

Supported Decision-Making & Supported Decision-Making Agreements: *An Overview for Parents, Caregivers, & Students*



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

- What is Supported Decision-Making?
- What are Supported Decision-Making Agreements?
- Benefits and Risks
- Virginia's SDMA documents
- Resources



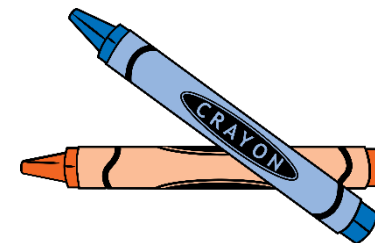


What's a choice?

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?



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?



Have you ever made a decision that didn't turn out well?



What are your rights?

- Vote
- Drive
- Work
- Relationships
- Where you live
- Owning a gun/firearm
- What you do during the day



Virginia's Continuum of Decision-Making Supports

Supported Decision-Making Agreements

- § 37.2-314.3- formal document written by an adult capable of making an informed decision with the support of others, that states when they want to receive support with decisions, who they want to support them, and how they want to receive support

Advance Directives

- § 54.1-2982- when 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

Powers of Attorney

- § 64.2-1600- granting someone to act in your place

Authorized Representatives

- 12VAC35-115-146- individuals designated to act as substitute decision makers for persons receiving care with DBHDS-licensed providers, who are found to lack capacity, and who do not already have a designated substitute decision maker

Temporary Guardianship and Limited Guardianship

- § 64.2-209- when a person is appointed by the court to be responsible for an incapacitated person's personal affairs for a specific period of time or for a limited purpose

Full Guardianship

- § 64.2-200- when a person is appointed by the court to be responsible for the personal affairs of an incapacitated person

Least Restrictive

Most Restrictive

"We're proud of him... we are less stressed.... It's good to see him go on with his life and we go on with our life... We know he is okay."

Video 1

"We have to find that balance... put the right people around him... made a point through the years to surround ourselves with people that are there for his good... You will have some failures... Going through that experience helps both you and them... walking this journey together so you're both growing."

Video 2



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)



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



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



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




Risks

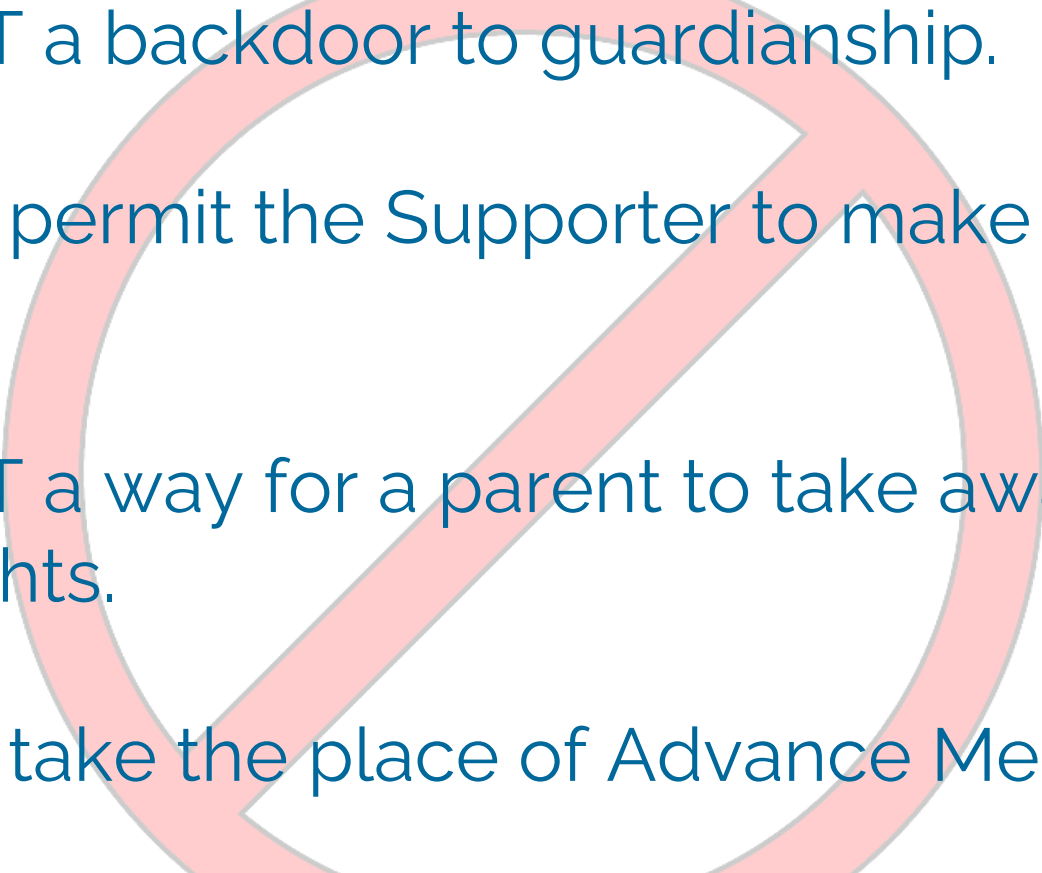
- Nothing is free of risk/danger
 - Abuse and exploitation



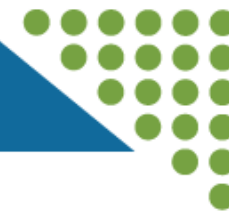
Protocol for Addressing Abuse and Exploitation: Supporters agree to not use their position to abuse, exploit, manipulate, neglect, or provide undue influence on you. Should you have concerns, discuss these with someone you trust (another Supporter, your Supported Decision-Making Facilitator, your service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





- 
- A large, light red prohibition sign (a circle with a diagonal slash) is centered over the list of bullet points.
- 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.

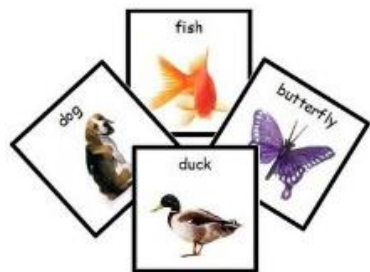
	I can do this <u>on my own</u> . 	I can do this <u>with support</u> . 	I need <u>someone else</u> to do this for me. 
Health and Personal Care			
Get my health care information.			
Choose when to go to the doctor.			
Make and keep my doctor and dentist appointments.			
Understand and make medical choices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

What Kind of Support Do I Want?

What do you like people to help you
with?



What does this help look like?







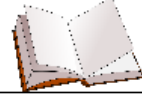


What is NOT helpful to you?



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?

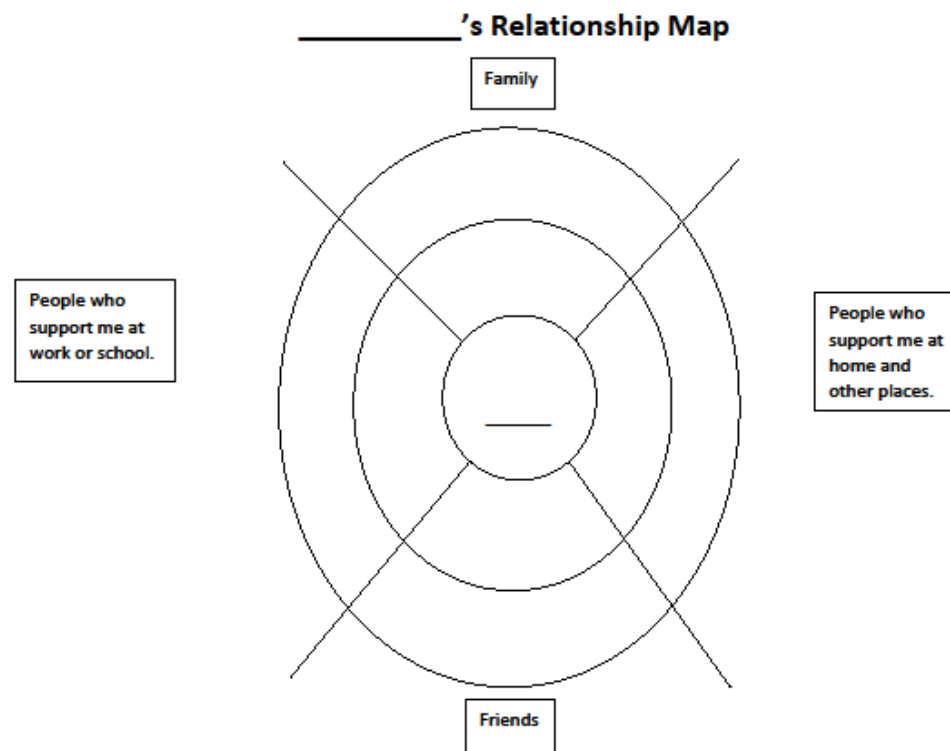


Commonwealth of Virginia:
Supported Decision-Making Discovery Tool

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:

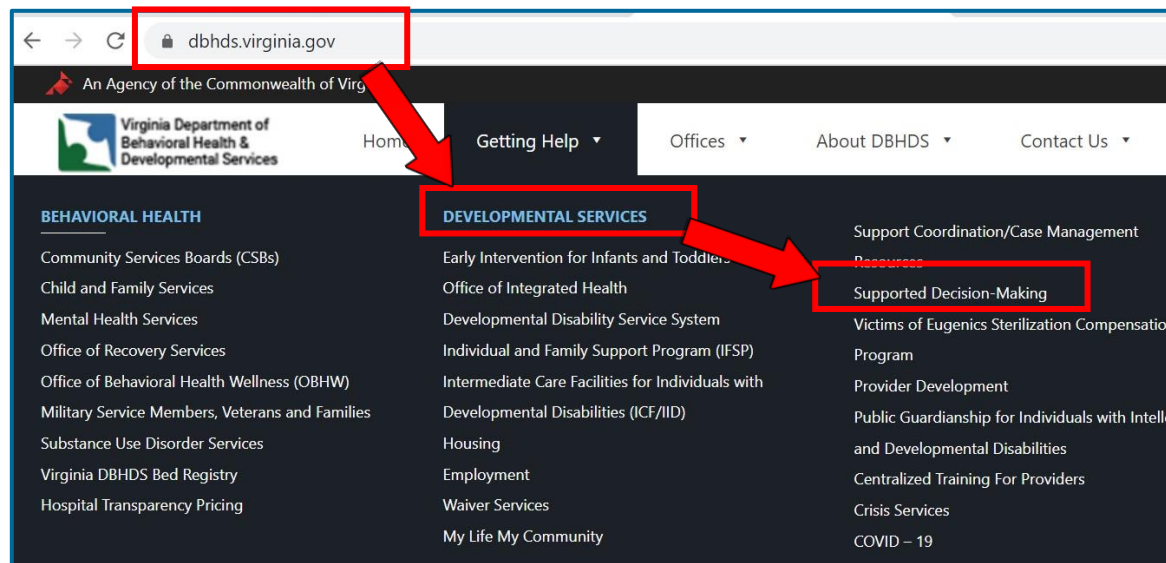
<input type="checkbox"/> Durable Power of Attorney	<input type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT Attached
<input checked="" type="checkbox"/> Advance Medical Directive	<input checked="" type="checkbox"/> Documents Attached/ <input type="checkbox"/> Documents NOT 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

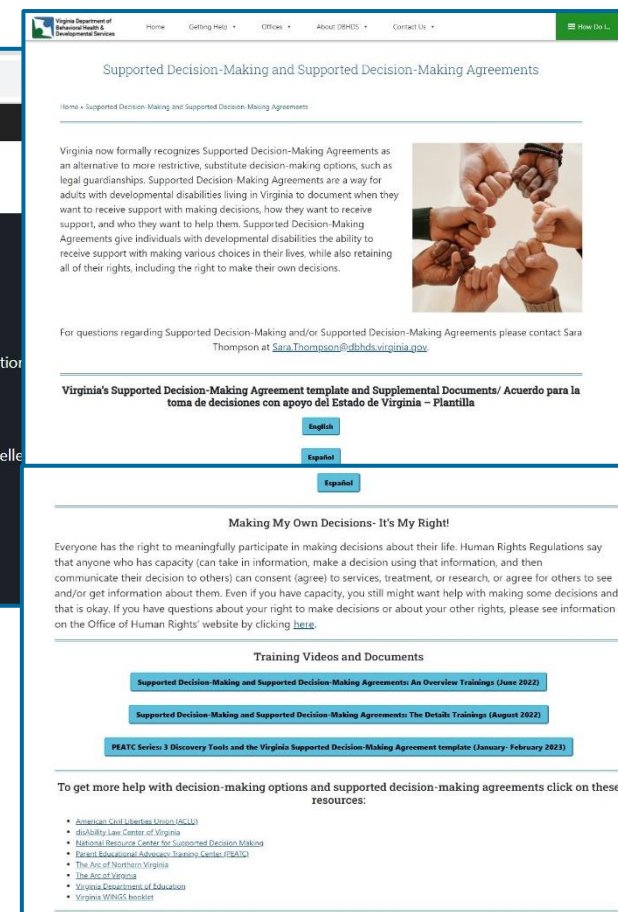
Other Documents:

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





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



How is one created?

- 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





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)





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

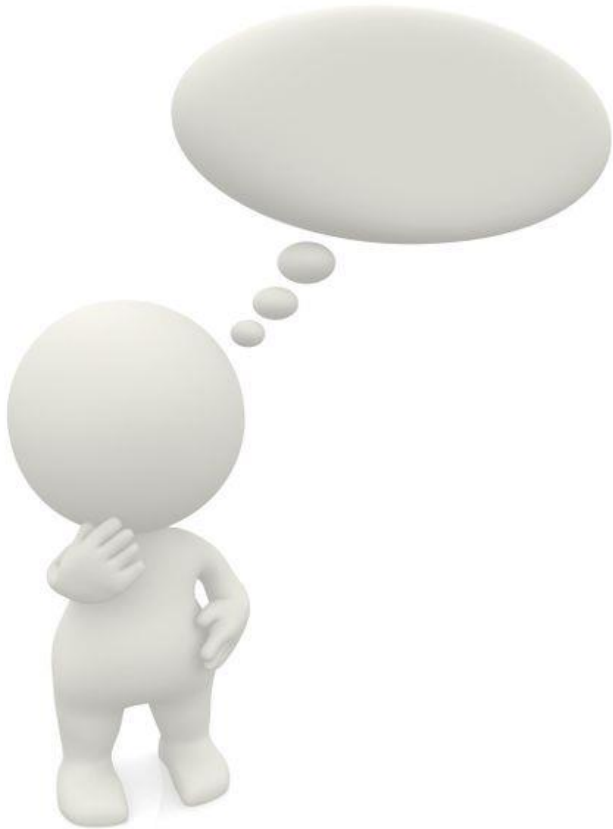
Core Elements:

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



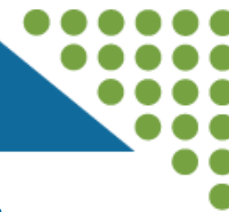
Decision-Making Option	Compatible With	Not Compatible With
Supported Decision-Making Agreement	Power of Attorney, Advance Medical Directive, DBHDS Authorized Representative, Representative Payee/ Fiduciary	Legal Guardian*, Conservator*
Power of Attorney	Supported Decision-Making Agreement, Advance Medical Directive, DBHDS Authorized Representative, Representative Payee/ Fiduciary	Legal Guardian, Conservator
Advance Medical Directive	Supported Decision-Making Agreement, DBHDS Authorized Representative, Representative Payee/ Fiduciary, Power of Attorney*, Legal Guardian**, Conservator**	None (if created when individual still had legal competency or capacity)

Decision-Making Option	Compatible With	Not Compatible With
DBHDS Authorized Representative	Supported Decision-Making Agreement, Advance Medical Directive, Power of Attorney, Representative Payee/ Fiduciary, Conservator	Limited Legal Guardian, Full Legal Guardian
Representative Payee/ Fiduciary	Supported Decision-Making Agreement, Advance Medical Directive, Power of Attorney, DBHDS Authorized Representative, Limited Legal Guardian, Full Legal Guardian	Conservator
Conservator	Limited Legal Guardian, Full Legal Guardian, Power of Attorney, DBHDS Authorized Representative, Advance Medical Directive*	Supported Decision-Making Agreement, Representative Payee/ Fiduciary

Decision-Making Option	Compatible With	Not Compatible With
Limited Legal Guardian	Conservator, Representative Payee/ Fiduciary, Advance Medical Directive*, DBHDS Authorized Representative**	Supported Decision-Making Agreement, Power of Attorney
Full Legal Guardian	Conservator, Representative Payee/ Fiduciary, Advance Medical Directive*, DBHDS Authorized Representative**	Supported Decision-Making Agreement, Power of Attorney

Find a printable version of the Decision-Making Options Compatibility Chart [here](#).





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/>

Knowledge
is
power!



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



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/>

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!



"I'm Determined | Empowering Self-Determined Behavior." *Imdetermined.org*, 2019, www.imdetermined.org/.

"Law Reform on Legal Capacity & Supported Decision-Making: Initiatives from Around the World", Prepared for the Bulgarian Center for Not-for-Profit Law, By: Samantha Backman, student, McGill University Faculty of Law. <https://sdmny.hunter.cuny.edu/download/samantha-backman-initiatives-from-around-the-world-2019/>

SDM Timeline. http://timemapper.okfnlabs.org/sdm_timeline/sdm-international#0

"Supported Decision Making." *Www.americanbar.org*, www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/supported-decision-making/#:~:text=Supported%20decision%2Dmaking%20describes%20the. Accessed 2 May 2023.

University of Massachusetts Dartmouth. "Decision-Making Process." *Umassd.edu*, 2021, www.umassd.edu/fycm/decision-making/process/.

