



Supported Decision-Making in Virginia: *An Overview for People with DD and their Families*



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
- Resources
- Q&A

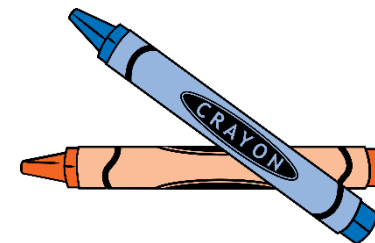




What's a choice?
What's a decision?



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



Before you can make a decision,
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 self-determination
 - Does NOT prevent the risk of abuse or exploitation
 - Restrictive
- 

SDM:

Supported Decision-Making - a concept or practice
(There are no “Supported Decision-Makers.”)

Substitute Decision-Maker - 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

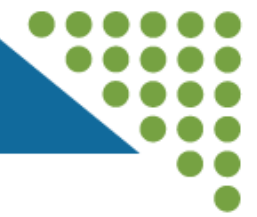




- Learn and understand how the individual best takes in information (understands, learns)
- Learn and understand how the individual communicates
- Be clear about what you know and do not know
- Ensure the individual has the information needed to make an informed decision



What's an informed decision?



Before you can make an informed decision,
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?





Around the World	In the United States	In Virginia
<p>1960's- 1970's:</p> <ul style="list-style-type: none"> • Deinstitutionalization <p>1992- mid-2000's:</p> <ul style="list-style-type: none"> • Canada, Sweden, & United Kingdom <p>2006/2008:</p> <ul style="list-style-type: none"> • United Nations' Convention of the Rights of Person with Disabilities <p>"Promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."</p> <p><u>Countries Must:</u></p> <ol style="list-style-type: none"> 1.Recognize legal capacity for all persons with disabilities in all aspects of life. 2.Eliminate all systems of substituted decision-making. 3.Establish supported decision-making mechanisms of differing kinds and intensities. 4.Put in place safeguards to secure the respect for the rights, will, and preferences of individuals who receive support. 	<p>2012 legal cases:</p> <ul style="list-style-type: none"> • Jenny Hatch (Virginia) • Dameris L. (New York) <p>2013 - 2014:</p> <ul style="list-style-type: none"> • 'Supported decision-making: An agenda for action' report <p>2014:</p> <ul style="list-style-type: none"> • The National Resource Center for Supported Decision-Making website <p>2015 - 2016:</p> <ul style="list-style-type: none"> • The National Resource Center for Supported Decision-Making State Project Partners • Ryan King (Washington D.C.) 	<p>2012/2013:</p> <ul style="list-style-type: none"> •Jenny Hatch's case <p>2014:</p> <ul style="list-style-type: none"> •Office of the Secretary of Health and Human Resources study; Study conducted <p>2019:</p> <ul style="list-style-type: none"> •Office of the Secretary of Health and Human Resources study; Request failed •The Arc of Northern Virginia Pilot Project <p>2020:</p> <ul style="list-style-type: none"> •Senate Bill 585/Chapter 855 •Supported Decision-Making Workgroup <p>2021:</p> <ul style="list-style-type: none"> •House Bill 2230/ Chapter 232 <p>2022:</p> <ul style="list-style-type: none"> • 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





Supported Decision-Making Agreement - 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)
- Supporter(s)
- Facilitator (optional)



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 any time.




Risks

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

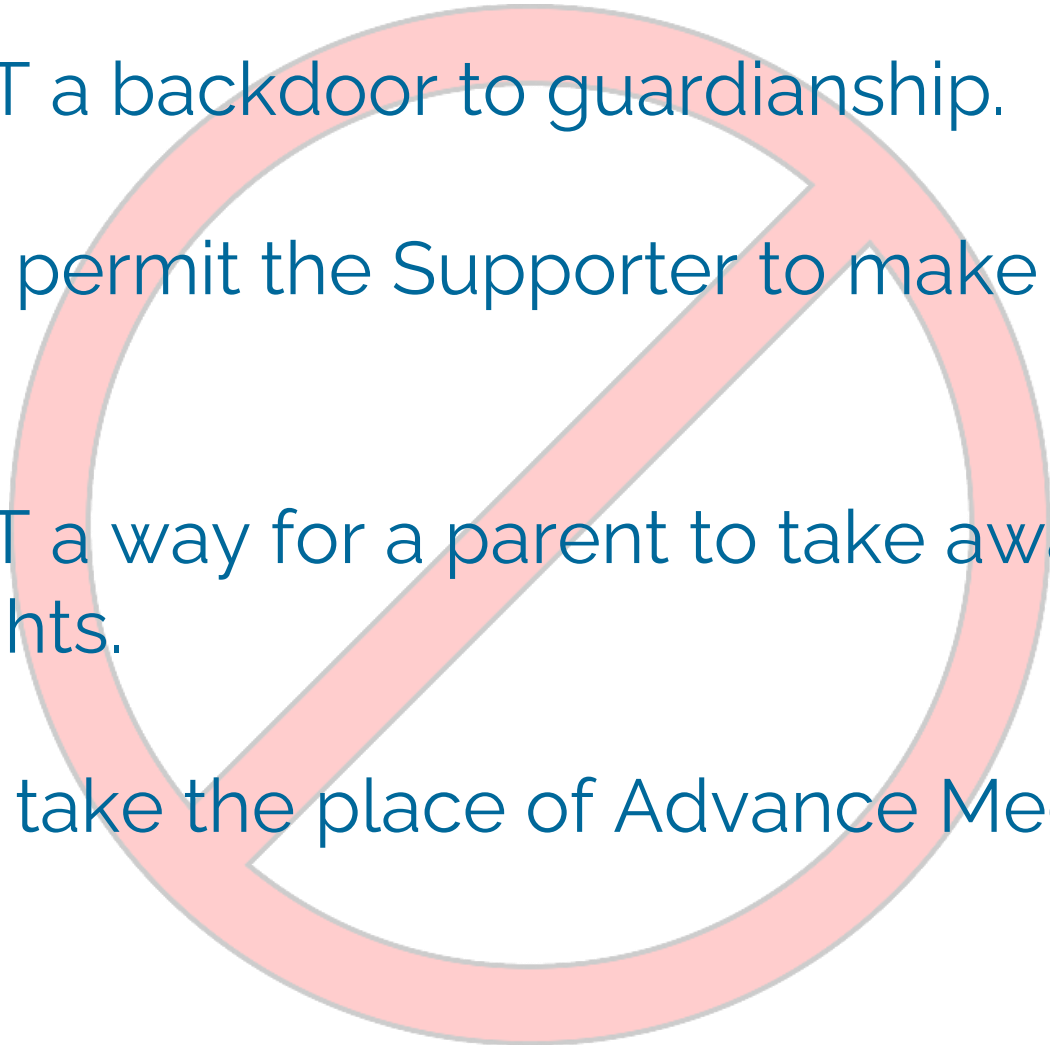


Protocol for Addressing Abuse and Exploitation: Supporters agree to not use their position to abuse, exploit, manipulate, neglect, or provide undue influence on you. Should you have concerns, discuss these with someone you trust (another Supporter, your Supported Decision-Making Facilitator, your service 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

3 Discovery Tools

- 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 (✓) 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.

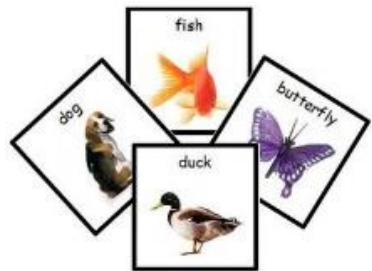
If you check "I can do this with support" think about who you might ask to support you, as well as what kind of support you want or need. You can also use the attached *Relationship Map* and/or *What Kind of Support Do I Want?* tools to help answer these questions.

	I can do this <u>on my own</u> .	I can do this <u>with support</u> .	I need <u>someone else</u> to do this for me.
			
Health and Personal 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.			

This document was adapted from *Supported Decision-Making – When Do I Need Support? A Resource Document*, developed by the American Civil Liberties Union (ACLU) and the Parent Educational Advocacy Training Center (PEATC).

What Kind of Support Do I Want?

What do you like people to help you
with?



What does this help look like?





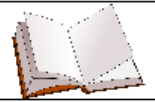


What is NOT helpful to you?



Commonwealth of Virginia:
Supported Decision-Making Discovery Tool


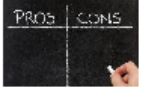







What kind of support do I want? Support (help) can look different for everyone and can be different for each choice or activity.

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).

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 Guide for People 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?

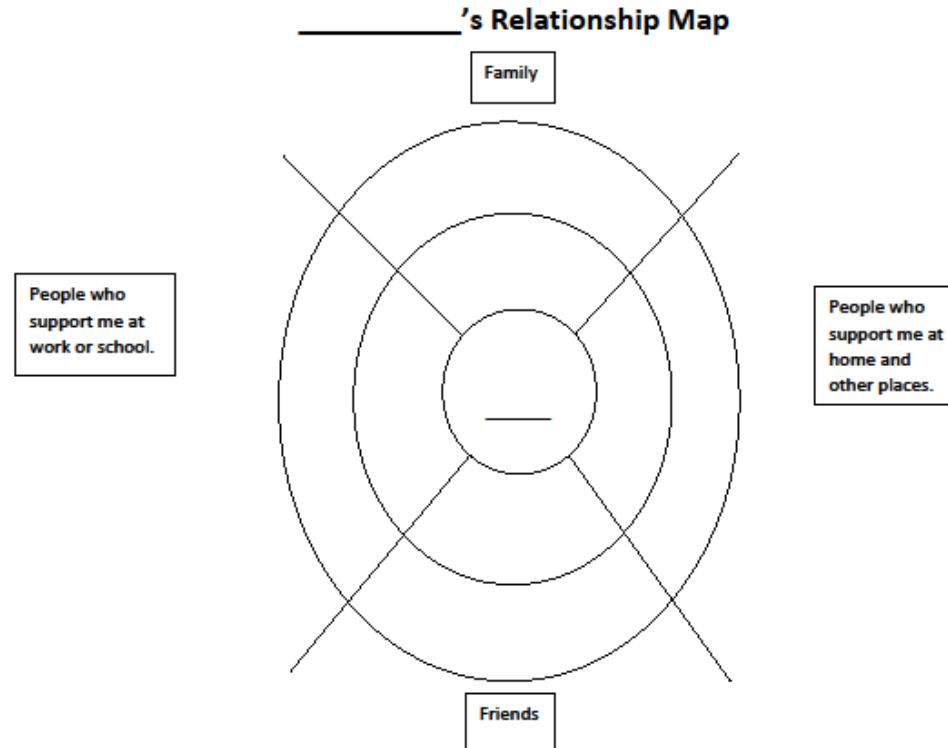


Commonwealth of Virginia:
Supported Decision-Making Discovery Tool

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.

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

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 preferences 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.

I, Sara Thompson, am the creator of this Supported Decision-Making Agreement 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* **DO NOT** 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:

<input type="checkbox"/> Durable Power of Attorney	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input checked="" type="checkbox"/> Advance Medical Directive	<input checked="" type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input type="checkbox"/> Financial Fiduciary	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input type="checkbox"/> HIPAA Release Form	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input type="checkbox"/> Educational Release Form	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input type="checkbox"/> Other: _____	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> 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



The screenshot shows the DBHDS website home page. A red box highlights the URL `dbhds.virginia.gov` in the browser's address bar. A red arrow points from this box to the 'DEVELOPMENTAL SERVICES' menu item, which is also highlighted with a red box. Another red arrow points from the 'DEVELOPMENTAL SERVICES' menu to the 'Supported Decision-Making' link, which is highlighted with a red box.

<https://dbhds.virginia.gov/supported-decision-making-supported-decision-making-agreements/>



The screenshot shows the 'Supported Decision-Making and Supported Decision-Making Agreements' page. The page title is 'Supported Decision-Making and Supported Decision-Making Agreements'. The content includes a paragraph explaining that Virginia now formally recognizes Supported Decision-Making Agreements as an alternative to more restrictive options. It also features a photo of several hands holding each other in a circle. Below the photo, there is contact information for Sara Thompson and a link to the 'Virginia's Supported Decision-Making Agreement template and Supplemental Documents/ Acuerdo para la toma de decisiones con apoyo del Estado de Virginia - Plantilla'. There are buttons for 'English' and 'Español'. Further down, there is a section titled 'Making My Own Decisions- It's My Right!' and a section for 'Training Videos and Documents' with links to various training materials. At the bottom, there is a list of external resources.

Is supported decision-making
or a supported decision-
making agreement right for
me?





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 I 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





Do I have to have a Supported Decision-Making Agreement?





When should we begin talking about decision-making options?



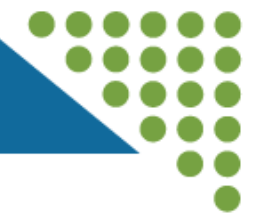


Children learn how to make good decisions by making decisions, not by following directions.

Alfie Kohn

 quote fancy







Sara D. Thompson,

Supported Decision-Making Community Resource Consultant Lead

Phone: 804-869-0591

Email: Sara.Thompson@dbhds.virginia.gov



HCBS Regulations: An Overview for Individuals with DD and Their Families

Participants will learn what the HCBS Final Rule is and how it applies to individuals receiving DD waiver services. They will learn how HCBS rules and regulations can help individuals receiving DD waiver services live a similar quality of life as individuals who do not receive waiver services by making sure that they understand their right to choose everything about their services, their providers and the things they do every day. The session will include a discussion about person-centered plans, HCBS and guardianship, the individual HCBS modification process, common areas for remediation, and provider requirements. The training will be conducted virtually through Microsoft Teams. Click the date below to register.

Time:

6:00pm- 7:30pm

Dates:[March 7th, Thursday](#)[August 5th, Monday](#) 



DD Waiver Waitlist ONLY:	Open to everyone:
<ul style="list-style-type: none"> • IFSP-Funding Program • Peer mentoring program* <p><i>* There is now some availability for people on the DD Waitlist to receive the Peer Mentoring service! Otherwise, people must be receiving Waiver services.</i></p>	<ul style="list-style-type: none"> • IFSP State and Regional Councils • IFSP Coordinated Council events • Family mentoring program • My Life, My Community website • My Life, My Community toll-free phone number • IFSP Facebook pages

- Learn about peer mentoring: <https://tinyurl.com/mlmc-peermentoring>
- Learn about family mentoring: <https://tinyurl.com/mlmc-family>



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

The Arc of Northern Virginia- <https://thearcofnova.org/programs-services/sdm-resource-library/>

disAbility Law Center of Virginia- <https://www.dlcva.org/supported-decision-making>

DBHDS Supported Decision- Making- <https://dbhds.virginia.gov/supported-decision-making/supported-decision-making-agreements/>

My Life My Community- <https://mylifemycommunityvirginia.org>

PEATC- <https://peatc.org/services/transition-to-adulthood/>

Virginia WINGS booklet-
https://www.vacourts.gov/courts/circuit/resources/guardian_options_pamphlet.pdf

Knowledge
is
power!



CHAT- Learn how to better communicate about your health- concerns with your doctors and people who help you.

<https://cdl.partnership.vcu.edu/health-advocacy-training-chat/>

LEAP- Learn all about what makes a health (good) relationship and what to do if you have a bad relationship.

<https://leap.partnership.vcu.edu/>

PEATC- Many classes about topics, such as my health, relationships, my IEP, becoming an adult, and more.

<https://peatc.org/trainings-workshops/workshops/>

Person Centered Thinking- Two-day training to learn about person-centered tools that help people learn how people communicate, problem solve, and identify what's important to/for.

https://www.personcenteredpractices.org/pct_schedule_reg.html

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