ways to support people to make decisions, and that the type of support used should be tailored to the person.[8]

Through these SDM relationships:

> an individual with limitations in decision-making abilities can receive support to understand relevant information, issues, and available choices, to focus attention in making decisions, to help weigh options, to ensure that decisions are based on her own preferences, and, if necessary, to interpret and/or communicate her decisions to other parties.[9]

While SDM is recognized across the United States and internationally as a less restrictive alternative to guardianship, it can – and should – also be used by and with people with disabilities who are in guardianship. As described in this Report, SDM can increase independence and self-determination, which studies have shown leads to improved quality of life and life outcomes for people with disabilities. For that reason, the National Guardianship Association - which is made up of, trains, and certifies guardians across the country - states that SDM should be used as an alternative to guardianship whenever possible and, if guardianship is necessary, incorporated into that guardianship.[10]

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[7] Kohn, N., Blumenthal, J., & Campbell, A. (2014). Supported decision-making*:* A viable alternative to guardianship? *Penn. St. Law. Review, 117,* 1111.

[8] *e.g.*, Dinerstein, 2012, at 10-11.

[9] Salzman, L. (2011). Guardianship for persons with mental illness – a legal and appropriate alternative? *St. Louis University Journal of Health Law and Policy, 4,* 279 [hereinafter "Salzman 2011"].

[10] National Guardianship Association (2017). Position statement on guardianship, surrogate decision making, and supported decision making. Retrieved from: https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf

People should use SDM in ways that are based on their individual strengths, interests, and needs.[11] However, as a general guideline, people may develop individualized SDM plans by:

(1) *Identifying Life Areas Where Support is Needed:* First, people with disabilities should be encouraged and empowered to identify the life areas (such as health care, money, work, and/or personal relationships) where they want support making decisions. Tools such as the Missouri Stoplight Tool[12] can help in this process;

(2) *Identifying how the Person Wants to Be Supported*. Next, people should explore ways they have been supported before or would like to be supported. If a particular method has been effective in the past, it should be attempted again. They may also be encouraged to think about other support methods they would like to try. Tools such as the Supported Decision-Making Brainstorming Guide[13] can help in this process.

(3) *Identifying and Working with Supporters*. In this step, people should consider the friends, family members, professionals, and others who are or could be their life and the way they may be able to provide support. They should then approach those potential supporters and discuss and develop plans for how they can work together. Tools such as the Setting the Wheels in Motion Guide[14] can help with this process.

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[11] Martinis, J. (2019). Making it happen: Strategies for supported decision-Making. *Impact, 32*(1), 45 (2019). The following guidelines for developing SDM plans are also from this article.

[12] Missouri Developmental Disabilities Council. (n.d.). Identifying alternatives to guardianship. Retrieved from: https://moguardianship.com/Alternatives%20to%20Guardianship%20Tool%20Revised%2011-2015.pdf

[13] American Civil Liberties Union and Quality Trust for Individuals with Disabilities. (n.d.). Supported decision-making brainstorming guide. Retrieved from: http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide

[14] Francisco, S. & Martinis, J. (n.d.). Supported decision-making teams: Setting the wheels in motion. Retrieved from:

(4) *Creating an SDM Plan*. Although a written agreement or plan is not required to use SDM, it is often helpful to create a document that outlines the life areas where the person wants support, the support the person wants, and the people who will provide that support. There are sample SDM agreement forms available[15] or people can create personalized plans or Powers of Attorney, Advanced Directives, Individualized Service Plans or other documents that outline how they will use SDM.

B. Supported Decision-Making as an Alternative to Overbroad or Undue Guardianship

The modern movement toward SDM as a preferred, less restrictive alternative to guardianship began in 1987. In September of that year, a U.S. House of Representatives Select Committee held hearings titled *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace.* Summarizing the Committee's findings, Chairman Claude Pepper stated:

> The typical ward has fewer rights than the typical convicted felon . . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception . . . of the death penalty.[16]

After this alarm, policymakers, scholars, and courts recognized that overbroad or undue guardianship – guardianships imposed on people who can make some or all of their own decisions[17] – "evokes a kind of 'civil death' for the individual, who is no longer permitted to

http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf

[15] *e.g.*, National Resource Center for Supported Decision-Making. (n.d.). Model supported decision-making agreements. Retrieved from: http://supporteddecisionmaking.org/node/390

[16] H.R. Rep. No. 100-641, at 1 (1987).

[17] *e.g.*, Hatch, M., Crane, S., & Martinis, J. (2015). Unjustified isolation is discrimination: The Olmstead case against overbroad and undue organizational and public guardianship. *Inclusion, 3*(2), 65.

participate in society without mediation through the actions of another if at all."[18] Since then, research has shown that overbroad or undue guardianship provides guardians with "substantial and often complete authority over the lives of [vulnerable people],"[19] extending to the most basic personal and financial decisions.[20]

For example, even though almost all state laws, including Virginia's, require that guardianship only remove the rights that a person truly cannot exercise, [21].research shows that over 90% of guardianships remove *all* of the person's rights regardless of his or her abilities and needs.[22] Therefore, people under guardianship, especially those under overbroad or undue guardianships, can lose fundamental rights recognized by the Supreme Court including the right to make decisions about their health care, property, living arrangements, and marriage.[23]

Even worse, research shows that people in overbroad or undue guardianships can suffer negative life outcomes from losing the right to make decisions and the opportunity to develop independent living skills.[24] Therefore, legislatures, courts, and policymakers across the United

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[18] Dinerstein, 2012.

[19] Hardy, D. (2008). Who is guarding the guardians? A localized call for improved guardianship systems and monitoring. *University of Nevada, Reno.*

[20] Karp, N., & Wood, E. F. (2007). Guardianship monitoring: A national survey of court practices. *Stetson L. Rev., 37,* 143

[21] See, Va. Code Ann. § 64.2-2007, 2009; Martinis, J., et al. (in press). State guardianship laws and supported decision-making in the United States after Ross and Ross v. Hatch: Analysis and implications for future research, education, and advocacy. *Journal on Disability Policy Studies*.

[22] Teaster, P. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review, 37,* 193.

[23] *See Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) (recognizing the significant liberty interest in refusing unwanted medical treatment); *Turner v. Safley*, 482 U.S. 78, 95 (1987) (recognizing the decision to marry as a fundamental right); *Moore v. City of East Cleveland, Ohio*, 431 U.S. 494, 503-06 (1977) (finding the Constitution protects the ability of relatives to live together); *Lloyd Corp. v. Tanner*, 407 U.S. 551, 570 (1972) (broadly interpreting the right to own and control private property).

[24] *See, e.g.*, Salzman 2011, at 289-93; Kohn, *et al.*, 2014; Wright, J. (2010). Guardianship for your own good: Improving the well-being of respondents and wards in the USA. *International Journal of Law and Psychology, 33,* 350.

States have acknowledged the need to identify and implement less restrictive alternatives to guardianship that protect and advance the fundamental rights of people with disabilities.[25]

C. Supported Decision-Making in Virginia and the United States

State courts, legislatures, and policy makers across the United States are increasingly recognizing SDM as a less restrictive and preferred alternative to guardianship.[26] For example, in 1999, the Supreme Court of Pennsylvania ended the guardianship of Patricia Peery because she "has in place a circle of support to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety."[27]

Similarly, in 2012, a New York Appellate Court ended the guardianship of Dameris L. in part because she is "able to engage in supported decision making."[28] The Court held "proof that a person with an intellectual disability *needs* a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends, and mental health professionals."[29]

However, the recent "avalanche" of SDM may be traced to Margaret "Jenny" Hatch, a Virginian with Down syndrome.[30] In 2013, Jenny emerged from a Newport News courtroom as the first person to win the legal right to choose where and how to live using SDM.[31]

One year earlier, in the same courtroom, Jenny was ordered into a guardianship even

[25] See, *e.g.*, Kohn et al., 2014, at 1115-1120.
[26] Blanck & Martinis, 2015.
[27] *In re Peery*, 727 A.2d 539, 540 (Pa. 1999).
[28] *In re Dameris L.*, 956 N.Y.S.2d 848, 856 (N.Y. Sur. Ct. 2012).
[29] *Id.* at 854 (emphasis in original).
[30] Vargas, T. (2013, August 2). Woman with Down syndrome prevails over parents in guardianship case. *The Washington Post.* Retrieved from: https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html?utm_term=.388282f441c8
[31] Blanck & Martinis, 2015

though she had worked at the same community-based job for five years, had her own apartment, and was active socially, politically, and in her church.[32] Despite Jenny's history of deciding where she lived and worked, what she did, and who she spent time with, her guardians were given the power "to make decisions regarding visitation of individuals with [Jenny], [and her] support, care, health, safety, habilitation, education, therapeutic treatment and . . . residence."[33]

At her trial, Jenny showed that she uses SDM to make her own decisions and, therefore, did not need a guardian to make decisions for her. Jenny demonstrated that she had friends she relied upon when needed, who help her understand, make, and communicate her life choices. Experts testified that Jenny's use of SDM increased her independence and improved her quality of life. Jenny also argued that under Virginia state law and best practices, guardianship should only be used as a last-resort. Therefore, if there were alternatives such as SDM that could help her make her own decisions, guardianship was not appropriate.[34]

After six days of trial and argument, the court ordered Jenny into a one-year, limited guardianship, which expired in August of 2014. The court appointed the people Jenny wanted to live with as her temporary guardians and only authorized them to make medical and safety decisions on her behalf, with Jenny regaining all of her other rights. In a groundbreaking decision, the court then ordered the guardians to partner with Jenny so that she may fully transition "to the support[ed] decision making model" after one year. The court also ordered Jenny's temporary guardians, when they were making health and safety decisions during the one-year transition

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[32] *e.g.,* Hatch, Crane, & Martinis, 2015; Martinis, J. & Blanck, P. (2019). *Supported decision-making: From justice for Jenny to justice for all!* Stafford, Virginia: Something Else Solutions Press.

[33] *Ross and Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 27, 2012) (order appointing temporary guardians).

[34] Jenny Hatch Justice Project. (n.d.). The Justice for Jenny trial. Retrieved from: http://jennyhatchjusticeproject.org/trial

period, to "assist [Jenny] in making and implementing decisions we have termed 'supported decision making.'"[35]

With that order, after a long and lonely year in guardianship– when Jenny was not allowed to live in her home, go to her job, attend her church, or see her friends when she wanted[36] – Jenny became the first person to defeat, at trial, a petition for permanent, plenary guardianship because she uses SDM to make her own decisions.[37]

After the trial, Jenny moved back to her home, returned to her job, and was the subject of national and international news highlighting "an individual's right to choose how to live and the government's progress in providing the help needed to integrate even those with the most profound needs into the community."[38] Jenny's temporary guardianship expired in August of 2014. Since then, Jenny has been making all her own decisions, living and working where and how she wants, and using the SDM resources and skills that she developed and practiced throughout her life.[39]

Jenny is now known as the "rock that starts the avalanche" of SDM.[40] Shortly after winning back her rights, Jenny became the inspiration for and face of the **Jenny Hatch Justice Project** (JHJP), the first organization created specifically to advance knowledge and use of SDM.[41] Jenny's

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[35] *Ross and Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013) (final order).

[36] e.*g.*, Hatch, J. (n.d.). Jenny in her own words. Retrieved from: http://jennyhatchjusticeproject.org/jennys_words?q=jenny_speaks; Hatch, J. (2015). My story. *Inclusion 3*(1), p 34.

[37] Blanck & Martinis, 2015.

[38] Vargas, 2013. See, also, Jenny Hatch Justice Project (n.d.). Jenny in the News. Retrieved from: http://jennyhatchjusticeproject.org/jenny-in-the-news

[39] Vargas, T. (2019, October 12). Her case opened the way for people with disabilities to reclaim their freedom. Now, her words open a book that could help countless more. *The Washington Post.* Retrieved from: https://www.washingtonpost.com/local/her-case-opened-the-way-for-people-with-disabilities-to-reclaim-their-freedom-now-her-words-open-a-book-that-could-help-countless-more/2019/10/12/957c8580-ec6f-11e9-9c6d-436a0df4f31d_story.html

[40] Vargas, 2013.

[41] Jenny Hatch Justice Project. (n.d.). About the Jenny Hatch justice project. Retrieved from: http://jennyhatchjusticeproject.org/about

partners in the JHJP later received federal funding to create the **National Resource Center for Supported Decision-Making** (NRC-SDM)**,** which conducts research, policy, education, and advocacy activities designed to increase access to and recognition of SDM across the United States. Through the JHJP and NRC-SDM, Jenny and her partners have provided information, education, and technical assistance on SDM to policymakers, legislators, attorneys, and judges across the United States, including in every state that has passed a law recognizing SDM; made hundreds of in-person and virtual presentations on SDM, reaching tens of thousands of people with disabilities, families and supporters, and professionals; and, have written, co-written, and published scores of articles and books on SDM.[42]

After the "Justice for Jenny" case, several other courts, across the nation, have ended guardianships or refused to order people into guardianship because the person was able to use SDM to make his or her own decisions without a guardian.[43] In addition, several states, including Missouri, Texas, Maine, Delaware, Wisconsin, Alaska, Nevada, Indiana, North Dakota, Rhode Island, Minnesota, and Washington, DC, have passed laws recognizing SDM as a preferred, less restrictive alternative to guardianship.

In 2020, the Commonwealth of Virginia amended its laws to expand knowledge of and access to SDM. First, the new laws state that if a respondent to a guardianship petition is between 17.5 and 21 years of age, the guardian *ad litem* must review the student's **Individualized**

[42] *e.g.*, National Resource Center for Supported Decision-Making. (n.d.). In your state. Retrieved from: http://supporteddecisionmaking.org/states

[43] These include: *In Re: Ryan Herbert King*, D.C.Sup.Ct. (Probate) Case No.: 2003 INT 249; *In Re: Tecora Mickel*, DC Probate Case No: 2015 INT 000291; *In re: Tanya Powell*, DC Probate Case No. 2015 INT 529; *In Re: Beck*: Circuit Court, Wayne County, Indiana, Case No: 89CO1-1011-GU-025; *In re: KH*, Case No PR03-00264 (2nd Judicial District Court, County of Washoe, NV, 2017); *In re C.B.* (Superior Court of Vermont, Orleans Unit, 4/11/2017); *Matter of Eli T.*, 89 N.Y.S.3d 844, 849 (N.Y. Sur. Ct., Kings Cty. 2018).

Education Program (IEP), if one exists, and include the results of the review in reports filed with the court.[44] This requirement will provide a fuller picture of the person's strengths and abilities than is generally shown by psychological testing in guardianship cases.

In addition, Virginia law now requires the Department of Education to provide information on SDM and other alternatives to guardianship, such as Powers of Attorney, at annual IEP meetings.[45] Studies show that schools and educational professionals are the leading referral source for guardianship and that guardianship is often presented to parents as the only option for their children.[46] By requiring schools to provide information on alternatives to guardianship, the new law ensures that parents receive information on the full range of decision-making options for their children.

Furthermore, the Commonwealth now requires guardians *ad litem* to consider less-restrictive alternatives to guardianship, including SDM, and recommend them as appropriate.[47] Virginia law also mandates that courts inform guardians, when appointed, that the person must be actively encouraged to participate in making decisions whenever possible.[48]

Finally, Virginia law now requires the Virginia Department of Behavioral Health and Developmental Services to convene a workgroup to study the use of SDM agreements by and for people with disabilities.[49] It is anticipated that the workgroup will make recommendations for legislation to further the use of SDM in Virginia.

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[44] Va Code Ann. § 64.2-2003 (2020)
[45] Va Code Ann. § 22.1-217.2 (2020).
[46] Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities*, *40*(1), 36-51.
[47] Va Code Ann. § 64.2-2003 (2020).
[48] Va Code Ann. § 642.-2007 (2020).
[49] Va Code Ann. § 64.2-2009 (2020).

The U.S. government has also recognized SDM as a preferred, less restrictive alternative to guardianship. The Administration for Community Living in the U.S. Department for Health and Human Services described SDM as "an alternative to and an evolution from guardianship" and stressed the importance of people "retain[ing] their own decision-making authorities . . . with the assistance of appropriate services and supports."[50]

Prominent private organizations have also advocated for the use of SDM as an alternative to guardianship. For example, the American Bar Association adopted a resolution:

> urging state, territorial, and tribal legislatures to (1) amend their guardianship statutes to require that supported decision making be identified and fully considered as a less restrictive alternative, before guardianship is imposed, and (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights.[51]

The Resolution further urged courts to consider SDM as a less restrictive alternative to guardianship.[52]

The National Guardianship Association - which is made up of, trains, and certifies guardians across the country - has also issued a position paper on guardianship and SDM. The Association endorsed the use of SDM as an alternative to guardianship, stating:

> Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.[53]

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[50] *See* Admin. for Cmty Living. U.S. Dep't of Health & Human Servs., Funding Opportunity HHS-2014-ACL-AIDD-DM-0084, *Supported Decision Making*, *available at* http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168, at pp. 2, 6.

[51] American Bar Association. (2017). ABA urges supported decision-making as a less restrictive alternative to guardianship. *Bifocal: The Journal of the American Bar Association Commission on Law and Aging, 38*(6). Retrieved from: https://www.americanbar.org/groups/law_aging/publications/bifocal/vol_38/issue-6--august-2017-/aba-urges-supported-decision-making-as-less-restrictive-alternat.html

[52] *Id.*

[53] National Guardianship Association, 2017

D. Benefits of Supported Decision-Making

There are, of course, times when guardianship is appropriate. However, consistent with Virginia law,[54] national policy[55] and best practices,[56] SDM should be considered *before* a person is ordered into guardianship. Put another way, people should not be ordered into guardianship unless it is proven that they *cannot* use SDM to make their own decisions.

This is because, as shown, SDM can empower people to make their own decisions, be more independent and self-determined, and retain their legal rights. In addition, decades of research show that using SDM as an alternative to guardianship can improve people with disabilities' quality of life.

Because SDM maximizes the person's ability to make choices and direct his or her own life, [57] it is associated with **self-determination**, a fundamental human need recognized by Virginia law.[58] Self-determination "describe[s] actions that enhance the possibilities for people to control their lives."[59] People exercise self-determination when making choices that shape their lives.[60] By doing so, they become "causal agents . . . actors in their lives instead of being acted upon."[61]

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[54] *e.g.,* Va. Stat. Ann. § 64.2-2007(C) ("In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors . . . (iii) the availability of less restrictive alternatives."

[55] *e.g.,* U.S. Administration on Community Living, 2014.

[56] *e.g.,* National Guardianship Association, 2017.

[57] Dinerstein, 2012, at 10.

[58] EDWARD DECI, INTRINSIC MOTIVATION 208 (1975); Blanck & Martinis, 2015 (associating SDM and self-determination); Va. Stat. Ann. § 64.2-2007(C) ("In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors: . . . (ii) the development of the respondent's maximum self-reliance and independence.").

[59] Wehmeyer, M. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Several Disabilities, 30,* 113 (internal quotations omitted) [hereinafter Wehmeyer 2005].

[60] *e.g.,* Blanck & Martinis, 2015.

[61] Wehmeyer, M., et al. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Child, 66,* 439.

Research finds that people with disabilities who exercise more self-determination - who make more decisions and direct their lives – have a better actual and perceived quality of life.[62] For example, studies have repeatedly found that people with IDD who were more self-determined were more likely to live independently, be employed, and more involved in their communities.[63]

These studies build upon decades of research identifying a direct and positive relationship between self-determination and life outcomes. One study found that people with disabilities who exercised more self-determination were more likely to want to live independently, manage their money, and be employed.[64] Another study found that people with disabilities who exercised more self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and make greater advances in their employment.[65]

Finally, a study found that women with intellectual and developmental disabilities who are more self-determined were more likely to recognize and avoid abuse.[66] In other words, people with disabilities who have the right and opportunity to make decisions are safer.

However, losing self-determination "can be as harmful as having it is helpful."[67] When

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[62] *e.g*, McDougall, J., et al. (2010). The importance of self-determination to perceived quality of life for youth and young adults with chronic conditions and disabilities. *Remedial and Special Education, 31,* 252.

[63] *e.g.*, Shogren, K. et al. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *Journal of Special Education, 4,* 256; Powers, L., et al. (2012). My life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education. *Child and Youth Services Review, 34,* 2179.

[64] Wehmeyer, M. & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Child, 63,* 245.

[65] Wehmeyer, M. & Palmer, S. (2003). Adult outcomes for students with cognitive disabilities: Three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities, 38,* 131.

[66] Khemka, I., et al (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. Am. J. Mental Retardation *110,* 193.

[67] Martinis & Blanck, 2015, at 24.

people are in overbroad or undue guardianships, they lose the right "to make crucial self-defining decisions."[68] Decades of research have found that when people with disabilities are denied self-determination - when they lose their right to make life choices - their quality of life gets worse.

One study found that people with disabilities who were denied self-determination felt "helpless, hopeless, and self-critical. . . [and] will not behave because [they] can see no use in behaving."[69] Another study found the denial of self-determination to be associated with "self-handicapping" behaviors such as learned helplessness - where people with disabilities who lose the right to do something will not try to do other things - decreasing their quality of life.[70] Therefore, ordering a person with disabilities into guardianship for his or her "own good" may actually worsen "the negative behaviors and symptoms that led to the guardianship proceeding in the first place."[71]

Recent research shows the negative impact overbroad or undue guardianship can have on the lives of people with disabilities. The National Core Indicators Study analyzed the quality of life of people with IDD. It found that people with disabilities in guardianship were *less* likely to live independently, work, be involved in their communities, have their rights respected, date, and get married than people of similar abilities and limitations *without* guardians.[72]

For these and other reasons, researchers and scholars find that overbroad or undue

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[68] Salzman 2011, at 291.
[69] Deci, 1975, at 208.
[70] *e.g.*, Jones, E. & Berglas, S. (1978) Control of attributions about the self through self-handicapping strategies: The appeal of alcohol and the role of underachievement. *Personality & Social Psychology Bulletin, 4, 200*.
[71] Blanck & Martinis, 2015, at 26.
[72] Bradley, V., Hiersteiner, D., St. John, J., & Bourne, M. L. (2019). What do NCI data reveal about the guardianshp status of people with IDD? *National Core Indicators Data Brief*. Retrieved from https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf?fbclid=IwAR3H3203x5nI_G6bZ

guardianship can cause a "significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being."[73] For example, people who are denied the legal right to make financial decisions may "become[] gradually disengaged from the management of those finances as well as the interactions with others involved in that management—banking, shopping, financial planning . . . even giving gifts to loved ones."[74] Similarly, when people lose the right to make medical decisions, they "may get little information about [their] condition or treatment options."[75] Additionally, overbroad or undue guardianship "can also isolate the individual by explicitly depriving a ward of the right to make certain social decisions regarding how or with whom he will spend time."[76]

As stated, there are certainly times when guardianship is necessary and appropriate. However, as the National Guardianship Association states, "the supported decision-making process should be incorporated as a part of the guardianship, if guardianship is necessary."[77] In that way, the person under guardianship will have full and appropriate opportunities to, as required by Virginia law, "participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs."[78]

THE VIRGINIA SUPPORTED DECISION-MAKING PILOT PROJECT

In 2019, the **Virginia Board for People with Disabilities** (The Board) awarded a grant to the Arc and BBI to create and implement this Pilot Project. The Pilot Project was designed to increase knowledge, access to, and use of SDM in Northern Virginia through three separate, but

[73] Wright 2010, at 354; See also Salzman 2011, at 291.
[74] Salzman 2011, at 291.
[75] *Id.*
[76] *Id.*
[77] National Guardianship Association, 2017
[78] Va Code Ann. § 64.2-2019(E).

interconnected, steps:

(1) Developing and disseminating outreach, educational, and training material to people with disabilities, families, and professionals demonstrating ways to use SDM as an alternative to guardianship and a way to increase independence, self-determination, and quality of life for people with disabilities.

(2) Working with 10 young adults with IDD and their chosen supporters to develop and implement individualized SDM plans that reflect their unique interests, abilities, and needs; and

(3) Studying how using SDM impacted the self-determination and quality of life of the 10 project participants.[79]

Below, we summarize the work and accomplishments of the Pilot Project in each of these areas.

A. Education and Outreach Efforts

From its beginning, the Pilot Project worked to increase knowledge, access, and use of SDM and create a sustainable demand for and supply of SDM supports and services in the Northern Virginia area. To date, the Pilot Project has: (1) Provided education and training to over 2,000 people with disabilities, families, and professionals through live and web-based presentations; (2) Created educational materials on SDM to help people and families explore and implement SDM in their lives; and (3) Launched a dedicated website where people can learn about SDM and review project materials. These efforts are designed to promote systems change and build system capacity by demonstrating to people with IDD, families, and professionals that SDM is an available and

[79] *e.g.*, Beadnell, L. & Martinis, J. (2020). Re-thinking guardianship and substitute decision-making: Supported decision-making and the reform of Virginia law, policy, and practice to protect rights and ensure choice. *Developments in Mental Health Law 39*(1), 1-13.

effective alternative to guardianship and consistent with existing law, policy, and best practices in Special Education, Vocational Rehabilitation, Medicaid Waivers, and other programs.

The Pilot Project's website, https://thearcofnova.org/programs-services/sdm-resource-library/, houses information, educational material, and archived training on SDM from the Project and other state and national efforts. The website includes handouts and factsheets on SDM created and distributed by the Pilot Project including:

- Supported Decision-Making: An Introduction
- Supported Decision-Making with Guardianship
- Common Myths about Guardianship
- The Basics of Supported Decision-Making
- 100 Ways to use Supported Decision-Making
- Getting Started with Supported Decision-Making
- Working with your Supported Decision-Making Team

The Pilot Project also provided, and archived on its website, 7 live, full-length presentations on SDM, including:

- Creating Your Circles of Support
- Exploring Supported Decision Making (Full Presentation)
- Exploring Supported Decision Making for Employment Transition Representatives
- Introduction to Supported Decision Making
- Supported Decision Making in Education and Vocational Rehabilitation
- Supported Decision Making in Healthcare and Life Planning
- Supported Decision Making: The Expert Panel for All Your Unanswered Questions

The Pilot Project also created and archived a series of "3 Minute Webinars," designed to provide basic information on SDM in a user-friendly format, including:

- Exploring Supported Decision Making
- Ways to Use Supported Decision Making
- Guardianship Myths
- Supported Decision Making In Plain Language
- Supported Decision Making with Guardianship
- Working with Your Supported Decision Making Team

Finally, the Pilot Project was invited to, and did, provide training on SDM for professionals working with people with IDD, including:

- Educational Professionals
- Social Work students
- Vocational and Transition Counselors
- Attorneys

B. Empowering Young Adults with IDD to use SDM

The primary purpose of the Pilot Project was to empower young adults with IDD to develop and implement individualized SDM plan based on their unique abilities, interests, and needs. The Arc conducted outreach to individuals and families in Northern Virginia, encouraging people to apply to be part of the Pilot Project. After receiving applications, the Pilot Project chose a diverse group of 10 people with IDD to participate in the project.

Representatives of the Arc and BBI met individually with project participants and their supporters to provide them with information and background on SDM so that they could consider and decide whether they wanted to use SDM in their lives. Project participants were also provided

with SDM resources including Where Do I Want Support,[80] the Supported Decision-Making Brainstorming Guide,[81] and the Setting the Wheels in Motion Guide[82] to help them think about and identify life areas where they wanted support making decisions, how they wanted to be supported, and who they wanted to support them.

After reviewing the material, all participants stated that they wanted to use SDM to make decisions. Pilot project staff then met again with participants and their supporters to assist them in developing individualized SDM plans. In keeping with research and best practices, participants were not required to use any particular methodology or form.[83] Instead, participants were encouraged to create plans that reflected their individual interests and skills. For example, one participant created a chart to summarize her plan, stating "This shows what I want, who will help me, and how. That's it!" Two participants worked with their supporters to create plans using a spreadsheet. Three participants chose to describe their plans to Pilot Project staff who provided a written summary to them while 4 chose not to memorialize their plans in writing.

Project participants then implemented their plans, making decisions with support when needed and appropriate. Pilot project staff met periodically with participants and their supporters to discuss their progress, whether they had made any changes to their plans, and which decision-making methods worked well and which did not. If participants wanted assistance changing their plans, staff worked with them to develop new ideas or identify new supporters.

In a final meeting with participants, Pilot Project staff asked them to sum up their

[80] American Civil Liberties Union. (n.d.). Where do I want support. Retrieved from: https://www.aclu.org/other/when-do-i-want-support-supported-decision-making-self-assessment-tool

[81] American Civil Liberties Union and Quality Trust for Individuals with Disabilities, n.d.

[82] Francisco & Martinis, n.d.

[83] *e.g.*, Quality Trust, 2014; Martinis, 2019.

experiences, describe the lessons they learned about SDM and themselves, and say what they would tell other people with disabilities who want to explore using SDM. Responses included:

- I learned that it's really important for me to make my own decisions. Just meeting and talking with you guys helped me learn that it's great to have a group of people to go to get help when you need it.
- I learned that I have a voice in my future.
- I can make my own decisions.
- Autistics now can make their own decisions, too, and improve their lives.
- It feels good to make your own decisions when you can. You will feel power and a freedom of choice. As you get older, it will get easier.
- I am working on my own behaviors with their reminders, which is really helpful. I want to light up the world!

Supporters also commented on their experience in the Pilot Project, including:

- As your kid gets older, parents forget to let their kid become an adult with decision-making power. This experience has helped us remember to ask [Participant] what he wants rather than assuming we know.
- It's been helpful for parents to fade the prompt.
- Participation in the project really boosted my son's awareness of supported decision-making principles and served as a catalyst to find strategies to improve his quality of life.

We look forward to continuing to work with project participants and their supporters, as they want and need, to help them continue their SDM journeys.

C. Studying the Impact of SDM on Quality of Life

The Pilot Project also set out to analyze and document what, if any, impact using SDM had on participants' independence and quality of life. To do so, staff developed and used quantitative and qualitative tools to collect demographic and other data designed to determine whether using SDM had an impact on participants' objective and subjective quality of life.

Pilot Project staff collected data and information using two tools: (1) The Supported Decision Making Inventory System (SDMIS), developed for the National Resource Center for Supported Decision-Making by the University of Kansas,[84] which examines the relationship between use of SDM and self-determination; and (2) Semi-structured interviews with project participants and their supporters about the ways and times in which they used SDM, whether and how they feel SDM is impacting their lives, and whether they have had new, more positive, individual and community-based experiences since they began using SDM.

The study methodology and instruments were submitted to the Syracuse University Institutional Review Board (IRB) for review and approval, to ensure that the study was appropriate and adequately protected the rights and privacy of participants and their supporters. With the IRB's approval, participants and supporters were invited to take part in the study. Nine of the 10 project participants and their supporters agreed to be interviewed for the study.

Eight of the project participants took part in 3 interviews and 1 participant took part in 2 interviews. Supporters engaged in 1 interview each. The interviews were conducted at different points in the project to determine whether people's experiences using SDM changed over time.

[84] Shogren, K. A., & Wehmeyer, M. L. (2016). Supported Decision Making Inventory System [Pilot version]. *Lawrence, KS: Kansas University Center on Developmental Disabilities/Beach Center on Disability;* Shogren, K. A., Wehmeyer, M. L., Uyanik, H., & Heidrich, M. (2017). Development of the supported decision making inventory system. *Intellectual and Developmental Disabilities*, *55*(6), 432-439.

SDMIS survey responses were recorded by the Pilot Project interviewer and semi-structured interview sessions were audio-recorded and transcribed, with permission.

STUDY FINDINGS

Based on the demographic, objective, and subjective data collected through our interviews with project participants and their supporters, which is detailed below, **we conclude that project participants who used SDM showed improved independence, self-determination, and decision-making skills, made better decisions, and had enhanced quality of life.**

A. Demographic Data

Demographic data was collected during each interview with project participants and their supporters. When this data changed over time (such as when one participant went from living with his parents to living independently), we have noted only the final response.

1. Project Participant Demographics

Gender: Male: 7 Female: 2

Age: 20-30: 8 30-40: 1

Ethnicity: Caucasian: 6 African-American: 1 Asian: 1 Bi-racial: 1

Disability: Autism: 5 Intellectual Disability: 2 Multiple Diagnosis: 2

Communication Method: Verbal: 5 Spelling/Letter Board: 4

Education: Less than High School Graduate: 2 High School Graduate: 4

Some College: 2 Bachelor's Degree: 1

Living Arrangement: Independent: 5 With Parent or Guardian: 4

Employment Status: Unemployed: 3 Vocational Preparation Program: 2

Volunteer: 1 Work Part Time: 2

Work Full Time: 1

Guardianship Status: Under Guardianship: 4 Not Under Guardianship: 5

2. Supporter Demographics

Gender: Female: 9

Age Range: 50-60: 4 60-70: 5

Ethnicity: Caucasian: 7 African-American: 1 Asian: 1

B. Quality of Life Data

The Pilot Project collected objective and subjective data on participants' quality of life through interviews with project participants and their supporters. We have grouped this data under several headings that correspond to interview questions and topics. For each, we first list objective data (e.g. Yes or No responses) and then provide quotes from the interviews that illustrate the subjective views and experiences of participants and supporters.

1. Project Participant Interviews

Before you started working with Virginia Supported Decision-Making Pilot Project, did you make your own decisions, or did it feel like other people made decisions for you?

Others made decisions for them: 7 They made their own decisions: 2

- I felt nothing mattered about what I wanted. . . My mom and dad made decisions.
- [Other people made decisions] in terms of medical, medical issues, and definitely when there were issues with work.
- Others. Parents. [About] school, travel, schedule.
- I felt like on a legal level, someone else. . . . Mainly mother.

Did you like working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- The best part of working with the project is I am a free person that can make any decisions I want to make. . . I learned that you want to make any decisions of your own, and that's okay.
- [The best part was] learning that there are more options for me to become independent.
- [The best part of working with the project was] [t]hat I get to, for a good portion of the time, be the captain of the self-decision making team . . . . and, also, basically that we people with disabilities do really have rights under out name in states like Virginia.
- The best part of it . . . like, talking to them and they think higher of me and my work – like that.
- The best thing is I learn about information that helps me be more independent.

Do you feel like you are more in charge of making your own decisions since you started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- Yes, I am way more in charge.
- [N]ow, since I'm doing the project, I've been making more decisions of what I want and what I need.
- I learned that I have options to decide the choices I make.
- I definitely do and feel my team supports me in it.

Did you learn to be more in charge of making your own decisions from working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- I learned that sometimes when I make a decision I can do it myself, but sometimes I need help with some others.
- Yes, it does. It makes me be a grown man.

- [Now], I know what to do, like do chores or sit outside and sit in the shade, or get some exercise. I do know now what it takes, and I know I have control of myself. I know that advice helps you.

- [I learned] I can communicate my thoughts even if they differ from my mom and dad.

- Yes, I think I learned my options and methods to achieve them.

Do you think all the work you've done with the Virginia Supported Decision-Making Pilot Project has been worth it?

Yes: 9

- Because in the past, I hadn't made my own decisions. My parents would ask me, but I don't know. Since this project with you guys, it actually changed me more, because it makes me even more responsible in my life to my parents.

- I don't think I would find this support and guidance anywhere else.

- I am more aware that I can be in control, and my parents are also more aware of that.

- Because its helping me be a strong, independent adult. I can live by myself someday.

- Yes. It has provided a framework for moving forward with my independence.

Do you sometimes like help in making decisions?

Yes: 9

- I certainly do . . . Because this is one of the things that makes the world a better place.

- I don't mind getting help making decisions because I know that because I have a lot of higher forms of sense, but because I lack common sense . . . Everyone can always use advice from experts.

- I appreciate guidance, but the decision is mine.

- Yes, I love my team and the voice they give me for myself.

Do you like the way the [Pilot Project] staff help you make decisions?

Yes: 8 N/A: 1 [participant said staff did not help him make decisions]

- Yes, you explained how it works. . . You said things clear.
- [Y]ou guys actually changed me more than I used to be. . . . Because you teach me new stuff that I have learned and makes me become a more responsible person. If my parents pass on something, I have people I can still contact, and I have some support that I learned stuff about.
- Definitely, it's very helpful in terms of recommending to my parents, like that I'm supposed to be the captain of my self-decision making.
- You built up my thoughts.
- You helped me make the decision to identify my support network.

Do you think you've gotten better at making decisions since you've been working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- Yes, I know the decision is mine.
- [I've gotten better] by thinking it through, of course.
- I've definitely improved.
- Yes. Before, I wasn't practicing my decision-making because I didn't think I could.

Do you think working with the Virginia Supported Decision-Making Pilot Project has helped you make better decisions?

Yes: 9

- Yes, I have much better ways, decisions, didn't get myself in trouble for doing something that I'm not supposed to be doing. Since I've been with you guys, I've been making better decisions.
- Definitely. I've been making better decisions, helps me have better common sense.
- Yes, I am actually. . . I'm still learning. I'm not perfect, but I try my best.

- Yes, because I can express my wishes and know that they must be considered.
- Yes, I think decision making takes practice . . . so I do think I've improved since starting practicing with the pilot

Do you think that working with the Virginia Supported Decision-Making Pilot Project and making your own decisions has made your life better in any way?

Yes: 9

- I think it just shows that I'm capable of more than I think I am.
- Yes, I have more hope.
- I now know that I can, and I will keep on doing it.
- [It made my life better] by making me a better person. . . Being kinder, and friendlier, and stronger.
- Oh, definitely . . . I've come to better terms, not only with what I plan to do in a year, nine months from now, but I'm also living a better, peaceful life.
- Yes. I have more confidence to advocate for myself.
- I'm happy now and I love my life.
- I feel like I have more control.

Do you think your relationships with your family and friends have gotten better or worse now that you're making your own decisions?

Yes: 9

- It's been much better. The whole family and that stuff, like I haven't been seeing my brother for a long time, and we get along much better.
- They say I look more confident and they ask for my opinion more.
- As opposed to previous this and that, I'm getting along so much better.
- Yes, because they see me as a partner and not a child.
- They said its wonderful, and when I showed them the plan I had, they were amazed by it.

- They respect my opinion.
- Yes, definitely. It feels more like two adults communicating.

Do you think you advocate for yourself more since you started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- The study has helped me get better at advocating for myself. Now, my mother [has] been a very good self-advocate for myself, and this study has gotten me much better at advocating for myself, because I had the idea that I would get to be the captain of my self-decision-making team.
- Yes, I am. I'm actually asserting what I want and what choices I want and how I feel about them.
- Yeah, I've been doing that. I know they are listening to me.

Do you think you're better at telling people what you want since you started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- I do speak for myself. . . [My] family listens to me, and even my friends listen to me, too.
- Yes, I'm better at describing my needs and wants.
- I let them know when I'm tired and I don't feel like doing homework.
- I'm definitely taking some initiative to go out of my comfort zone and ask for help.
- I am taking charge.

Have you joined any groups or organizations since you started working with the Virginia Supported Decision-Making Pilot Project? Do you think you started working with them because of your experience with Virginia Supported Decision-Making Pilot Project?

Yes: 4 No: 5

- Yes, because I want to meet other advocates who are independent as adults.

- [In addition to a group he joined] As time permits, I want to join more groups to share what I learned.

- [On joining new groups]. I definitely think so. It gave me perspective on the extent of my capabilities and rights.

[For participants under guardianship]. Has using Supported Decision-Making made you want to modify or end your guardianship?

Yes: 3 Don't Know: 1

- I want to communicate more freely and independently, so I will work on that.

- Yes, in regard to health issues.

- I know I can, if needed.

[For participants not under guardianship]. Has using Supported Decision-Making made you want to live your life without a guardian?

Yes: 5

- It made me realize I can do a lot with support, but don't need someone to be my legal guardian.

- That's correct. I do want to.

- I feel like it does. It gives me avenues of who to go to when I need help, depending on the scenarios.

2. Supporter Interviews

Before you and [Participant] started working with the Virginia Supported Decision-Making Pilot Project, did they make their own decisions or did other people made decisions for them?

Others: 6 Participant made own Decisions: 2 Both: 1

- [W]e made all his decisions . . . until we started with SDM, we didn't even consider it. We didn't discuss it. We saw the guardianship document as basically the operating guidelines.

- We definitely made a lot of decisions for him. I think we did.

- Well, it was mostly her father and I.

- After we participated in Supported Decision-Making, he has more opportunities to make decisions for himself.

- When he was in school, everybody was making the decisions for him. No one gave him the opportunity to make his own. . . . I was trying to get him to learn how to make more decisions for himself, which is why this program is perfect for us.

Did you like working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- I love it. I think it's great.. . . [Participant] is different. [Participant] is so confident. . . . He doesn't waffle so much about decisions. He seems to just have a confidence about decisions.

- It made me realize that I should relinquish my hold on his future, and its ok for me to do that.

- I do. . . I like hearing [Participant's] answers. I feel like I'm learning a bit more about what he's thinking.

- I think it has made [Participant] and me more aware of some long-range planning opportunities.

- Yes . . . the pilot project has given me some new tools to use with [Participant].

- The best part is learning about options and learning how to increase [Participant's] agency, which I think is very important for people with disabilities, and learning how to create a system so that the circle of support becomes a functioning tool.

Do you feel like [Participant] makes his/her own decisions since s/he started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- I think absolutely. I think he's expressing an interest in making his own decisions. He's weighing in more. . . I think going to the pilot project has empowered him to know that I want to do more and I can do more and I should do more.

- We do. I do and so does my husband. We do feel he's much better about it.

- Yes . . . its more of a group effort.

[If yes] Do you feel [Participant] learned that from working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- Yes, I think it's gotten him to think, because now he'll say something like, 'I can do this by myself' or 'I can do this, but I need some help.'
- I think it's definitely given him, again, some of that confidence and the ability to say 'Well, this is a decision I can make. I can make this decision.'
- I believe so. I think it's more of a collective effort. It allows us as guardians to realize that it's okay for us to have him make his own decisions and that he can make decisions for himself and be happy with them.
- I think the pilot project also helps us remember . . . that my husband and I have to be reminded on a regular basis that we do have to give [Participant] as much choice as possible.
- Yes, I think she realizes she can do more and will do more.
- I think he had gained the confidence through SDM . . . to be able to make that decision.

Do you think all the work you've done with the Virginia Supported Decision-Making Pilot Project has been worth it?

Yes: 9

- Absolutely. . . I just think that I'm seeing results, and I think it will be something that will benefit him his entire life.
- We had this notion that he could not take care of himself, so we always had to be very protective, but with this, we've realized that it's okay to let him make decisions on his own.
- I think it's definitely worth it and it's not something I had considered in the past.
- I think, especially, that one tool around negotiation, has been almost a game changer for us, that this has been something we can use, that we have a common language about.
- [I]t's opened a new horizon for us and has helped us understand areas where we need to grow as a team. As we go through the pilot project, we know that we need to institutionalize some of these relationships, and institutionalize some of the strategies that have been used to support him.

Do you think [Participant] likes making his/her own decisions?

Yes: 9

- Yes. . . I see him being more confident and I see him asserting himself more. I see more independence and he's more assured of himself.
- He has pride. I think he's proud of himself, and I think everybody likes to make their own decisions.
- He does. I do think that this is something he's proud of, because he does have two friends that have guardians.
- She's very happy when she makes a decision, a good decision. She gets frustrated and anxious when she makes what she considers a bad decisions, but she's very aware of her maturation and she realizes that decision-making is part of the process. She just beams when she makes a good decision.
- Yes . .. It's an air of confidence he has about it. He's just proud of himself, and we just see him having grown just a little bit more into adulthood through this.

How does [Participant] let you know that s/he needs help?

- He will say I don't know or I'm not sure, and so we will kind of elaborate more and ask what happens if you say this or that. Then, after that, he will be more assertive in making a decision.
- Sometimes he touches me, sometimes he uses verbal, and sometimes it's just an action I can see and hear. It kind of varies.
- He'll text me, or call me or come over and see me and suggest it.
- We're working on that, even like her picking up the letter board and giving it to me. That seems like a pretty small thing, but it historically been difficult for her, so that's something we're working on now as an emerging skill.

Do you think [Participant] learned how to ask for help making a decision from working with the Virginia Supported Decision-Making Pilot Project?

Yes: 5 **No: 4**

- I believe so, because I think it starts from us allowing him to make decisions and then he started to blossom from that.

- Yeah, because I think some of the way that he's worded things I recognize from how it's worded in the papers that he's read.

- I think he's a bit more forthcoming about things he wants to do, definitely.

Do you think [Participant] has gotten better at making decisions since you've been working with the Virginia Supported Decision-Making Pilot Project?

Yes: 7 Don't Know: 2

- I believe so. I think it's kind of like a domino effect that we feel comfortable in letting him make decisions for his life, and so as a result, he will feel more confident making those decisions.

- It's given the ability to say 'we're doing supported decision making which means we have to get this together and work together to help go forward' as opposed to two years sitting down and saying 'you know, there's probably something we could be doing to help you'

- Yes, I do. I think he's gotten a little bit more confident, and then he's looking at things where, before, maybe he didn't even think about it was a decision.

- Yes . . . I think he is realizing that he has support on his team from family members that he didn't realize before.

- I think he feels more backup, like those little people on your shoulder saying 'uh-huh,' the little SDM angel.

Do you think working with the Virginia Supported Decision-Making Pilot Project has helped [Participant] make better decisions?

Yes: 7 Don't Know: 2

- I believe so. . . . It's all kind of coming together – us being more confident and him being more confident.

- Yes, exactly, because she is being more thoughtful about it. She understands better . . . and I think the project has helped her get to that point.

- Yeah, I think his thought process, I think he's thinking more about the pros and cons of it.

- Certainly the opportunities have presented themselves. I would say yes.

Do you think that working with the Virginia Supported Decision-Making Pilot Project and making your own decisions has made [Participant's] life better in any way?

Yes: 9

- I think so, because I think that has heightened to him the process of this, that it's a skill that you can learn. It's something that can be practiced, a set of skills that can be applied no matter what.

- She's given more thought to the more serious questions, as I keep calling them, and she's more willing to sit down and talk things through with me, whether on paper or reviewing through the computer. So, yes.

- I think it has. . . . I think we're at the very beginning stage . . . where he's having to understand what it means to be an adult.

- It has . . . I think all of this is adding to making him feel better about who to go to for in what different areas, and that there are people there, so many more people besides just his mom that can help him make decisions.

Do you think [Participant's] relationship with his/her family and friends has gotten better or worse now that s/he's making his/her own decisions?

Yes: 8 **Same as Before: 1**

- I think so because, as I've said, I've had to learn how to work with [Participant] as a team member, as opposed to as my charge . . . I think the discussions we've had as part of SDM have helped me move in that direction of being an advisor, as opposed to an authoritarian.

- Yes, because it's like we believe in him and he tries on that.

- Yeah, because it's given him a little bit more of an opportunity to speak to them and to tell them what it is that he would like that he may reach out to them for their opinions on, and so I think it's given mutual respect for them.

- Yes because there's a higher level of respect.

Do you think [Participant] advocates for him/herself and other people more since s/he started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- He is, and I attribute that to the pilot program.

- I remember on the job, before COVID happened . . . It was something that happened and he sought out some guidance, and we were really proud of that. He was working it out. . . It was something and [Participant] basically said 'I've got this, I'll be fine.'

- I think so . . . It's just like, geez, that's crazy. She totally just had a need and she took care of it.

Do you think [Participant] is better at telling people what s/he wants since s/he started working with the Virginia Supported Decision-Making Pilot Project?

Yes: 9

- It's a lot more how he feels. Now he's kind of got an opinion . . . where before, whatever I asked of him, he just automatically did . . . and now he might say 'You know, I really don't like that,' and I'm just like 'Oh, wow.'

- I feel like he showed the confidence to come to me and ask for help.

- She's trying to engage us to get what she needs or what she thinks she needs – what she wants.

Has [Participant] joined any groups, boards, or organizations since s/he started working with the Virginia Supported Decision-Making Pilot Project? Do you think [Participant] started working with them because of his/her experience with the Virginia Supported Decision-Making Pilot Project?

Yes: 5 No: 4

- [Participant joined a new group where he could support others]. It made him feel good to help others and inform them that there are options out there besides guardianship. He's always been an advocate, but it gives him another really strong thing to help others learn about and help them help themselves.

- He's definitely better about wanting to get more involved and more likely to say yes . . and he's helped out with our events and gets involved greeting people, and I do see a change there.

[For participants under guardianship]. Has using Supported Decision-Making made you want to modify or end the guardianship?

Yes: 4

- Yes, I'm hoping for that.

- Absolutely. I do want to talk with my husband and his siblings and see if there are things we want to change. I think we want to update.

- Yes . . . we really trust our team and she's fortunate that she does have siblings and a good support network. But it's good to think, moving forward, that things could absolutely change. We definitely recognize that.

- I want to incorporate more of his decision-making support.

[For participants not under guardianship]. Has using Supported Decision-Making made you believe the participant can live without a guardian?

Yes: 5

- Yes. It's kind of solidified for me that he does not . . . yes, he might need some support on signing contracts or certain financial things, but hey, I know a lot of people that are not autistic that also need a lot of help in those areas.

- Yes, that if he learns the tools, if he learns how to set it up, that he can make pretty much any decisions with just a little bit of guidance.

- Yes . . . [SDM] has been great for us and, again, we were a ship on the ocean and didn't know where to put our anchor, going from port to port to port.

RECOMMENDATIONS

Based on our findings and existing U.S. and international scholarship and research showing how SDM can be an effective alternative to guardianship and a way to increase the independence, self-determination, and life outcomes for people with disabilities,[85] we recommend that the Commonwealth of Virginia take actions that will increase knowledge, access to, and use of SDM by people with disabilities. Specifically, we recommend that the Commonwealth: (1) Increase education and research on SDM as an alternative to guardianship and a way to improve self-

[85] *e.g.*, Blanck & Martinis, 2015; Martinis, et al., (in press); Martinis & Blanck, 2019; Bulgarian Ctr. for Not-For-Profit Law. (2014). Cost benefit analysis of supported decision-making. Retrieved from: https://www.bapid.com/bapid/wp-content/uploads/2014/08/SDM_report_engED.pdf.

determination and quality of life for people with disabilities; (2) Encourage the use of SDM in Special Education, Vocational Rehabilitation, and Medicaid Waiver supports and services, consistent with existing law and best practices; and (3) Explore legislation formally recognizing SDM as an alternative to guardianship, as other states and the District of Columbia have done.

A. Increasing Education and Research on Supported Decision-Making

Since Jenny Hatch began the "avalanche" of SDM, publicity and grass roots activity have resulted in people across the United States using SDM to avoid or end overbroad or undue guardianships and increase their independence, self-determination, and quality of life.[86] Nevertheless, and despite research showing the benefits of self-determination and harms of overbroad or undue guardianship, the use of guardianship is increasing.[87] The estimated number of adults under guardianship in the United States has tripled since 1995, from 500,000 to 1,500,000, and 1,300,000 of these individuals are people with disabilities.[88] Moreover, as

[86] *e.g.,* Commonwealth Council on Developmental Disabilities. (2017). Freed form guardianship. A Kentucky first: Woman wins her rights in court using supported decision-making. *Exceptional Family Kentucky.* Retrieved from: https://issuu.com/lexingtonfamily/docs/exfam_sumfall_17; Emery, M. (2018). 28-year-old Jamie Beck makes Indiana history as 1st to regain decision-making rights. *The Richmond Palladium-Item*. Retrieved from: https://www.pal-item.com/story/news/local/2018/06/13/jamie-beck-makes-state-history-1st-regain-decision-making-rights/698874002/; National Resource Center for Supported Decision-Making. (n.d.). Stories of supported decision-making. Retrieved from: http://supporteddecisionmaking.org/impact; Glen, K. B. (2017). Piloting personhood: Reflections from the first year of a supported decision-making project. *Cardozo L. Rev., 39*, 495.

[87] e.*g,* National Council on Disability. (2019). Turning rights into reality: How guardianship and alternatives impact the autonomy of people with intellectual and developmental disabilities. Retrieved from: https://ncd.gov/publications/2019/turning-rights-into-reality; National Council on Disability. (2018). Beyond guardianship: Toward alternatives that promote greater self-determination. Retrieved from https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives

[88] National Council on Disability, 2018; Reynolds, S. L. (2002). Guardianship primavera: A first look at factors associated with having a legal guardian using a national representative sample

mentioned, studies find that the vast majority of guardianships remove *all* of the person's decision-making rights,[89] even though "in many cases, if not most, individuals with impairments affecting decision-making abilities would be able to participate in the decision-making process with appropriate assistance."[90]

This research strongly suggests that there is a lack of knowledge about SDM and other alternatives to guardianship. Therefore, even if states like Virginia pass laws formally recognizing SDM as a less restrictive alternative to guardianship (as discussed below), that may not be enough to ensure that people with disabilities, families, professionals, and courts actually know about, consider, and, when appropriate, use SDM.

Accordingly, we recommend that Virginia increase education, outreach, and research on the recognition, practice, and efficacy of SDM. While there have been some efforts to educate people with disabilities, families, and professionals in Virginia about SDM,[91] further and more coordinated efforts are needed to educate the public and examine how SDM operates in theory and practice

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of community-dwelling adults. *Aging and Mental Health, 6*, 109-120. Schmidt, W. C. (1995). *Guardianship: Court of last rest for elderly and disabled.* Durham, NC: Carolina Academic Press; Uekert, B. & Van Duizend, R. (2011). Adult guardianships: A "best guess" national estimate and the momentum for reform. In Future trends in state courts 2011: Special focus on access to justice. Retrieved from https://ncsc.contentdm.oclc.org/digital/collection/ctadmin/id/1846

[89] Teaster, P. B., Wood, E. F., Lawrence, S. A., & Schmidt, W. C. (2007). Wards of the state: A national study of public guardianship. *Stetson L. Rev.*, *37*, 193-242. Lisi, L. B., Burns, A., & Lussenden, K. (1994). National study of guardianship systems: Findings and recommendations. Ann Arbor, MI: Center for Social Gerontology; Millar, D. S., & Renzaglia, A. (2002). Factors affecting guardianship practices for young adults with disabilities. *Exceptional Children, 68*, 465-484.

[90] Salzman, 2011, at 201

[91] *e.g.*, disAbility Law Center of Virginia. (n.d.). Supported decision-making resources. Retrieved from: https://www.dlcv.org/supported-decision-making

Therefore, we recommend a multi-pronged approach for outreach, education, and research on SDM. First, we recommend that the Virginia Working Interdisciplinary Networks of Guardianship Stakeholders ("VA-WINGS") focus on educating people and professionals about SDM and other less restrictive alternatives to guardianship. WINGS groups, funded by the U.S. Department of Health and Human Services, Administration on Community Living, and the American Bar Association, are partnerships between state court systems and stakeholders intended to change guardianship law, policy, and practice so that people have more opportunities to make decisions, exercise their rights, and direct the lives.[92]

Virginia received funding to form a WINGS group in 2016. Since then, VA-WINGS has created or contributed to several resources,[93] but all focus more on how to become or act as a guardian than how to access and use alternatives like SDM when appropriate.

For example, in 2020, VA-WINGS created and issued a publication titled "Appointment of Guardians and Conservators for Incapacitated Adults, Frequently Asked Questions."[94] This 5-page guide addresses and describes how a person can become a guardian. One of the questions addressed is "What other options are available?" Even though the publication was written almost 7 years after Jenny Hatch - *a Virginian* - won the right to use SDM and became "the rock that starts the avalanche" of SDM throughout the United States, it does not even mention SDM as an

[92] American Bar Association. (n.d.). WINGS court-stakeholder partnerships. Retrieved from: https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships/

[93] *e.g.*, Virginia WINGS Training & Resources Subcommittee. (2020). Appointment of guardians and conservators for incapacitated adults: Frequently asked questions. Retrieved from: http://www.courts.state.va.us/courts/circuit/resources/guardianship_faqs.pdf; Office of the Secretary, Division of Judicial Services. (2020). You've been appointed: Information for Virginia guardians and conservators. Retrieved from: http://www.vacourts.gov/courts/circuit/resources/guardian_conservator_pamphlet.pdf

[94] Virginia WINGS Training & Resources Subcommittee, 2020.

"option."[95]

VA-WINGS' focus on guardianship, rather than addressing or promoting alternatives to it, stands in contrast to several other state WINGS workgroups. For example, WINGS groups in Missouri, Minnesota, and Wisconsin have developed and disseminated information and resources on SDM.[96] WINGS workgroups in Mississippi, Missouri, Minnesota, Washington, and Wisconsin have hosted or sponsored presentations on SDM for stakeholders including people with disabilities, families, professionals, attorneys, and judges.[97] Significantly, several state WINGS workgroups have contributed to efforts to change their state's guardianship laws. In fact, there were active WINGS workgroups in almost three-quarters of the states that have passed laws formally recognizing SDM as an alternative to guardianship.[98]

VA-WINGS should follow the example set by its sister state workgroups, and seek out and provide education and information on how to avoid guardianship when it is unnecessary and on ways to enhance independence, self-determination, and quality of life through SDM. Because WINGS groups are made up of court personnel as well as people with disabilities and family members, they can reach, educate, and influence the people who are most likely to consider seeking

[95] Virginia WINGS Training & Resources Subcommittee, 2020, at 3. The "options" listed in the publication are Durable Medical Power of Attorney, Durable Power of Attorney, Representative Payee, Limited Guardianship, and Limited Conservatorship.

[96] Missouri Working Interdisciplinary Networks of Guardianship Stakeholders. (n.d.). Supported decision-making. Retrieved from: https://www.mo-wings.org/add-2nd-tab-supported-decision-making/; Minnesota Working Interdisciplinary Networks of Guardianship Stakeholders (n.d.). Supported decision-making. Retrieved from: http://wingsmn.org/supported-decision-making/; Wisconsin Working Interdisciplinary Networks of Guardianship Stakeholders. (n.d.). WINGS online resources for alternatives to guardianship. Retrieved from: https://gwaar.org/api/cms/viewFile/id/2004435;

[97] The presentations were provided by Jonathan Martinis of BBI, a co-author of this report.

[98] Martinis, et al., (in press).

guardianship, the attorneys who litigate guardianship cases, and the judges who ultimately decide whether a person should be placed in guardianship or use a less restrictive alternative like SDM.

Secondly, we recommend that the Board sponsor or create educational programs and materials on SDM and other alternatives to guardianship. These efforts should build on and expand the education and outreach provided by the Pilot Project.

Several state Developmental Disabilities Councils have played lead roles in educating stakeholders about the existence and benefits of SDM. For example, the Missouri Developmental Disabilities Council issued a position statement on self-determination and guardianship that it shared with state legislators and policymakers. The Council stated, "[p]eople should only be ordered or kept under guardianship when less-restrictive alternatives have failed to help them direct their own lives. Guardianship, when absolutely necessary, should restrict the ward's rights to the minimum extent possible."[99] The Council also urged the legislature to explore and adopt a proposed state law formally recognizing SDM as an alternative to guardianship[100].

Building upon its policy statement, the Missouri Commission sponsored and issued educational materials for people with disabilities, families, and professionals to help them learn about SDM as an alternative to guardianship[101] and a way to improve independence, self-determination, and outcomes in several life areas and programs, including:

[99] Missouri Developmental Disabilities Council. (n.d.). Position statement on self-determination and guardianship. Retrieved from: https://moddcouncil.org/wp-content/uploads/2019/04/SES-Missouri-DD-Council-Guardianship-Paper-FINAL.pdf

[100] The Missouri state legislature subsequently passed legislation formally recognizing SDM as a preferred alternative to guardianship. MO Rev. Stat. 475.075(13) (4) (2019).

[101] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). Do I HAVE to get guardianship? Retrieved from: https://moddcouncil.org/wp-content/uploads/2019/04/MODDC-Do-I-Have-to-Get-Guardianship-9-5-2018.pdf

- Special Education Programs[102]
- Special Education Transition Services[103]
- Vocational Rehabilitation Programs[104]
- Health Care[105]
- Person Centered Planning[106]
- Money Management[107]
- Aging[108]
- Emergency Preparedness[109]

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[102] Something Else Solutions, LLC and Missouri Developmental Disabilities Council (n.d.). "Education, employment, and independent living": Supported decision-making in special education programs. Retrieved from: https://moddcouncil.org/wp-content/uploads/2019/04/MODDC-Education-Employment-and-Independent-Living-Supported-Decision-Making-9-5-2018.pdf

[103] Something Else Solutions, LLC, and Missouri Developmental Disabilities Council. (n.d.). "Planning for the rest of their lives": Supported decision-making in special education transition services. Retrieved from: https://moddcouncil.org/wp-content/uploads/2019/04/moddc-SDM-booklet-3.pdf

[104] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Maximizing employment and independence": Supported decision-making in vocational rehabilitation programs. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/02/moddc-SDM-booklet-4.pdf

[105] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "My health, my decisions": Supported decision-making in health care. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/02/moddc-SDM-booklet-5.pdf

[106] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Living your best life": Supported decision-making and person centered planning. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/02/moddc-SDM-booklet-6.pdf

[107] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Everyone deserves a shot at the American dream": Supported decision-making and managing your money. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/04/moddc-SDM-booklet-7-Managing-Your-Money.pdf

[108] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Getting older, getting better": Supported decision-making through the years. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/04/SDM-BOOKLET-8-AGING-FINAL-1.pdf

[109] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Shelter from the storm": Supported decision-making and emergency planning. Retrieved

- Staying Healthy and Connected During the Pandemic[110]

Similarly, the Tennessee Council on Developmental Disabilities led efforts to "introduce[e] Supported Decision-Making to Tennessee's disability community on two fronts: legislative advocacy and information dissemination."[111] The Council collaborated with several other state agencies and stakeholders to consult with state and national experts to learn about SDM theory and practice. Then Council and its partners then created and sponsored educational presentations for people with disabilities, families, and other supporters describing the dangers of overbroad or undue guardianship, the benefits of self-determination and, the potential of SDM.[112]

At the same time, the Council and its partners created outreach and education programs and materials targeted to specific professionals to teach them about SDM, including:

- Teachers
- Vocational Rehabilitation Counselors
- Medicaid Waiver case managers
- State agencies
- Attorneys
- Judges and court personnel
- State agencies

While these presentations discussed the discussed the benefits of self-determination and

from: https://moddcouncil.org/wp-content/uploads/2020/04/SDM-BOOKLET-9-EMERGENCY-PREPAREDNESS-FINAL.pdf

[110] Something Else Solutions, LLC and Missouri Developmental Disabilities Council. (n.d.). "Staying healthy, staying connected": Supported decision-making in a pandemic. Retrieved from: https://moddcouncil.org/wp-content/uploads/2020/07/moddc-SDM-booklet-10-draft-2.pdf

[111] Pearcy, L. (2017). Supported decision-making in Tennessee. *TASH Connections, 42*(3), 28-33.

[112] Pearcy, 2017

SDM, they also showed each group how SDM can and should be incorporated into their work:

- Presentations to teachers encouraged them to use SDM to create individualized IEP and Transition goals and objectives;
- Training for judges, court personnel and state agencies showed how SDM is consistent with state laws on guardianship and state supports and services;
- Sessions for attorneys demonstrated how SDM can be incorporated into Powers of Attorney, Advanced Directives, and other alternatives to guardianship; and
- Conferences for Vocational Rehabilitation counselors and Medicaid Waiver case managers discussed how SDM should be a part of the Informed Choice and Person Centered Planning processes.[113]

Finally, several Developmental Disabilities Councils, including those in Wisconsin,[114] Tennessee, [115] New York,[116] Nevada,[117] Delaware,[118] Colorado,[119] Michigan,[120] Texas,[121] and Georgia,[122] have created and sponsored educational presentations and materials on SDM for people, families, and professionals.

Like its sister Councils, the Board should play a leadership role in educating people with disabilities, families, and professionals about the existence and benefits of SDM. The Board has begun to do so by sponsoring this Pilot Project. While this Project, as shown in this and other reports, has been successful, its efforts have largely targeted the Northern Virginia area. Therefore, we recommend that the Board expand these efforts to conduct targeted and comprehensive

[113] Pearcy, 2017.
[114] *e.g*, https://wi-bpdd.org/index.php/supporteddecision-making/
[115] *e.g*, https://www.tn.gov/cdd/public-policy/supported-decision-making.html
[116] *e.g.*, https://ddpc.ny.gov/supported-decision-making
[117] *e.g.*, https://www.nevadaddcouncil.org/supported-decision-making/
[118] *e.g.*, https://ddc.delaware.gov/index.shtml?dc=mediaGallery
[119] *e.g.*, http://www.coddc.org/Documents/SDM%20Web%20Version.pdf
[120] *e.g.*, https://www.michigan.gov/documents/mdhhs/Supported_Decision_Making_Brochure_Final_Draft_652346_7.pdf
[121] *e.g.*, https://tcdd.texas.gov/public-policy/position-statements/position-statement-guardianship/
[122] *e.g.*, https://gcdd.org/calendar-of-events/1483.html

outreach and education on SDM throughout the Commonwealth.

Third, we recommend that the Board and/or Commonwealth sponsor additional research into the practice and efficacy of SDM. As researchers and scholars have pointed out, qualitative and quantitative research are needed to increase understanding and documentation of the relationship between SDM and quality of life.[123] While the Pilot Project had very positive findings and results - demonstrating that participants who used SDM improved their independence and decisions making skills, made better decisions, and enhanced their quality of life - it was, by design, limited in size and geographic scope. Further and larger-scale research is needed to document SDM best practices and identify effective SDM methodology across demographics, disabilities, and geography. Research should also be performed to determine whether people who use SDM are less likely to be ordered into guardianship or more likely to have their guardianships terminated. In addition, research should examine whether SDM relationships result in improved societal interactions, including whether and how they are recognized and respected by professionals in the health care, financial, legal and other professions.

B. Encouraging the use of SDM in Programs Supporting People with Disabilities

Given the importance of self-determination to individual growth and quality of life, SDM concepts and practice should be incorporated throughout the programs and services that support people with disabilities. Therefore**,** we recommend that the Commonwealth encourage the use of SDM in Special Education, Vocational Rehabilitation, and Medicaid Waiver programs and services consistent with existing law, research, and best practices.

[123] Kohn, et al, 2014; Blanck, P. (2015). The Efficacy of Supported Decision-Making, Grant Proposal Funded by the National Council on Independent Living and Rehabilitation Research.

1. Encouraging Supported Decision-Making in Special Education

Under the Individuals with Disabilities Education Act, schools must provide students receiving Special Education with "education and related services designed to meet their unique needs and *prepare them for further education, employment, and independent living.*"[124] As mentioned, studies have found that people with disabilities who have more self-determination are more likely to live independently and be better employed.[125] Similarly, studies have shown that students with disabilities who are provided with education and services emphasizing and building their self-determination were more likely to have positive adult outcomes including employment, community integration, and independent living.[126] Consequently, studies and scholars have stressed that schools should focus on building students' self-determination, decision-making, and problem solving skills.[127]

Nevertheless, research shows that schools play a key and unfortunate role in people with disabilities being ordered into overbroad or undue guardianships. One study asked parents and guardians to identify who first suggested that they seek guardianship. The most frequent response

[124] 20 U.S.C. § 1400(d) (1)(A) (emphasis added).

[125] *e.g.,* McDougall, J., Evans, J., & Baldwin, P. (2010). The importance of self-determination to perceived quality of life for youth and young adults with chronic conditions and disabilities. *Remedial and Special Education, 31,* 252-260; Powers, L. E., Geenen, S., Powers, J., Pommier-Satya, S., Turner, A., Dalton, L., . . . Swand, P. (2012). My Life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education. Children and Youth Services Review, 34, 2179–2187; Wehmeyer, M.L., & Schwartz, M, (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63(2),* 245-255.

[126] *e.g.,* Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education, 48,* 256-267; Wehmeyer & Schwarz, 1997

[127] Wehmeyer, M. L., & Gragoudas, S. (2004). Centers for independent living and transition-age youth: Empowerment and self-determination. *Journal of vocational rehabilitation*, *20*(1), 53-58.

was "school personnel."[128] Research by the National Council on Disability also documented the "school to guardianship pipeline," finding that more than half of young adults with intellectual and developmental disabilities have guardians.[129]

Consequently, state-wide educational policy and practice initiatives are needed to ensure that schools identify and implement self-determination and decision-making supports and services for students with disabilities in order to maximize their opportunities to live independently and avoid overbroad or undue guardianships.[130] Therefore, we recommend that the Board advocate for the Virginia Board of Education to create a statewide policy similar to that developed by the District of Columbia Public Schools ("DCPS").

DCPS has created the nation's first system-wide policy focused on building students' decision-making and self-determination skills through SDM. DCPS teaches students as young as 3 and their parents to use SDM and build networks of support to make decisions in school and in their day-to-day lives.[131]

When DCPS students reach 9th grade, they are encouraged and empowered to use formal SDM processes to discuss educational and life situations and choices with people they trust so they may make informed decisions that meet their needs.[132] When students turn eighteen, DCPS offers

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[128] Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for persons with Severe Disabilities*, *40*(1), 36-51.

[129] National Council on Disability, 2019.

[130] Martinis, J. (2014). One person, many choices: Using special education transition services to increase self-direction and decision-making and decrease overbroad or undue guardianship. *Quality Trust for Individuals with Disabilities*, 1-29. Retrieved from: http://jennyhatchjusticeproject.org/docs/publications/jhjp_publications_draft_article_guardianship.pdf

[131] Downing-Hosten, P. (2015). Planning for transition by creating a supported decision-making network. Retrieved from: http://supporteddecisionmaking.org/sites/default/files/event_files/041615_ppt_handouts.pdf

[132] District of Columbia Public Schools, Office of Specialized Instruction. (n.d.). Supported

them the opportunity to create educational SDM agreements identifying the people they want support from in their education, areas where they want support, and the authority their supporters will have, with the student maintaining final decision-making authority.[133]

Similar state and system-wide initiatives may help to reduce the "school to guardianship pipeline" by involving students in an SDM process from a young age. In particular, it may help parents learn and understand – like the supporters in the Pilot Project - that their children can use SDM to make decisions and, therefore, guardianship is not necessarily inevitable.

If a statewide SDM policy is not possible or feasible, we recommend that the Board advocate for districts and schools to engage in SDM-based processes that will improve student's self-determination. For example, the Student Led IEP gives students an opportunity to build and practice their self-determination and SDM skills. In this process, students play a leadership role on their IEP teams and work collaboratively with team members to develop their goals, objectives, programs, and services. As students age and progress, their leadership role and responsibilities will evolve: they may progress from introducing themselves when they are very young, to talking about their goals and preferences, to "Chair[ing] the meeting" "and "Cooperatively develop[ing] all aspects of the IEP.[134]

The Student Led IEP, with its emphasis on students working with educational professionals

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decision-making in DCPS before the age of majority. Retrieved from: http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_faqs_0.pdf

[133] District of Columbia Public Schools, Office of Specialized Instruction. (n.d.). Supported decision-making in DCPS after the age of majority. Retrieved from: http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_faqs_0.pdf

[134] I'm Determined (n.d.). Student-led IEPs: Increasing self-determination through involvement in the IEP process. Retrieved from: www.imdetermined.org/files_images/general/StudentLed-IEPs.ppt

to understand, discuss, develop, and decide upon goals and objectives, is "the very definition" of an SDM-based process.[135] By giving students the opportunity to use SDM throughout their educational careers, the Student Led IEP also empowers students to "practice different decision-making methods in a 'safe environment.'"[136] Through this process, students will, consistent with research and best practices, have a full opportunity to develop and practice critical "goal setting, problem solving, decision-making and self-advocacy skills."[137]

Research shows the many ways that students may benefit from this process. One study finds that students who led their IEP meetings "gained increased self-confidence and were able to advocate for themselves, interacted more positively with adults, assumed more responsibility for themselves, [and] were more aware of their limitations and the resources available to them."[138] Put another way, students who used the Student Led IEP process showed similar improvements in independence and self-determination as participants in the Pilot Project.

2. Encouraging Supported Decision-Making in Vocational Rehabilitation

The Vocational Rehabilitation (VR) program is designed to help people with disabilities identify, gain, retain, and advance in employment.[139] Specifically, state VR agencies are charged to support people with disabilities in finding and succeeding in jobs that are "consistent with [their]

[135] Martinis, J. & Gustin, J. (2017). Supported decision-making as an alternative to overbroad and undue guardianship. *The Advocate*, *60*(6), 41-46.
[136] Martinis, J. (2015). Moving supported decision-making from theory to practice: Youth in transition. Retrieved from: http://supporteddecisionmaking.org/sites/default/files/event_files/041615_ppt_handouts.pdf
[137] Wehmeyer & Gragoudas, 2004.
[138] Mason, C. Y., McGahee-Kovac, M., & Johnson, L. (2004). How to help students lead their IEP meetings. *Teaching Exceptional Children*, 36(3), 18-24.
[139] 29 U.S.C. § 720 (2011). `

unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice."[140]

As mentioned, studies have repeatedly shown that people with disabilities who exercise more self-determination are more likely to be employed and earn higher wages.[141] Therefore, we recommend that the Board advocate for the Virginia Department on Aging and Rehabilitative Services (DARS) to identify and provide, where appropriate, SDM-based supports and services that build self-determination and decision-making skills.

SDM is consistent with legal requirements for VR. Federal law requires VR agencies to provide people with "Informed Choice" throughout the VR process.[142] To do so, the agency and its counselors must give people the information and support they need to choose:

- The job they want to get with the agency's assistance;
- The VR services they need to get that job; and
- The agencies and organizations that will provide those services.[143]

We recommend that the Virginia Board for People with Disabilities encourage DARS to use SDM to ensure that people can truly exercise Informed Choice throughout the VR process**.** This will empower people, like the Student Led IEP empowers students, to effectively exercise Informed Choice as well as develop and practice decision-making skills in a controlled, safe environment.[144] Also like the Student Led IEP, an SDM-based Informed Choice process will help people build and exercise self-determination and gain the skills they need to avoid overbroad or

[140] 34 C.F.R. § 361.5 (2001).
[141] *e.g.*, Shogren, et al, 2015; Wehmeyer, M.L., & Schwartz, M, (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63(2),* 245-255.
[142] 34 C.F.R. § 361.52 (2001).
[143] 34 C.F.R. § 361.45 (2001).
[144] *e.g.* Martinis & Blanck, 2019.

undue guardianship.

3. Encouraging Supported Decision-Making in Medicaid Waiver Services

Health and daily wellness are part of our everyday lives and everything we do. As discussed, SDM can help people be more self-determined, increasing their chances to be healthier, more independent, and safer in their day-to-day lives.[145] Accordingly, health care systems should help people, whenever appropriate, learn about and exercise SDM and self-determination. This could help people avoid the "significant negative impact on physical and mental health" that can result from overbroad or undue guardianship.[146]

Thousands of Virginians with IDD receive Medicaid Home and Community Based Waiver Services to help them plan for, choose, and receive medical and other services they need to lead healthy and independent lives.[147] Therefore, we recommend that the Board advocate for the Virginia Department of Medical Assistance Services (DMAS) and Department of Behavioral Health and Developmental Services (DBHDS) to incorporate and implement SDM in the Medicaid Waiver planning process.

Federal requirements state that Medicaid Waiver programs must use Person Centered

[145] *e.g.*, Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and training in developmental disabilities*, 131-144; Wehmeyer, M., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional children*, *63*(2), 245-255. Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110, 193–204

[146] Wright, 2010

[147] *e.g*, Ng, T., Harrington, C., Musumeci, M, & Ubri, P. (2016). Medicaid home and community-based programs: 2013 Data Update. *Kaiser Family Foundation.* Retrieved from: https://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/

Planning (PCP) with Waiver recipients to develop support plans with "individually identified goals and preferences, including those related to community participation, employment, income and savings, health care and wellness, education and others."[148] In PCP, the person creates his or her plan "with assistance from a trained, competent, assessor, care manager or similar facilitator [and] . . . from people who are important to him or her." The person should lead the PCP team, and his or her plan must be "informed by family members, caregivers, and other individuals that the beneficiary has identified as playing an important role in his or her life"[149] The team should collaborate to develop a plan that:

- Is focused on the person's strengths and interests;
- Identifies what the person likes to do and doesn't like to do; and
- Describes activities and programs the person would like to take part in.[150]

Thus, the Medicaid Waiver PCP process mirrors those in the Student Led IEP and Informed Choice processes.[151] In each, people collaborate with others to help them identify, consider, and choose the supports and services they want and need to achieve their goals.

Therefore, like the Student Led IEP and the Informed Choice process, PCP should incorporate SDM to ensure that people can make informed decisions about their supports, services, and day-to-day lives. This approach will empower people to develop and practice decision-making skills, exercise self-determination, and "ensure delivery of services in a manner that reflects

[148] Centers for Medicare and Medicaid Services (2014). Fact sheet: Summary of key provisions of the 1915(c) home and community-based services (HCBS) waivers final rule. *Retrieved from:* https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf

[149] Centers for Medicare and Medicaid Services (2016). FAQs concerning Medicaid beneficiaries in home and community-based settings who exhibit unsafe wandering or exit-seeking behavior. Retrieved from: https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf

[150] Centers for Medicare and Medicaid Services, 2016

[151] Martinis & Blanck, 2019

personal preferences and choices, and contribute to the assurance of health and welfare."[152]

In addition, we recommend that the Board advocate for DMAS and DBHDS to provide specific Medicaid Waiver services and supports, where appropriate, to help people learn to use SDM**.** Under Federal rules, the PCP process must help people identify, choose, and receive the supports they need to live independently, "including those related to community participation, employment, income and savings, health care and wellness, education and others."[153] Therefore, if people need assistance to understand, make, or communicate financial, educational, employment, health care, or other decisions, they should receive SDM supports and services to help them develop and exercise those skills.

C. Exploring Legislation Formally Recognizing Supported Decision-Making as an Alternative to Guardianship

As mentioned, the Commonwealth recently amended its laws to increase access to SDM in education and in guardianship cases. We recommend that the Commonwealth build on these advances and explore enacting legislation formally recognizing SDM as an alternative to guardianship, as several states and the District of Columbia have done.[154]

While state laws recognizing SDM have similar features, none are exactly the same. In general, though, these laws identify SDM as an alternative to guardianship where people receive assistance understanding, making and communicating decisions. For example, the District of Columbia's law defines SDM as:

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[152] Centers for Medicare and Medicaid Services, 2014.

[153] Centers for Medicare and Medicaid Services (2014). Fact sheet: Summary of key provisions of the 1915(c) home and community-based services (HCBS) waivers final rule. *Retrieved from:* https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf

[154] Martinis, et al., (in press).

> [A] process of supporting and accommodating an adult with a disability in order to: (A) Assist the adult with a disability in understanding the options, responsibilities, and consequences of life decisions; and (B) Enable the adult with a disability to make life decisions, without impeding the self-determination of the adult with a disability or making decisions for the adult with a disability.[155]

Several state laws differ in the way they require people to establish their SDM relationships. Some states, including Texas, Delaware, and the District of Columbia, require that people enter into a written **Supported Decision-Making Agreement** (SDMA). These statutes provide a model SDMA and state that people must use that form, or one substantially like it, in order for their SDM relationships to be legally recognized. Other states, such as Missouri and Nevada, recognize people's right to enter into an SDMA and say that SDMAs must be respected. However, these states do not *require* people to have SDMAs or use a particular SDMA form for their SDM relationships to be legally recognized and effective.[156]

We recommend that the Commonwealth of Virginia explore enacting legislation that formally recognizes SDM as an alternative to guardianship and provides legal recognition of SDM relationships. With that said, it must be noted that nothing in Virginia law *prevents* a court from considering whether a person uses SDM when deciding whether or not to order that person into guardianship. In fact, Virginia law *requires* such consideration, stating, "In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors: . . . (iii) the availability of less restrictive alternatives, including advance directives and durable powers of attorney."[157]

[155] D.C. Code § 7-2131(11).
[156] Martinis, et al (in press).
[157] Va Code Ann. § 64.2-2007(c)

As shown, SDM is and has been recognized as a less restrictive alternative to guardianship by the U.S. Department of Health and Human Services, American Bar Association, National Guardianship Association, and other public and private agencies and organizations.[158] Thus, under existing Virginia law, if a person effectively uses SDM to make decisions and direct his or her life, a court *must* consider that fact and decline to order the person into guardianship. Indeed, in Jenny Hatch's case, the court refused to order her into a permanent, plenary guardianship because she uses SDM to make her own decisions, *even though* Virginia law does not specifically recognize SDM as a less restrictive alternative to guardianship.[159]

Even so, we recommend that the Commonwealth explore amending its law to explicitly recognize SDM as a less-restrictive alternative to guardianship. We take this position because, as noted, the number of people with disabilities entering into guardianship continues to increase at an alarming rate.[160] This strongly suggests that people with disabilities, families, attorneys, and judges are unaware of the existence or potential of SDM to empower people to make their own decisions and avoid overbroad or undue guardianship.

Thus, we recommend, at a minimum, amending Va. Code Ann. § 64.2-2007(C) to read, "In determining the need for a guardian or a conservator and the powers and duties of any guardian or conservator, if needed, consideration shall be given to the following factors: . . . (iii) the availability of less restrictive alternatives, including advance directives, durable powers of attorney, and Supported Decision-Making." This amendment would result in Virginia expressly recognizing SDM as a less restrictive alternative to guardianship of the same order as powers of

[158] Admin. for Cmty Living. U.S. Dep't of Health & Human Servs., 2014; American Bar Association, 2017; National Guardianship Association, 2017.
[159] *Ross and Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013) (final order).
[160] *e.g.*, National Council on Disability, 2018, 2019.

attorney and advanced directives. In addition, the amendment would increase knowledge and consideration of SDM by, at the very least, attorneys and judges in guardianship cases.

However, we recommend that Virginia go beyond simply recognizing SDM as a less-restrictive alternative to guardianship. For SDM to truly be effective and serve as a way to protect and increase self-determination for people with disabilities, Virginia law should expressly recognize the effectiveness and enforceability of SDM relationships. This will ensure that courts and society at large respect people's choice to seek, receive, and use support to make decisions. If, for example, a court were able to disregard a person's effective use of SDM to make decisions and order the person into guardianship, laws that merely *identify* SDM as a less-restrictive alternative to guardianship would be meaningless.

Therefore, we recommend that any Virginia SDM law pattern itself after Missouri's law formally recognizing SDM as a less-restrictive alternative to guardianship. Missouri law states, "Before appointing a guardian or conservator, the court shall consider whether the respondent's needs may be met without the necessity of the appointment of a guardian or conservator, or both, by a less restrictive alternative including . . . . (4) Supported decision-making agreements or the provision of protective or supportive services or arrangements provided by individuals or public or private services or agencies."[161] Thus, before ordering a person into guardianship, Missouri courts must consider *and rule out* whether a person is using or *could* use SDM to make decisions.

While Missouri law recognizes the validity of SDM relationships and agreements, it does not require that such agreements be in writing or take any particular form. We recommend that any Virginia SDM law follow this example. We recognize that several other states require specific, written SDMAs in order for SDM relationships to be recognized and enforceable. However, we

[161] MO Rev. Stat. Chapter 475.075(13)(4).

believe that these laws, while well intentioned, are antithetical to principles of person-centered thinking and the self-determination they seek to protect. Put simply, if a person has an effective SDM relationship, but does not wish to create a written agreement, then law and society should respect that choice.

To give a specific example, Jenny Hatch does not have, and never has had, a written SDM agreement. Nevertheless, she and her supporters created effective, working SDM relationships that empower her to make her own decisions and direct her life without the need for a guardian.[162] If Virginia law only recognized written SDM relationships, Ms. Hatch would likely be in guardianship today.

Of course, there is nothing *wrong* with memorializing SDM relationships in writing and, in fact, we believe it is a good idea to do so.[163] However, we do not believe that written SDMAs should be *required* for SDM relationships to be legally recognized. Many people with disabilities, like Jenny Hatch, have developed and are using effective and supportive relationships to help them make decisions, but, like Ms. Hatch, do not have SDMAs. If Virginia law requires SDM relationships to be memorialized in writing, these relationships will be invalidated.

The experience and findings of the Pilot Project support our recommendation. Consistent with best practices,[164] we encouraged participants to create and use individualized SDM plans but did not require that those plans take any particular form. Indeed, 4 project participants chose not to put their plans in writing while other participants used methods ranging from dictation, to spreadsheets, to creating a chart to memorialize their plans. Nevertheless, all participants showed similar improvements in independence, decision-making skills, decision-making quality, and

[162] *e.g.*, Martinis & Blanck, 2019.
[163] Martinis, 2019.
[164] *e.g,* Dinerstein, 2012; Quality Trust for Individuals with Disabilities, 2014; Martinis, 2019.

quality of life regardless of whether they had created a written plan, or the form any such plan took.

Finally, we recommend that any Virginia SDM law require that SDM be used, as appropriate, when a person is ordered into guardianship. As the National Guardianship Association states, people under guardianship should be provided "with every opportunity to exercise those individual rights that the person might be capable of exercising." Consequently, "the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary."[165]

Virginia law currently requires guardians to "encourage the incapacitated person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs" and "in making decisions, [to] consider the expressed desires and personal values of the incapacitated person to the extent known."[166] As shown in this Project and other research, SDM can empower people – both in and out of guardianship – to make decisions, demonstrate capacity to manage personal affairs, and communicate their personal desires and values.

Therefore, we recommend that Virginia law expressly require guardians, as appropriate, to use SDM to support people to exercise, gain, or regain the ability to understand, make, and communicate their own decisions. This will ensure that people in guardianship have a full and appropriate opportunity to exercise choice and receive the recognized benefits of self-determination.

[165] National Guardianship Association, 2017.
[166] Va. Code Ann. § 64.2-2019(E)

CONCLUSION

We thank the Board for their support and encouragement of the Pilot Project and, far more importantly, of Virginians with disabilities. We hope the Board feels, as we do, that this Project demonstrates the power and potential of SDM to "increase the self-determination of . . . people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration."[167]

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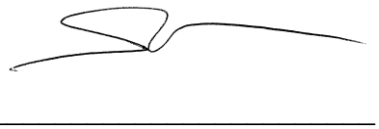

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[167] Blanck & Martinis, 2015