

COMMONWEALTH of VIRGINIA

ALISON G. LAND, FACHE COMMISSIONER

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Wednesday, October 28, 2020

The Honorable John S. Edwards, Chair Senate Judiciary Committee Pocahontas Building 900 East Main Street Richmond, Virginia 23219

Dear Senator Edwards:

Chapter 855 of the 2020 Acts of Assembly (Senate Bill 585) directs the Department of Behavioral Health and Developmental Services (DBHDS) to convene a workgroup to study the use of supported decision-making agreements in Virginia and develop recommendations around the use of supported decision-making. Specifically, the language states:

That the Department of Behavioral Health and Developmental Services (the Department) shall convene a group of stakeholders to study the use of supported decision-making agreements in the Commonwealth, including making recommendations as to the use of supported decision-making agreements as a less restrictive alternative to the appointment of a guardian or conservator for an incapacitated person. The Department shall report the findings and recommendations of the stakeholder group's study to the Chairmen of the Senate Committee on the Judiciary and the House Committee on Health, Welfare, and Institutions no later than November 1, 2020.

The report that follows includes 1.) an overview of supported decision-making, including its use in Virginia and other states, as well as 2.) key findings and recommendations from a workgroup comprised of a broad group of stakeholders representing the intellectual and developmental disability (ID/DD) community, the elderly, persons with mental illness, and the legal community. Staff are available should you have any questions.

Sincerely,

auson Land

Alison G. Land, FACHE Commissioner, Department of Behavioral Health & Developmental Services

CC: Vanessa Walker Harris, MD Susan Massart Mike Tweedy



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The Honorable Mark D. Sickles, Chair Health, Welfare, and Institutions Committee Pocahontas Building 900 East Main Street Richmond, Virginia 23219

Dear Delegate Sickles:

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Report of the Workgroup on Supported Decision-Making

To the Chairmen of the Senate Committee on the Judiciary and the House Committee on Health, Welfare, and Institutions

As directed by Senate Bill 585

Wednesday, October 28, 2020

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Preface

Chapter 855 of the 2020 Acts of Assembly (Senate Bill 585) directs the Department of Behavioral Health and Developmental Services (DBHDS) to convene a workgroup to study the use of supported decision-making agreements in Virginia and develop recommendations around the use of supported decision-making. Specifically, the language states:

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The report that follows includes 1.) an overview of supported decision-making, including its use in Virginia and other states, as well as 2.) key findings and recommendations from a workgroup comprised of a broad group of stakeholders representing the intellectual and developmental disability (ID/DD) community, the elderly, persons with mental illness, and the legal community.

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Executive Summary

Chapter 855 of the 2020 Acts of Assembly (Senate Bill 585) directed the Department of Behavioral Health and Developmental Services (DBHDS) to convene a workgroup to study the use of supported decision-making agreements in Virginia and develop recommendations around its use. Supported decision-making, or SDM, is a model that allows individuals to identify supporters to provide assistance in decision-making without losing autonomy. For some individuals, use of SDM may obviate the need for a substitute decision-making arrangement, including guardianship. For other individuals, SDM can be used within substitute decision-making arrangements (such as guardianship) to help the substitute decision-maker understand the individual's preferences and maximize the individual's autonomy.

SDM is currently in use throughout the country, though specific requirements and levels of formalization vary from state to state. In Virginia, SDM has been studied in both 2014 and 2019, resulting in recommendations to codify SDM as a less restrictive alternative to guardianship that must be considered by a guardian ad litem following a petition for guardianship, for example. Currently, individuals in Virginia may enter into SDM agreements informally, but no law specifically recognizes them.

The Workgroup agreed on core principles that should guide the conversation around SDM in Virginia:

- 1. That every individual should be presumed capable of making his or her own decisions.
- 2. When an individual requires assistance in making decisions, the least restrictive option that meets the individual's needs should be pursued, and every effort should be made to maximize an individual's autonomy and independence.
- 3. Supporters, guardians, substitute decision-makers, and other agents should always take into consideration an individual's expressed personal preferences to the extent appropriate.
- 4. Making good decisions takes practice and individual growth. Everyone should have the opportunity to learn and grow from making poor decisions, sometimes called "Dignity of Risk". Poor decision-making should not be motivation for restricting an individual's rights through guardianship or substitute decision-making.

Finally, the Workgroup made the following recommendations:

- 1. Elevate the use of SDM while avoiding over-formalization, which may include introducing a broad definition or general recognition of SDM into Virginia's Code in order to encourage consideration of alternatives to guardianship in cases in which an individual may be capable of making many of his or her own decisions with additional support. The inclusion of SDM would also emphasize recognition that it is a best practice for substitute decision-makers to seek input and provide guidance on an individual's preferences. SDM should also be considered for recognition in regulations relating to authorized representatives.¹
- 2. Invest in education and training, which is critical to the success of SDM and requires concerted time, effort, and resources. This should target key groups that may benefit

¹ 12VAC35-115-146. Authorized Representatives. An "Authorized Representative " is an individual designated by a DBHDS-licensed provider to provide consent or authorization for health care decisions relating to that provider, for an individual who lacks capacity.

from SDM as well as their communities, healthcare and service providers, legal advocates, educators.

3. Support research and data collection including the efficacy of education and training in increasing the use of SDM, health outcomes for individuals using SDM, and any subsequent reductions in number of guardianship petitions, and determine criteria for assessing success of SDM.

Background About Supported Decision-Making

The American Bar Association defines supported decision-making as a "decision-making model in which an individual makes decisions with the support of trusted individuals."² Supported decision-making, or SDM, allows people needing decision-making assistance to select their own supporters who can help them make and communicate these decisions. An individual may choose different supporters from among family and friends for different situations. For example, he or she may designate an aunt for assistance with financial decisions and a friend for assistance in personal relationships. That same individual may designate a family friend for assistance communicating their medical preferences to a care team and a cousin for assistance with living arrangement decisions. Examples of tools used in SDM can include helping the person discuss different choices, creating pros or cons lists or role-play activities, and using plain language materials with relevant information. SDM may also involve bringing the supporter to appointments or other important conversations to help take notes, understand choices, and even opening a joint banking account to help make financial decisions.³ The goals and details of these designations and authorizations could be spelled out in written agreements.

SDM must be differentiated from substitute decision-making, in which someone makes decisions on behalf of another. Key to SDM is that the individual is not bound to take the advice of the supporter, but uses the supporter as a resource, and he or she is free to change supporters or use supporters only for particular types of decisions as he or she pleases. Kohn, Blumenthal, and Campbell identified four principle characteristics of SDM: "(1) the individual retains legal decision-making authority; (2) the relationship is freely entered into and can be terminated at will; (3) the individual actively participates in decision-making; and (4) decisions made with support are generally legally enforceable."⁴ SDM can be used as a model for any individual requiring decision-making supports.

An "excessive use of guardianship" for individuals requiring decision-making supports has been documented in particular for the ID/DD community at least in part "because guardianship proceedings are frequently treated as a central part of permanency planning for adults with ID."⁴ While SDM first gained traction in the ID/DD community, the model holds promise for the elderly and other groups needing decision-making support. In particular, SDM may be successfully used by individuals with serious mental illness. Individuals with an ID/DD or with a serious mental illness may have very specific preferences relating to their decisions and need assistance understanding their options, due to their condition or a lack of experience resulting from their condition.⁵

Unlike full guardianship, SDM recognizes that individuals have varying need for decision support in different situations. While full guardianship may be the only option for persons lacking sufficient capacity to make decisions in all areas of his or her life, SDM recognizes that "mental capacity is not a binary concept and that people can have varying levels of mental

³ "Supported Decision-Making: Frequently Asked Questions". National Resource Center for Supported Decision Making.

² "Supporting Decision Making Across the Age Spectrum". The American Bar Association Commission on Law and Aging. March 2020.

⁴ Kohn, Blumenthal, and Campbell. "Supported Decision-Making: A Viable Alternative to Guardianship?". Penn State Law Review. (Apr 2013).

⁵ Pathare and Shields. "Supported Decision Making for Persons with Mental Illness: A Review". Public Health Review. (Dec 2012).

capacity to make different kinds of decisions."⁶ An individual may require assistance making particular kinds of decisions, like healthcare or financial decisions, or he or she may require assistance in communicating decisions. The capacity to make decisions can vary by subject matter, health status, level of external stressors, or year, month, day, or even time of day.⁷ The PRACTICAL Tool from the American Bar Association recognizes this complexity and is designed to help lawyers "identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship" by laying out the following steps for supported decision-making:

- Presume guardianship is not needed
- Clearly identify the *reasons* for concern.
- Ask if a triggering concern may be caused by temporary or reversible conditions
- Determine if concerns can be addressed by connecting the individual to family or *community* resources and making accommodations.
- Ask the person whether he or she already has developed a *team* to help make decisions
- *Identify* areas of strengths and limitations in decision-making.
- Screen for and address any potential *challenges* presented by the identified supports and supporters.
- Appoint legal supporter or surrogate consistent with person's values and preferences.
- *Limit* any necessary guardianship petition and order.⁸

While SDM and its outcomes have yet to be extensively studied, the autonomy afforded to individuals under SDM arrangements, as opposed to more restrictive substitute decision-making arrangements, may be linked to "patient satisfaction, treatment adherence, and improved health outcomes" for those with mental health issues.⁹ In addition, elevating SDM as an option for individuals is in line with the American with Disabilities Act, the Individuals with Disabilities Education Act, and the *Olmstead Decision*, all of which affirm the importance of affording individuals with disabilities the same rights and opportunities as anyone else and ensuring the individual receives services in the most integrated, least restrictive setting appropriate to his or her needs.¹⁰

Supported Decision-Making across the Country

In recent years, supported decision-making has gained increasing attention nationally and in a handful of states. In 2015, Texas became the first state to adopt an SDM agreement law, defining SDM and legally recognizing the model as an alternative to guardianship. In 2017, the American Bar Association urged state legislators to require that SDM be considered as a less restrictive alternative prior to guardianship, and in proceedings for termination of guardianship.¹¹

To date, nine states, including Texas, have adopted SDM agreement laws.¹² These laws vary in their approach but in general 1.) outline how an individual may enter into an SDM agreement, including the specific language such an agreement should include; 2.) detail eligibility and

L.C., 527 U.S. 581, 587 (1999)

⁶ Browning, Bigby, and Douglas. "Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice.". *Research and Practice in Intellectual Disabilities*. (Feb 2014).

⁷ "Beyond the Binary: Using a Supported Decision-Making Lens in Evaluating Competence". ACLU.

⁸ "PRACTICAL Tool for Lawyers: Steps in Supported Decision-Making". American Bar Association. (May 2016).

 ⁹ Pathare and Shields. "Supported Decision Making for Persons with Mental Illness: A Review". *Public Health Review*. (Dec 2012).
¹⁰Americans With Disabilities Act, 42 U.S.C. § 12101 (1990); Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004); *Olmstead v.*

¹¹ "Report to the House of Delegates". American Bar Association. (Aug 2017).

¹² Texas, Delaware, District of Columbia, Alaska, Indiana, Wisconsin, Nevada, Rhode Island, and North Dakota

responsibilities of the supporter; 3.) offer limitation of liability for third parties (such as healthcare providers or financial institutions) honoring SDM agreements; and 4.) lay out provisions for terminating an SDM agreement. Other states have taken a more limited approach to codifying SDM, by simply defining it and recognizing it in guardianship statutes as a less restrictive model that should be considered prior to guardianship.¹³

Virginians and Supported Decision-Making

In 2013, the case of Ms. Jenny Hatch in Newport News, Virginia brought broad attention to the issues of guardianship and the role of a person under guardianship to exercise any decision-making autonomy. Ultimately, the Virginia Circuit Court in Newport News rejected Ms. Hatch's parents' petition for full guardianship in favor for a limited, temporary guardianship arrangement between Ms. Hatch and two of her long-time friends. Since then, in Virginia, the topic of SDM as a possible alternative to guardianship has been studied, first in 2014 by the Office of the Secretary of Health and Human Resources, and then in 2019 by the Joint Commission on Health Care. Both studies recommended adding SDM as a less restrictive alternative in Virginia's guardianship Code. The 2014 report also recommended that SDM be added to Regulations related to authorized representatives, that guardians and authorized representatives be required to receive training in SDM as well as person-centered planning, and that providers be trained on capacity and SDM including various forms of decision making assistance and "what type of clinical presentation is appropriate for each".¹⁴

Currently, though not defined in the Code, Virginia law provides sufficient authority to allow individuals to enter into SDM agreements. Current Virginia law directs guardians ad litem in guardianship proceedings to consider less restrictive alternatives to guardianship (though SDM is not explicitly named as a less restrictive alternative).¹⁵ Less restrictive alternatives that are named include advance medical directives (where an adult capable of making an informed decision makes a written statement to address any or all forms of health care in the event he or she is later incapable of making an informed decision), and powers of attorney (authorizing someone authority to act for you and on your behalf).¹⁶ Additionally, individuals may enter into temporary or limited guardianship arrangements in which they lose decision-making autonomy for a specific duration of time or related to a particular area of decision-making.¹⁷ In Virginia, as in other states, there is a continuum of decision-making supports, with SDM on the least restrictive side and full guardianship on the most restrictive side, though SDM can be used as a best practice within all substitute decision-making arrangements (see Figure 1). Under a SDM arrangement, the individual retains full autonomy; while under guardianship, he or she typically loses all or most legal autonomy. Throughout the continuum, SDM can be used to help identify and understand an individual's preferences which should be always be prioritized for consideration.

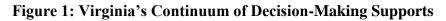
¹³ Missouri, New Mexico

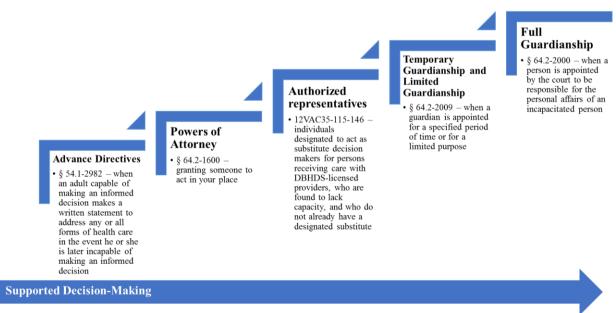
¹⁴ "Supportive Decision-Making Study (HJR 190, 2014)". Office of the Secretary of Health and Human Resources. (Nov 2014). & "Supported Decision Making", Joint Commission on Health Care. (Oct 2019).

¹⁵ § 64.2-2003. Appointment of guardian ad litem.

¹⁶ Advance directives § 54.1-2981; Powers of attorney § 64.2-1600

¹⁷ § 64.2-2009 Temporary Guardianship; § 64.2-2009 Limited Guardianship





The Supported Decision-Making Workgroup

The SB 585 Supported Decision-Making Workgroup held its first meeting on June 24, 2020. There were 35 participants from a range of stakeholder groups representing the interests of the ID/DD community, the elderly, and individuals with serious mental illness. It included legal advocates, subject matter experts, provider associations, special interest groups, and others. A full list of workgroup participants can be found in Appendix A. The workgroup heard from Marisa Brown, MSN, RN, a volunteer with the Arc of Northern Virginia who uses SDM with her adult son and has 38 years of experience working with the ID/DD community, as well as Dari Pogach, J.D., of the American Bar Association, who has national expertise on adult guardianship and alternatives to guardianship, including SDM. Marisa Brown discussed her personal use of SDM as well as the benefits it can hold for the ID/DD population including individuals whose parents may be considering guardianship. Dari Pogach discussed the use of SDM in other states including SDM legislation, and differing approaches on whom SDM can benefit.

The Workgroup met for a second time on July 22, 2020. During this meeting, the group split into four subgroups to focus on the following areas:

- 1. Who can best benefit from SDM
- 2. What protections should be in place for individuals under an SDM agreement
- 3. What protections may be needed for supporters and other third parties, such as healthcare providers or banks
- 4. What resources, training, and education may be necessary to make SDM a successful approach

Finally, the Workgroup met on September 3, 2020 to review the key findings and recommendations that were discussed during July's meeting.

Findings and Core Principles

The United Nations' Convention on the Rights of People with Disabilities states a goal that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and that "parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity".¹⁸ Throughout the Workgroup, participants raised related points regarding the core principles that should guide Virginia's next steps around SDM. These principles were raised as important guideposts for considering SDM agreements, and the workgroup agreed that they should be included in this report to help inform future action around SDM.

SDM Core Principles for Virginia:

- 1. That every individual should be presumed capable of making his or her own decisions.
- 2. When an individual requires assistance in making decisions, the least restrictive option that meets the individual's needs should be pursued, and every effort should be made to maximize an individual's autonomy and independence.
- 3. Supporters, guardians, substitute decision-makers, and other agents should always take into consideration an individual's expressed personal preferences to the extent appropriate.
- 4. Making good decisions takes practice and individual growth. Everyone should have the opportunity to learn and grow from making poor decisions, sometimes called "Dignity of Risk". Poor decision-making should not be motivation for restricting an individual's rights through guardianship or substitute decision-making.

Recommendations

In general, the SB 585 Workgroup agreed that SDM should be better understood and put to use in Virginia. Family members and others may often resort to guardianship in part due to a lack of awareness of less restrictive models. Recognizing less restrictive models that preserve an individual's autonomy could help prevent unnecessary guardianship petitions. Additionally, even within substitute decision-making arrangements such as guardianship, SDM can be a valuable tool to help the individual express his or her preferences and improve his or her decision-making skills.

Elevating SDM as a Model

The Workgroup recommended investing in education and training about SDM, and proposed a phased implementation with different constituent groups, beginning with youth and young adults with an ID/DD, then adults with an ID/DD, adults age 60 and over, and finally, individuals with serious mental illness. Focusing on specific communities for SDM use could help adapt distinct models, templates, training materials, and approaches to assist each person with identifying the decision supports that best fit his or her life.

Additionally, the Workgroup recommended the development of standardized training and materials, including possible template SDM agreements, to facilitate the use of SDM in Virginia.

¹⁸ "Article 12 – Equal Recognition Before the Law." Convention on the Rights of People with Disabilities. (2006).

Training materials should be available, and education should be targeted to and for a wide range of individuals and groups:

- Individuals interested in pursuing a SDM arrangement, which could include individuals with an ID/DD, adults over the age of 60, or individuals with a serious mental illness
- Families and friends looking for options for their loved ones
- Pediatricians, primary care providers, and mental health providers
- School counselors, related service providers and special education teachers (with a focus on secondary level staff)
- Guardians ad litem, judges, magistrates, legal advocates, and others in the legal community
- Public and private guardians

Training and education should focus on SDM as one tool that may be useful to avoid guardianship or other restrictive substitute decision-making arrangements, within guardianship and substitute-decision making arrangements to help understand an individual's preferences, or to phase out of guardianship as an individual develops or regains capacity. Opportunities for grants should be considered for organizations to help coordinate, develop, and disseminate training and education.

The Workgroup did raise concerns that individuals under SDM arrangements may, in rare cases, be subject to abuse, undue influence, manipulation, or exploitation. Though the Workgroup did not recommend codifying specific processes or protocols for SDM protections, since doing so might open SDM up to time-consuming or confusing court processes, it did recommend including protocols in statewide training materials to help individuals and fellow supporters prevent, identify, and stop abuse, undue influence, manipulation, and exploitation using actions similar to those used for addressing abuse and exploitation for the general population of individuals with developmental disabilities. It was also noted that preserving an individual's autonomy and allowing him or her to select multiple, trusted supporters may help to prevent the type of exploitation experienced by individuals with a single, court-appointed guardian, although it was also noted that court-appointed guardians are answerable to the courts where supporters are not. Resources to develop comprehensive training materials through consultation with experts in SDM would benefit Virginians.

Recognizing SDM in Virginia

In order to raise awareness of SDM and increase its use, introducing a broad definition of SDM in Virginia's Code and recognizing SDM arrangements may help bring attention to its power as a model that can, in certain cases, prevent the pursuit of substitute decision-making. Some Workgroup participants thought that SDM should not be added explicitly to Virginia's Code as doing so could and would complicate the use of SDM and, in any case, not make significant progress toward elevating the use of SDM in Virginia without the education and training described in the Workgroup's second recommendation. In addition, SDM should be considered as a possible "best practice" for individuals who may periodically need substitute decision-making arrangements to reduce how often a substitute decision maker is needed and to communicate the individual's preferences, which the substitute decision maker must prioritize if known.

Furthermore, including SDM in regulations dealing with "Authorized Representatives" may encourage the appointment of an Authorized Representative to best represent an individual's preferences.¹⁹ In cases in which an attorney-in-fact, healthcare agent, legal guardian, or family member is not available, consideration should be given to whether the individual has an SDM agreement and, if so, who has been appointed to assist the individual with healthcare-related decisions.

While the Workgroup agreed that formal recognition of SDM could be beneficial to elevating its use and increasing individual autonomy, the Workgroup warned against over-formalization of the model, and some participants thought that defining SDM in Virginia's Code constituted over-formalization. The workgroup agreed that detailing specific requirements for SDM agreements, including the specific agreement form, provisions for terminating relationships with supporters, and protections for third parties would decrease the flexibility necessary to reflect each person's unique preferences.

Further Research and Data

Finally, the Workgroup agreed that further research and data is necessary to help provide the resources and supports individuals need. Understanding individuals and family preferences regarding decision-making authority when presented with a continuum of options, may help determine the tools and resources individuals, families, and communities need to put their preferences into action. Furthermore, studying the outcomes of SDM, including possible health outcomes and improvements in decision-making skills, would help identify the best candidates for SDM as well as fine-tune SDM models.

If SDM is meeting its goal of preventing the pursuit of guardianship arrangements when appropriate, there may be no centralized way to collect data on SDM. Therefore, resources must be allocated to study its use within a sample of the population. This study should examine:

- When and how often families pursue SDM over guardianship, when presented with a full continuum of options
- When and how individuals pursue SDM prior to losing capacity due to a serious mental illness or aging
- Any increase in SDM and or decrease in guardianship after investment in training and education
- Perceptions of SDM, health outcomes, and improvement in decision-making skills for individuals who have leveraged an SDM agreement for a specific period of time
- Use and outcomes of SDM by race and ethnicity to understand and better address disparities in access to less restrictive decision-making arrangements

It should be considered how to foster communities of supporters for individuals who lack the natural trusting relationships that are currently a requisite for SDM, particularly should additional training and education lead to an increase in SDM use and positive outcomes.

¹⁹ 12VAC35-115-146. Authorized Representatives.

Conclusion

SDM is an important concept that may help individuals who require decision-making support avoid restrictive substitute decision-making arrangements. The SB 585, Supported Decision-Making Workgroup recommends studying SDM's use in Virginia, without prescribing a particular model or particular requirements for its use, leaving it available for use by any adult for whom this support would be beneficial. Investment in training and education as well as study is critical to fine-tuning SDM and better understanding its potential uses and benefits in Virginia.

Appendix A: Workgroup Participants

Workgroup Chairs:

Heather Norton, Assistant Commissioner for Developmental Services Heidi Dix, Deputy Commissioner for Compliance, Regulatory, and Legislative Affairs

Workgroup Members:

Ben Beaux, The Arc of Virginia Catherine Harrison, Department for Aging and Rehabilitative Services Charlotte Woodward, The Arc of Virginia Colleen Miller, Disability Law Center of Virginia Dana Traynham, Disability Law Center of Virginia Emily Hardy, Virginia Poverty Law Center Ginie Cabaniss, Virginia Network of Private Providers Jennifer Faison, Virginia Association of Community Services Boards Jennifer Fidura, Virginia Network of Private Providers Kathryn Jones, Department of Education Lucy Beadnell, The Arc of Northern Virginia Marcia Dubois, Department for Aging and Rehabilitative Services Marianne Moore, Department of Education Marisa Brown, The Arc of Northern Virginia Michelle (Shelly) Harris, Virginia Bar Association Morgan Theilacker, Arlington CSB Paige McCleary, Department for Aging and Rehabilitative Services Patti Meire, Department for Aging and Rehabilitative Services Rhona Levine, Virginia Academy of Elder Law Attorneys Robert Haley, Virginia Bar Association Samantha Hollins, Department of Education Stephen Weiss, Joint Commission on Health Care Stephen Burns, Virginia Academy of Elder Law Attorneys Teri Morgan, Board for People with Disabilities Tonya Milling, The Arc of Virginia Vasa Clarke, Disability Law Center of Virginia

Other Participants and Advisors:

Delegate Kaye Kory Delegate Mark Levine Alisa Padden, Office of the Executive Secretary Hannah Kowitz, Senator Dunnavant's Office Karen Taylor, Office of the Attorney General Kristi Wright, Office of the Executive Secretary Sarah Stanton, Division of Legislative Services

DBHDS Staff:

Alex Harris, Policy and Legislative Affairs Director John Cimino, Legal and Regulatory Manager, Office of Licensing Lana Hurt, ID/DD Human Rights Advocate Taneika Goldman, Deputy Director, Office of Human Rights