

Supported Decision Making: How Can I Be A Supporter?



Community of Practice Supporting Families Meeting
Quality Trust for Individuals with Disabilities
Rhonda White, Family and Community Engagement Liaison
March 8, 2019



- ▶ Independent advocacy and monitoring
- ▶ Children and adults with disabilities
- ▶ Dignity, respect, and autonomy
- ▶ Rights protection and decision-making supports
- ▶ Partnering with families
- ▶ Jenny Hatch Justice Project (2013)
 - www.JennyHatchJusticeProject.org
- ▶ National Resource Center for Supported Decision-Making (2019)
 - www.SupportedDecisionMaking.org

Today's Topics

1. Overview of Supported Decision Making
2. What is a Supporter?
3. Supported Decision Making Agreements
4. Areas of Support

Supported Decision-Making

- ▶ **Supports and services** that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts:
 - ▶ to **help understand** the issues and choices
 - ▶ **ask questions**
 - ▶ **receive explanations** in language he or she understands, and
 - ▶ **communicate** his or her own decisions to others.

(See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

Or, as Defined in DC Law 22-93

- ▶ “Supported decision-making” means “a process of **supporting and accommodating** an adult with a disability in order to:
 - **Assist** the adult with a disability **in understanding** the options, responsibilities, and consequences of life decisions; and
 - **Enable** the **adult with a disability to make life decisions**, without impeding the self-determination of the adult with a disability or making decisions for the adult with a disability”

D.C. Continuum of Decision-Making Supports

Supported Decision-Making

- ▶ **Advance Directive &/or Power of Attorney**
- ▶ **Educational Representative**, appointed by OSSE
- ▶ **Substitute Health Care Decision-Maker** under DC Code § 21-2210
- ▶ **Representative payee**, appointed by SSA
- ▶ **Court-appointed Guardian or Conservator**
 - ▶ Time-limited Emergency or Health Care Guardian
 - ▶ Permanent Limited Guardian
 - ▶ Conservator
 - ▶ Permanent General Guardian

These are examples of less-restrictive alternatives to guardianship.

Call QT to learn about more options!

When Should You Contact Quality Trust's JHJP?

If a person with a disability is a DC resident who:

- ▶ Has **questions about decision-making rights**?
- ▶ Is **unhappy with a guardian** and wants help?
- ▶ Wants help with **less-restrictive forms of decision-making support**?
 - Supported Decision-Making
 - Powers of Attorney
 - Advance Directives

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“Human Decision-Making”

Everyone needs supports to make decisions.

A person with disabilities may need more and/or different kinds of supports.

Rethink “Human Decision-Making”

- ▶ **Many decisions** are made every day
 - Some are big, and some are small.
- ▶ Typical decision-making is **flawed**
- ▶ **No standard way to measure “goodness”**
- ▶ **Culture and personal values** are important
 - Most life decisions are **personal**
- ▶ **History, experience, and relationships** often reflect personal preference and identity
- ▶ **Brain and decision making science** are deepening our understanding of ways to help

Supported Decision-Making: HOW?

- ▶ There is **no “one size fits all” method** of Supported Decision-Making
 - SDM **looks different** for different people and families
- ▶ **It is a paradigm**, not a process or program
 - It means **working with the person** to identify where help is needed and finding a way to provide any help that’s needed, so the person can **make his or her own decisions**.
 - The key question is **“what will it take?”**

Supported Decision Making: HOW?

Learning to make good choices is a SKILL.

People can learn to make a better, safer, and more informed choices with...PRACTICE AND SUPPORT

Who is in Charge?

Decider (Decision Maker) - A person who makes the final decision through supported decision making

Supporter - Trusted family friends, staff chosen by the person helps a person, decider, make the decision

Being a supporter is a choice.

The opportunity to be supporter is a choice of trust
and respect.

If you do not have time or don't want to be
supporter...answer respectively No.

Being a supporter is a choice.

If you choose to be a supporter....

- ▶ Need to get know the person and discuss and learn what kind of support want
- ▶ Ask if you are the only supporter and if you can meet with them

What does a supporter do?

Helps a person

A way to get help in making their own choices

Reminder of dates, appointments, and schedules

Organizing and planning meetings/appointments

Supports a person

Providing accessible information

Researching information

Explaining and brainstorming options

Attend classes

What does a supporter do?

Advises a person

Advice-list pro and cons

Advising the person about their choice

Reminding person about her values and preferences

SDM Tools

▶ **Effective Communication**

- ASAN with the UCF Office of Developmental Primary Care, “Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations
- <http://odpc.ucsf.edu/communications-paper>

▶ **Informal** or **Formal** Supports

▶ **Peer Support**

▶ **Practical Experiences**

▶ **Role Play** and **Practice**

▶ **Life Coaching**

▶ **Mediation**



Communication is KEY!

- ▶ Make sure the person has plenty of time to think and talk about wants, needs, and choices
- ▶ Help the person communicate their choice, support in the person's choice to be understood, recognized, and respected.
- ▶ Listen and suggest ways to make the wishes happen

When Does a Decider Want Support?

Consider the levels of support:

I can do it ***alone***

Discuss make their own decision/does a task independently

I can do this ***with support***

Can make decision or do the task with support Find out what the supports needed

I need ***someone else to do*** this for me.

Person cannot make decisions or complete the task even with supports

Supported Decision-Making Ryan's Story



“Don’t judge me before you know me”

– Ryan

For more on Ryan’s story, visit
<http://www.supporteddecisionmaking.org/>

Supported Decision-Making Ryan's Story



“Ryan is a whole person. We want him to be whole. **The decision process is part of being whole . . .** If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him.**”

– Ryan's father

For more on Ryan's story, visit
<http://www.supporteddecisionmaking.org/>

More SDM Tools

▶ Written Documents

- Release of Information forms – “HIPAA” or “FERPA”
- Other Written Plans





Supported Decision-Making Agreements

▶ Supported Decision-Making Guides

- <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

▶ Law, Regulations, and Policy

- Americans with Disabilities Act, 42 U.S. Code § § 12101 et seq.
- 
- [D.C. Disability Services Reform Amendment Act](#), D.C. Law 22-93, D.C. Code § § 7-2131 to 7-2134
- 
- [D.C. Special Education Students Rights Act](#), D.C. Act 20-486, § 104(b)(1) & (2)
 - D.C. Mun. Regs. Title 5-E, § § 399.1, 3034.1-3034.3
 - D.C. Public Schools Transfer of Rights Guidelines (Aug. 2013), available at <https://transitioncentral.files.wordpress.com/2011/12/transfer-of-rights-guidelines.pdf>

What is a “Supported Decision-Making Agreement”?

- ▶ A way of **officially putting an SDM relationship in writing.**
- ▶ While people can use SDM informally instead, SDM Agreements **add clarity** to the relationship and **can be enforced under D.C. law.**
- ▶ If SDM relationships are put in writing, they **must follow certain requirements** to be enforceable in D.C.

2 Ways to Create a Supported Decision-Making Agreement in DC

1. With a **OSSE or DCPS Supported Decision-Making Form**, for adults students in special education.
 - Available at <https://osse.dc.gov/service/education-decision-making> and <https://dcps.dc.gov/node/1138951>
2. With a **Statutory Supported Decision-Making Agreement (“SSDMA”)**, which can be used to support a person with many kinds of life decisions

Option 1: OSSE & DCPS SDM Forms

- ▶ **Special Education Student Rights Act of 2014**
 - ▶ “[S]tudent[s] who ha[ve] reached 18 years of age may receive support from another competent and willing adult to aid them in their decision-making”
 - ▶ See D.C. Act 20-486, Sec. 104(b)(1) & (2) (March 2015)
- ▶ **Office of the State Superintendent of Education Regulations (July 2016)**
 - ▶ Includes a definition of Supported Decision-Making and a section to implement it.
 - ▶ See D.C. Mun. Regs. Title 5-E, Secs. 3001.1, 3034.1-3034.3
 - ▶ Available at <https://osse.dc.gov/service/education-decision-making>

More on OSSE & DCPS SDM Forms

- ▶ **D.C. Public Schools, *Transfer of Rights Guidelines* (8/2013)**
 - ▶ Recognizes supported decision-making as an alternative to guardianship for adult students with disabilities in D.C.
 - ▶ Available at: <https://transitioncentral.files.wordpress.com/2011/12/transfer-of-rights-guidelines.pdf>
- ▶ **DCPS Supported Decision-Making Form**
 - ▶ Available at http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form.pdf
- ▶ **OSSE Supported Decision-Making Model Form**
 - ▶ Available at <https://osse.dc.gov/service/education-decision-making>
- ▶ **DSRAA Background Requirements for Formal Supporters Do Not Apply**

Supported Decision Making Form

Adult Student: _____

Address: _____
Cell Phone Home Phone
Street Washington, DC Zip Code

I understand that I may create a network of individuals to help me inform my educational decisions related to my Individualized Education Program (IEP) once I reach the age of majority. I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to the documents listed below.

NAME	RELATIONSHIP	HOME ADDRESS	EMAIL ADDRESS	PHONE NUMBER
1.				
2.				

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENT	ACCESS
IEP meeting invitations, and agendas	
Requests for assessments	
Requests for changes in placement	
Requests for changes in services	
Exit requests	
Progress reports	
Report cards	
Attendance information	
Assessment results	
Other	

It is my understanding that I make the final decisions about my educational future after communicating with members in my network, and can remove a member from my network, or their access to my educational documents at any time.

 Adult Student Signature Date

 Network Member Signature Date

 Network Member Signature Date

► **Q: What does this DCPS SDM Form look like?**

► **A: A modified FERPA Form!**



DISTRICT OF COLUMBIA
OFFICE OF THE STATE SUPERINTENDENT OF

EDUCATION

Supported Decision-Making Model Form

This is a model form intended to provide assistance to local education agencies (LEAs) and adult students to document supported decision-making decisions described in Title 5-E, Section 3034 of the District of Columbia Municipal Regulations (DCMR). Supported decision-making is supports, services, and accommodations that help a student with disability under the Individuals with Disabilities Education Act (IDEA), who has reached age 18 and to whom all IDEA rights have transferred, make his or her own decisions, by using adult friends, family members, professionals, and other people he or she trusts to help understand the issues and choices, ask questions, receive explanations in language he or she understands, and communicate his or her own decisions to others. LEAs are encouraged to use this form or create an alternative process for meeting the documentation requirements in 5-E DCMR § 3034.3.

Adult Student Name: _____
(Last) (First) (Middle)

Date of Birth: ____/____/____ Unique Student Identifier (USI): _____
MM DD YYYY

Address: _____

City: _____ State: _____ Zip: _____

Telephone Number(s): _____

Email address: _____

I understand that I may create a network of individuals to help me make educational decisions related to my Individualized Education Program (IEP) once I reach the age of eighteen (18). I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to my educational records if I grant them access.

Name:	Relationship to me:
Address:	Phone number(s):
	Email address, if applicable:

Name:	Relationship to me:
Address:	Phone number(s):
	Email address, if applicable:

If there are additional people you would like in your network, please list all of their information on a separate piece of paper.

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENTS	✓	DOCUMENTS	✓
IEP meeting invitations and agendas		Progress reports	
Requests for assessments		Report cards	
Requests for changes in placement		Attendance information	
Requests for changes in services		Assessment results	
Exit requests		Other	

I understand that I make the final decisions about my educational future and I can remove a member from my network or revoke their access to my educational documents at any time.

Adult Student Signature _____
(Date)

I understand that the student makes all final decisions about his or her educational future and the student may remove me as a member of his or her network or revoke my access to his or her educational documents at any time.

Network Member Signature _____
(Date)

Network Member Signature _____
(Date)

Option 2: Statutory SDM Agreement

- ▶ **Disability Services Reform Amendment Act of 2018**
(Official Law Date: May 5, 2018):
 - ▶ Formally **recognizes Supported Decision-Making** for people with disabilities
 - ▶ Creates a **Statutory SDM Agreement (“SSDMA”) Form**
- ▶ Quality Trust and DDS developed a **“Frequently Asked Questions and Instructions”** to explain SDM Agreements and how to use the SSDMA Form.

SUPPORTED DECISION-MAKING AGREEMENT

Pursuant to D.C. Official Code §§ 7-2131 to 7-2134

NOTE: According to D.C. Official Code § 7-2133, a person or a District agency who receives a supported decision-making agreement shall rely on the agreement, unless the person or District agency has substantial cause to believe that the supported person is an adult in need of protective services. Neither a person nor a District agency shall be subject to criminal or civil liability, nor shall a person be considered to have engaged in professional misconduct, for an act or omission done in good faith and in reasonable reliance on a supported decision-making agreement.

PART 1: Appointment of Supporter

I, _____ (printed name of supported person), make this agreement of my own free will.

I agree to designate the following person as my supporter:

Name:

Address:

Phone Number: (____) _____ Email: _____

Form available at:
<http://www.supporteddecisionmaking.org/sites/default/files/DC-SDMA-Instruction-Form.pdf>



Who Can Use the SSDMA Form?

- ▶ **General Rule:** Adults (≥ 18 years old) who have a disability
- ▶ **Exception:** Adults with a legal guardian
 - ▶ Cannot use the SSDMA form for the decisions that the court has said they cannot make themselves.
- ▶ **Voluntary:** A person cannot be required to or pressured by other people to sign an SSDMA form.

Who Should Be a Formal Supporter under an SSDMA?

- ▶ A formal supporter should be someone who:
 - The **person trusts**
 - **Wants the person to make their own decisions**
 - Has **not taken advantage** of the person in the past and is not likely to do so in the future
- ▶ A formal supporter **may also serve** as a **power of attorney** or authorized **health care decision-maker**.

Who Cannot Be a Formal Supporter under a SSDMA?

- ▶ Even if they are your relative, a formal supporter **CANNOT**:
 1. have been **found by a government agency** to have **abused, neglected, or exploited** the supported person or **inflicted harm** upon a child, older adult, or person with a disability; and
 2. have, **within the last 7 years, been convicted of certain crimes**, including sexual offenses of aggravated assault against a child, older adult, or person with a disability; fraud, theft of \$1,000 or more; forgery; or extortion

UNLESS the SDMA is for **educational decisions only**.

- ▶ These background requirements are **not applicable** to supporters listed in **OSSE and DCPS SDM Forms**

How is the SSDMA Form Signed & Used?

▶ Sign the SSDMA Form

- ▶ Both the **person** and the **formal supporter** sign
- ▶ In front of **two witnesses** (who also sign) **or** a **notary public** (who also signs and uses a notary seal)
- ▶ People can have more than one supporter
 - ▶ **One SSDMA for each supporter**
- ▶ Keep the **original** SSDMA in a **safe place** and give a copy to the formal supporter
- ▶ **Share copies** of the SSDMA with other people and organizations that need to know about it.

How is a SSDMA Changed or Canceled?

- ▶ The person or the formal supporter **may cancel** the SSDMA **at any time**.
 - ▶ It is a good idea to put the cancellation **in writing**
 - ▶ **Share the cancellation** with anybody who knows about the SSDMA or has a copy of the SSDMA
- ▶ A person **can change** an SSDMA **by canceling** it and **making a new one**.
- ▶ A person can sign **new release-of-information forms**.

What if Problems Come Up?

- ▶ **General Rule:**

- ▶ The law says other people and District agencies who get an SSDMA must usually respect it.

- ▶ **Exceptions:**

- ▶ If people have a **good reason to believe the person is being abused, neglected, or exploited**, they may not honor the SSDMA and may be required to report to the police or Adult Protective Services

Supported Decision-Making: Opportunities Abound!

- ▶ **Person Centered Planning** in the Medicaid World
- ▶ **Informed Consent** in Medical Care
- ▶ **Student Led IEP** in Special Education
- ▶ **Informed Choice** in Vocational Rehabilitation
- ▶ **Within the Guardian/Person Relationship**

For Archived Webinars on the above, visit:

<http://www.supporteddecisionmaking.org/education>

Supported Decision-Making with Finances

- ▶ **Sign an SDM form**
- ▶ **Researching** financial assistance programs
- ▶ **Setting up** direct deposit and payment
- ▶ **Education** on writing and depositing a check
- ▶ **Researching and setting up** an ABLÉ account or Trust
- ▶ **Budgeting help**



Supported Decision-Making in Education

- Sign one of the available **SDM forms**
- The **student** can be **supported to get ready** for meetings ahead of time.
- **Support IEP goals and objectives** related to self-determination and decision-making.
- Work to make the IEP team meetings more **student-friendly**
- Slow the conversation down – **No rushing decisions**
- Support the student in **leading or participating** in his or her own IEP meeting
- **Start Early!**
- **Use and update** evaluations.

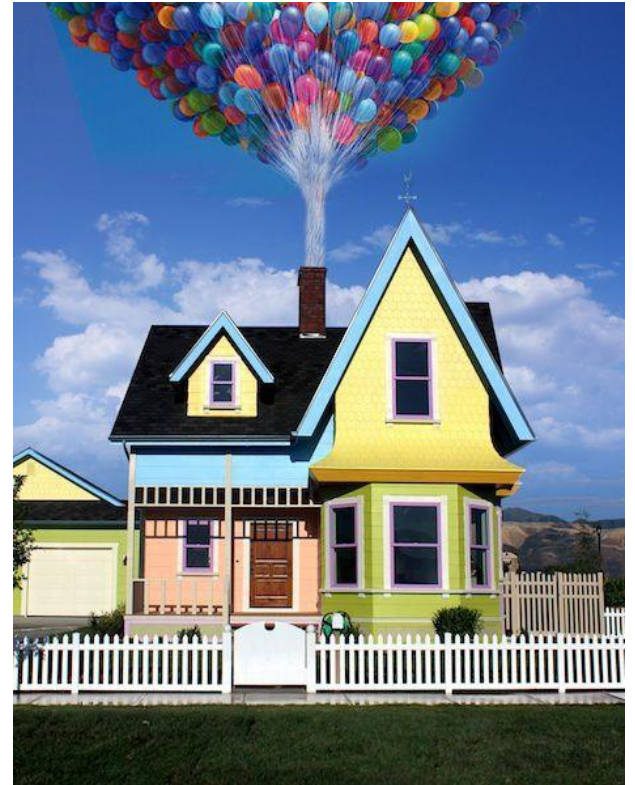
Supported Decision-Making in Health Care

- Bringing a supporter to a medical appointment
- Completing an SDM Agreement
- HIPAA Release Form
- Durable Power of Attorney for Health Care
- Advance Directive



Supported Decision-Making in Housing

- Completing an **SDM** agreement
- **Bringing someone** to search for apartments
- Having a supporter **research and help apply** for financial resources
- **Having conversations** to figure out what kind of home would be a good place to live, and what the person can afford

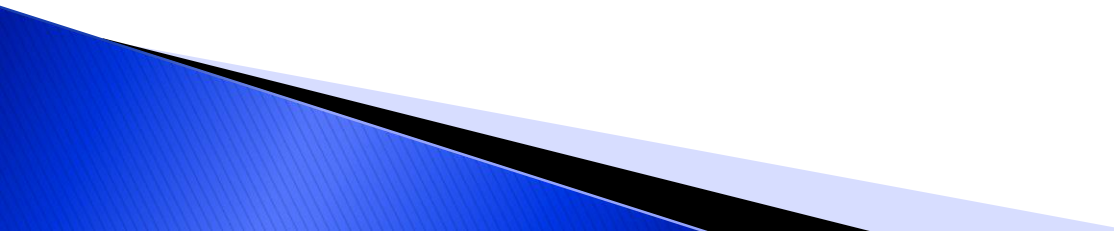


Resources for Supporters

- ACLU pamphlet: What is Supported Decision-Making and What Does a Supporter Do?
https://www.aclu.org/sites/default/files/field_document/supported_decision-making_for_supporters_-_pamphlet.pdf
- ASAN factsheet: Supported Decision-Making
<http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-2-Supported-Decision-Making-v3.pdf>
- ASAN effective communication toolkit:
<https://odpc.ucsf.edu/communications-paper/1-introduction-and-how-to-use-this-toolkit>

Want to Ask for Help?

Contact Quality Trust:

- ▶ Formed by Quality Trust in 2013, the **Jenny Hatch Justice Project** is dedicated to **protecting and advancing the rights of people with disabilities** to make their own decisions.
 - ▶ Thanks to the generous funding of the **D.C. Bar Foundation**, we provide **free legal services** to low-income D.C. residents at risk of or under overly restrictive and/or undue adult guardianships.
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When Should You Contact Quality Trust's JHJP?

If a person with a disability is a DC resident who:

- ▶ Has **questions about decision-making rights**?
- ▶ Is **unhappy with a guardian** and wants help?
- ▶ Wants help with **less-restrictive forms of decision-making support**?
 - Supported Decision-Making
 - Powers of Attorney
 - Advance Directives

Contact: Jessica A. Bronson, JHJP Staff Attorney
202-448-1448
jbronson@dcqualitytrust.org

Upcoming Training Opportunities

- Saturday, March 23, 2019** What you should know about preparing and planning for employment services
Our Lady of Mercy Catholic Church
10:00 a.m. – 2:00 p.m.
- Friday, March 29, 2019** Parent Session-Voices of Change Conference
Washington Convention Center
9:30 a.m. – 2:30 p.m.
- May 18, 2019** What you Should Know about Choosing a Service Provider
Quality Trust for Individuals with Disabilities
10 a.m. – 12:00 p.m.