



Supported Decision-Making in Virginia: An Overview for CSBs and Providers



Presented by Sara D. Thompson,
Supported Decision-Making Community Resource Consultant Lead







- Choices vs. Decisions
- Supported vs. Substitute Decision-Making
- Informed Choice
- Brief History of Supported Decision-Making
- Supported Decision-Making in Virginia
- Benefits and Risks
- Virginia's SDMA documents
- Q&A







What's a choice?

What's a decision?







You have to learn how to make a CHOICE before you can learn how to make a DECISION.



Before you can make <u>a decision</u>, you need to know:

- What do you like and do not like?
- What are your strengths/ what are you good at?
- What do you need/want help with?





Decision Making- "the process of making choices by identifying a decision, gathering information, and assessing alternative resolutions" (Umass Dartmouth)



Supported Decision- Making- "decision-making model in which an individual makes decisions with the support of trusted individuals" (American Bar Association)





Supported Decision-Making:

- Individual (Decision Maker) keeps ALL rights
- Individual (Decision Maker) makes ALL final decisions
- Increases the individual's feelings of self-determination
- Decreases the risk of abuse and exploitation
- Can reduce the need for restrictive alternatives (i.e., legal guardianship)

Substitute Decision-Making:

- Individual loses their rights
- Someone else makes decisions FOR the individual
- Can take away an individual's sense of selfdetermination
- Does NOT prevent the risk of abuse or exploitation
- Restrictive







SDM:

<u>Supported Decision-Making -</u> a concept or practice (There are no "Supported Decision-Makers.")

<u>Substitute Decision-Maker -</u> a person appointed to make decisions for someone else (NOT the same as Supported Decision-Making!)





Supported Decision- Making → Self Determination

- Power and Control (autonomy)
- Improve health (mental/physical) and relationships (relatedness)
- Responsibility and Independence (competence)
- Better employment outcomes
- Be able to make bigger/riskier decisions
- Advocate for themselves





Informal -or- Formal

- Individualized, Strengths-Based Approach
- Follows Person Centered Practices
- Americans with Disabilities Act -> Effective Communication
- HCBS → "...must have every opportunity to live with the same rights, freedoms, and degree of self-determination..."

There is an expectation that people with DD have the opportunity to:

- Exercise maximum self-determination
- •Receive supports with making decisions in the least restrictive manner possible
- •Identify who they want to help them make decisions and how









- Learn and understand <u>how the individual best takes</u> in information (understands, learns)
- Learn and understand <u>how the individual</u> <u>communicates</u>
- Be clear about what you know and do not know
- Ensure the individual has the information needed to make an <u>informed decision</u>



What's an informed decision?







Before you can make <u>an informed decision</u>, you need to know:

- 1. What is the decision that needs to be made?
- 2. What are my options?
- 3. What could happen if I choose each option? (pros/cons)
- 4. What are my next steps?





History of Supported Decision-Making

Around the World	In the United States	In Virginia
Deinstitutionalization 992- mid-2000's: Canada, Sweden, & United Kingdom 006/2008: United Nations' Convention of the Rights of Person with Disabilities Promote, protect, and ensure the full and equal njoyment of all human rights and fundamental eedoms by all persons with disabilities, and to romote respect for their inherent dignity."	 2012 legal cases: Jenny Hatch (Virginia) Dameris L. (New York) 2013 - 2014: 'Supported decision-making: An agenda for action' report 2014: The National Resource Center for Supported Decision-Making website 2015 - 2016: The National Resource Center for Supported Decision-Making State Project Partners Ryan King (Washington D.C.) 	 2012/2013: Jenny Hatch's case 2014: Office of the Secretary of Health and Human Resources study; Study conducted 2019: Office of the Secretary of Health and Human Resources study; Request failed The Arc of Northern Virginia Pilot Project 2020: Senate Bill 585/Chapter 855 Supported Decision-Making Workgroup 2021: House Bill 2230/ Chapter 232 2022: Supported Decision-Making Workgroup #2







4 Principles for Supported Decision-Making in Virginia

- 1. Presumed capacity
- 2. Least restrictive option, and maximize an individual's autonomy and independence
- 3. Always take into consideration an individual's expressed personal preferences
- 4. Dignity of Risk

SELF DETERMINATION









<u>Supported Decision-Making Agreement -</u> The formal process of documenting who an individual wants to support them, in what areas of life, and how they want to be supported.

Comprised of:

- Decision Maker (Principal)
- oSupporter(s)
- oFacilitator (optional)





Supported Decision-Making Agreements: Roles & Responsibilities



Decision Maker- the person making the Supported Decision-Making Agreement

Must be: at least 18 years old, have an intellectual or developmental disability, and be able to legally make your own decisions

Supporter(s)- the person/people the Decision Maker asks to support them in their SDMA, Supporters agree to help

Facilitator (optional)- the person the Decision Maker asks to make sure Supporters to what they agree to, can be a Supporter or can be someone else





Decision Maker

- The right to make their own decisions.
- The right to self-determination and to take risks when making decisions about their lives (also known as dignity of risk).
- The right to select who they want as Supporters, what areas of life they receive support in, and how they receive support.
- The right to amend or revoke their Supported Decision-Making Agreement at any time.





Supporters

- Be available to the Decision Maker, when needed, for decisions about the life areas they are assigned to in the agreement.
- Recognize they do not make decisions for the Decision Maker and are not legally responsible for the decisions a Decision Maker makes based on their advice.
- Provide the Decision Maker with honest and fair advice in the life areas they are selected for so that
 the Decision Maker is able to make the most educated and informed decision.
- Accept that Decision Makers have dignity of risk when making life decisions.
- Not offer advice or support if the Decision Maker hasn't asked for it.
- Not provide advice related to topics that could be a conflict of interest, i.e. benefits them as a Supporter, and/or they are not knowledgeable about.
- Provide advice that is honest and offered in a way that agrees with the Decision Maker's values, needs, and preferences.
- When requested by the Decision Maker, help them plan and arrange for supports and services that will help them live safely and successfully in the community without a legal guardian.
- Respect the confidentiality of the Decision Maker.





SDMA Facilitator

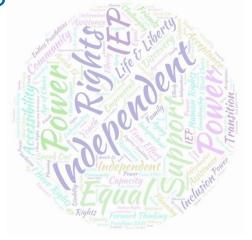
- Coordinate meetings with the Decision Maker and Supporters if and when needed.
- Provide help and advice to the Decision Maker, should they have issues or concerns with any of their Supporters.
- Make reasonable efforts to ensure that the Supporters are acting honestly, in good faith, and in accordance with the choices of the Decision Maker.
- Monitor for suspected abuse, exploitation, manipulation, neglect, or undue influence by Supporters.





Benefits

- People keep their rights & make all final decisions
- Increased independence and self-determination
- Opportunity to develop skills in order to live more independently
- Avoiding long and expensive legal processes
- Reduce options that are more restrictive/limiting
- Can be changed or cancelled at <u>any time</u>.







Risks

- Nothing is free of risk/danger
 - Abuse and exploitation









Protocol for Addressing Abuse and Exploitation: Supporters agree to not use their position to abuse, exploit, manipulate, neglect, or provide undue influence on you. Should you have concerns, discuss these with someone you trust (another Supporter, your Supported Decision-Making Facilitator, your service providers, or another trusted adult) and contact Adult Protective Services, if needed. If abuse, exploitation, or neglect is evident, contact Adult Protective Services and emergency services (911), as appropriate. The Virginia Adult Protective Services hotline is 888-832-3858 or find the number to your local Adult Protective Services at https://www.dss.virginia.gov/localagency/index.cgi.





- They ARE NOT a backdoor to guardianship.
- They DO NOT permit the Supporter to make decisions for the individual.
- They ARE NOT a way for a parent to take away an individual's rights.
- They DO NOT take the place of Advance Medical Directives or POAs.







Virginia Supported
Decision-Making
Agreement
template



- When Do I Want Support?
- What Kind of Support Do I Want?
- Relationship Map/ Selecting Your Supporters

Many other forms to help!







When Do I Want Support?



Can I do this on my own?



Can I do this with help?



Do I need someone to do it for me?



Commonwealth of Virginia: Supported Decision-Making Discovery Tool

When do I want support? Everyone needs support with making some decisions, not just people with disabilities. Some people ask for help from a doctor when they are sick or before taking medicine. Some people ask a mechanic before buying a new car, or ask a friend before moving into a new apartment. When you get help from others with making decisions this is called Supported Decision-Making.

You can use this form to help you fill out the *Commonwealth of Virginia's Supported Decision-Making Agreement*. Place a check (\checkmark) in box next to each sentence to say if you can do this on your own, if you can do it with support, or if you need someone else to do the task for you. You do not have to place a check in each area.

If you check "I can do this with support" think about who you might ask to support you, as well as what kind of support you want or need. You can also use the attached *Relationship Map* and/or *What Kind of Support Do I Want?* tools to help answer these questions.

	I can do this <u>on my</u> <u>own.</u>	I can do this <u>with</u> support.	I need <u>someone else</u> to do this for me.
	Health and Persona	i Care	
Get my health care information.			
Choose when to go to the doctor.			
Make and keep my doctor and dentist appointments.			
Understand and make medical choices in serious situations (for example, surgery, big injuries, mental or behavioral health crisis).			
Understand and make medical choices in an emergency.			





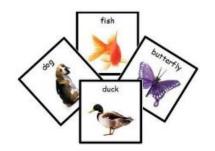
What Kind of Support Do I Want?

What do you like people to help you with?









What is NOT helpful to you?





Commonwealth of Virginia: Supported Decision-Making Discovery Tool

What kind of support do I want? Support (help) can look different for everyone and can be different for each choice or activity.

You can use this form to help you think about the different ways people can help and how you might want your Supporters to help you. Place a check (<) in the box next to each type of help you think you might want or need.

Types of Support
Have help filling out/writing on forms, such as my Supported Decision-Making Agreement.
Have information written and/or spoken in simple words (plain-language).
Have information provided in pictures.
Talk to your Supporters to know what your choices are.
Research to learn more about your choices on your own or with help from your Supporters.
Talk to experts (people who know a lot about your choices) about your options and choices.
Talk to your Supporters to get advice.

This document was adapted from How to Make a Supported Decision-Making Agreement, A Guide for People with Disabilities and their Families, developed by the American Civil Liberties Union (ACLU).

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Commonwealth of Virginia: Supported Decision-Making Discovery Tool

Types of Support
Take extra time to think about your choices.
Get help making a pros and cons list (a list of good and bad sides of each choice).
Have Supporters remind you about your values (what is most important to you) and how these might impact your choices.
Help trying out different choices to see how you feel and which choice you like.
Have help from your Supporters with communicating your choice to others.
Use technology (a phone or computer) to help communicate your choice to others.
Receive reminders about important dates and times.
Have a Supporter come to meetings and appointments with you.
Take classes (on-line or in person) to help learn more about choices.

This document was adapted from How to Make a Supported Decision-Making Agreement, A Gunce not a support with Disabilities and their Families, developed by the American Civil Liberties Union (ACLU).





Relationship Map

People who help you:

- Family
- Friends
- Home or Other Places
- School or Work

How close do you feel to them?



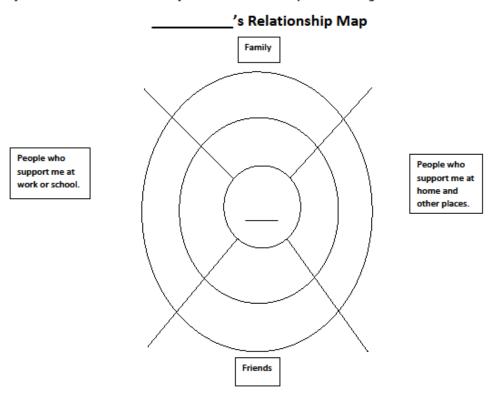


Commonwealth of Virginia: Supported Decision-Making Discovery Tool

Who do I want to support me? Supported Decision-Making Agreements are made up of Supporters and Decision Makers. You are the Decision Maker and the people you choose to help you are the Supporters. You can choose anyone you want to be your Supporter and you can choose to have many supporters. Some Supporters might help you in one area of life and others might help you in several areas. The decision is up to you.

When thinking about who you want as a Supporter, think about people that you trust and talk to them to see if they will agree to be your Supporter.

You can use this form to help you think about the different people who already help you in your life. Your name goes in the center circle. Write the names of the people who help you in the category that best fits them. People who you feel closest to will go in the circle closest to your name. People that you do not feel as close to or that you do not look to for help as often can go in the outer circle.



The Relationship Map is a Person Centered Thinking tool developed by The Learning Community for Person Centered Practiced.

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8 Life Areas:

- Health and Personal Care
 - Friends and Partners
 - Money
- Where I live and Community Living
 - School and Education
 - Working
 - My Rights and Safety
- Meeting and Talking with My Supporters
 - *Other



GUIDANCE

ADVICE

HELP

SUPPORT

ASSISTANCE

Other Parts:

- Other Types of Support
 - Agreements
- Cancellation of Agreement
- SDMA Facilitator (optional)
 - Notary (optional)
 - Changes
 - Cancellations



Commonwealth of Virginia: Supported Decision-Making Agreement

This agreement should be read out loud or otherwise communicated in a way that is accessible and understandable to all parties. The form of communication should be appropriate to the needs and preference of the person with a disability. A Supported Decision-Making Facilitator may be assigned to oversee this agreement, but is not required. Additionally, a notary may sign the agreement, but it is not required.
Sara Thompson, am the creator of this Supported Decision-Making Agreemer which is all about me, and that makes me the "Decision Maker". I made this agreement with my choices and have selected people that I trust to be my "Supporters".
The people I select as my Supporters are the people who have agreed to help me understand and make choices.
My Supporters <u>DO NOT</u> make decisions for me. They give me information, advice, and other support so that I CAN make decisions for myself.
This agreement can be changed at any time. I can change it by crossing out words and writing my initials next to the changes, or I can change it by writing new information onto the form and writing my initials next to what I add. I will keep track of anything I add by filling out and signing the "Changes" page attached to this agreement. I will also write the names of any Supporters that I no longer want to support me on the "Cancellation" page attached to this agreement and sign it.
If I decide that I no longer want to have a Supported Decision-Making Agreement, I can fill out the Cancellation of Supported Decision-Making Agreement section at the bottom of the "Agreements" page attached to this document.
Name of Decision Maker:Sara Thompson
Preferred Method of Contact (e.g. email address, phone number, how to contact you): Texting on cellphone- ***_****
Initial Effective Date of Agreement:08/01/2022
In addition to this Supported Decision-Making Agreement, I have the following forms of support:
Durable Power of Attorney Documents Attached/ Documents NOT Attached
_X Advance Medical Directive X Documents Attached/ Documents NOT Attached
Financial Fiduciary Documents Attached/ Documents NOT Attached
HIPAA Release Form Documents Attached/ Documents NOT Attached
Educational Release Form Documents Attached/ Documents NOT Attached
Other: Documents Attached/ Documents NOT Attached (e.g. DBHDS Authorized Representative, Health Passport, Person Centered 1 Page Health Profile)
Supported Decision-Making Agreement for: Sara Thompson





Other Documents:

- 1. Instructions
- 2. Medical Release of Information
- 3. Educational Release of Information
- 4. SDMA Tracking Tool
- 5. Frequently Asked Questions- Plain Language
- 6. Frequently Asked Questions
- 7. Identifying Possible Supporters
- 8. Asking Someone to be Your Supporter

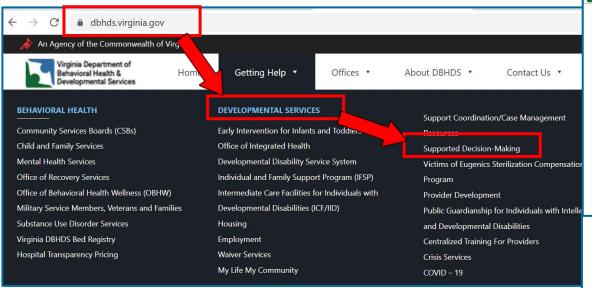






Where do I find more information?





https://dbhds.virginia.gov/supporteddecision-making-supported-decision-making-

agreements/











Is supported decision-making or a supported decision-making agreement right for someone I support?







Supported Decision-Making

- ✓ Can take information in and get it out (understand and communicate)
- ✓ Make decisions about their life on their own or with help from people they trust
- √ 18 years old or older
- ✓ Can legally make decisions for yourself (have legal competence) *Can/should be used even in cases of substitute decision-making

Supported Decision-Making Agreement

- ✓ Can take information in and get it out (understand and communicate)
- ✓ Make decisions about their life on their own or with help from people they trust
- √ 18 years old or older
- ✓ Can legally make decisions for yourself (have legal competence)
- ✓ Has a diagnosis of a developmental disability (including intellectual disabilities)









How is one created?

- With TIME!- Break into sections/ life areas
- Decision- Maker: Conversations and discovery with trusted people
- Support Coordinator, Providers, Family Members, etc.
- Ensure Supporters and Facilitator agree



Contact me!

Sara D. Thompson,

Sara.Thompson@dbhds.virginia.gov

804-869-0591







Do we have to use these forms or the Virginia Supported Decision-Making Agreement template?







Core Elements:

- 1. Who the Decision Maker wants as their Supporter(s)
- 2. When the Decision Maker wants help
- 3. How the Decision Maker wants to receive help
- 4. Signatures and dates that the Decision Maker and all Supporters agreed to the terms of the agreement









Does someone have to have a Supported Decision-Making Agreement?









When should we begin talking about decision-making options?









I received a copy of someone's Supported Decision-Making Agreement. What do I do now?







"Our lives are a sum total of the choices we have made." - Dr. Wayne Dyer













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