Supported Decision Making

Quality Trust
for Individuals with Disabilities

Quality Trust for Individuals with Disabilities

- Independent advocacy and monitoring
  - Children and adults with disabilities
- Dignity, respect, and autonomy
  - Rights protection and decision-making supports
- Jenny Hatch Justice Project (2013 to present)
  - www.JennyHatchJusticeProject.org
- National Resource Center for Supported Decision-Making (2014 to present)
  - www.SupportedDecisionMaking.org
- Family Ties of DC, parent to parent matching program

Today's Topics

- **Supported Decision-Making: What?**
  - What is it?
  - What is it not?
- **Supported Decision-Making: Why?**
  - Why is SDM important?
- **Supported Decision-Making: How?**
  - Overview of types of SDM Agreements in D.C.
  - Explanation on how to complete SDM agreements
  - How SDM is more than a piece of paper

Supported Decision-Making: What?

Ricardo and Donna

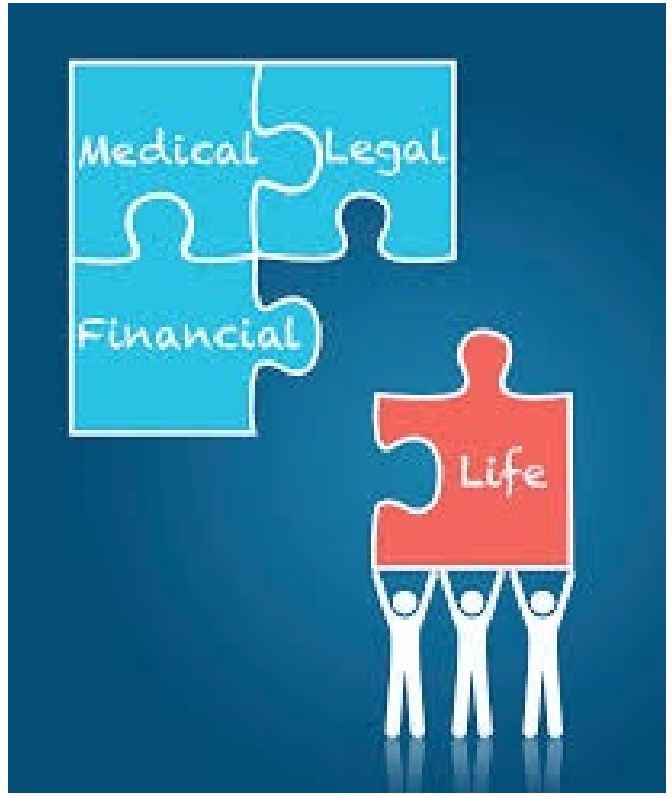
Ricardo: "**I can make my own decisions**. When I lived in an institution, I wasn't allowed to make decisions. When I got out, I could move towards **making my own decisions with the help I wanted**."

Donna: "I can think for myself. **We can do things for ourselves**. We can talk up for ourselves."

For more, see National Council on Disability, Report: "Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities" (June 2019)

Supported Decision-Making: What?

- **Supports and services** that help an adult with a disability make his or her own decisions, by using friends, family members, 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.
- Now formally recognized in **D.C. Law 22-93** (May 2018)

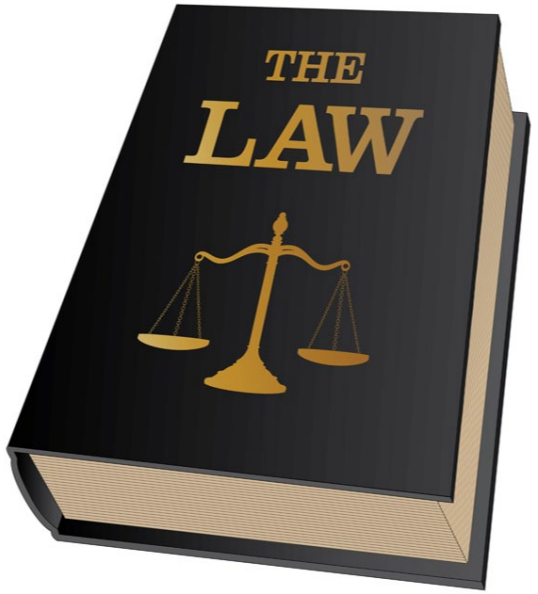


The Danger of Too Many “SDMs”

- **Supported Decision-Making is <u>NOT</u>**
  - **Shared Decision-Making**
    - When a doctor and patient make medical decisions through consensus
  - **Substitute Decision-Making**
    - When someone else makes the decision for the person

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:
  - **A. Assist** the adult with a disability **in understanding** the options, responsibilities, and consequences of life decisions; and
  - **B. 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. Code § 7-2131(11)

Supported Decision-Making: Why?
Ryan's Story

Ryan: **"Don't judge me before you know me."**

Herb, Ryan's father: "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."**

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?"**

Myths of Supported Decision-Making

- Supported Decision-Making isn't legally "official" ➡ FALSE
- People with certain kinds of disabilities don't have the capacity to use Supported Decision-Making. FALSE ➡

“Toolbox” for Supported Decision-Making

- **Effective Communication**
- **Informal** or **Formal** Supports
- **Peer Support**
- **Practical Experiences**
- **Role Play** and **Practice**
- **Life Coaching**
- **Technology**
- **Welcoming** and **Respectful Environments**
- **Supported Decision-Making Agreements**
- **Release-of-Information Forms**

Continuum of Main Legal Tools for Decision-Making in DC

Supported Decision-Making Agreements

- **Advance Directive &/or Power of Attorney**
- **Educational Representative**, appointed by OSSE
- **Substitute Health Care Decision-Maker** under DC Code §21-2210
- **Representative payee**
- **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.

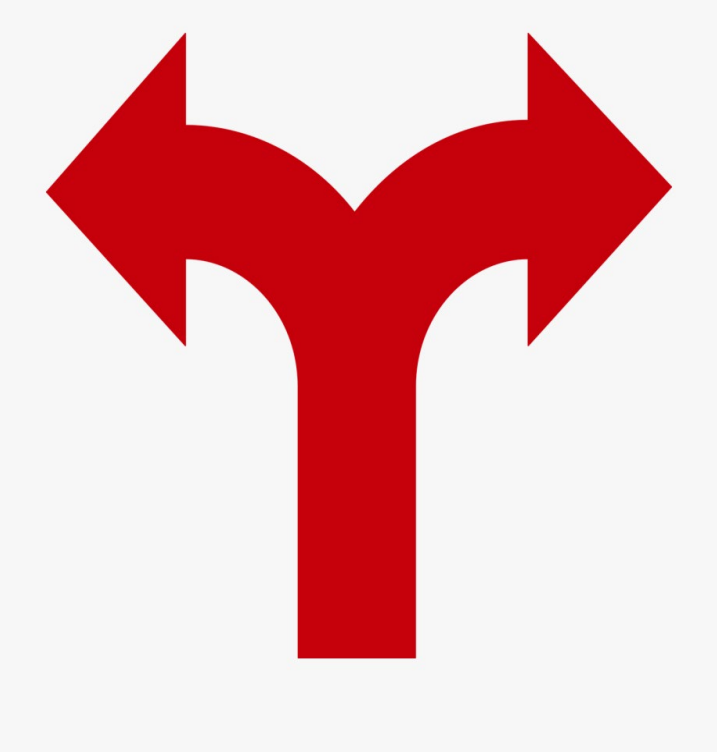
There are many more, like Trusts, MOST Forms, ABLE Accounts, etc.

Call QT to learn more!

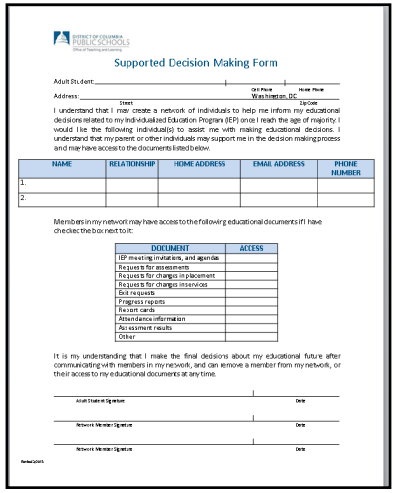
Supported Decision-Making Agreement – 2 Options in DC

1. With a **OSSE or DCPS Supported Decision-Making Form**, for adult students in special education

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: SDM in Education



Supported Decision Making Form

Adult Student: _____ Cell Phone _____ Home Phone _____

Address: _____ Washington, DC _____

Street 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

_____ _____

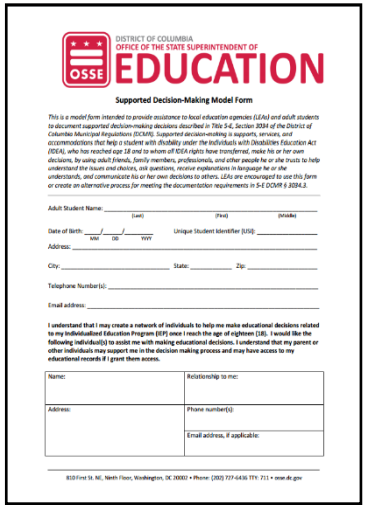
Network Member Signature Date

_____ _____

Network Member Signature Date

Revised 2015

- Help the adult student sign a **OSSE or DCPS SDM Form.**
- Help the student **send a letter** asking the school to invite the parent to all meetings.
- **Help the student get ready for meetings** ahead of time.
- **Support IEP goals and objectives** related to self-determination and decision-making.
- Make the IEP team meetings **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.



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 3004 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 § 3004.3.

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.

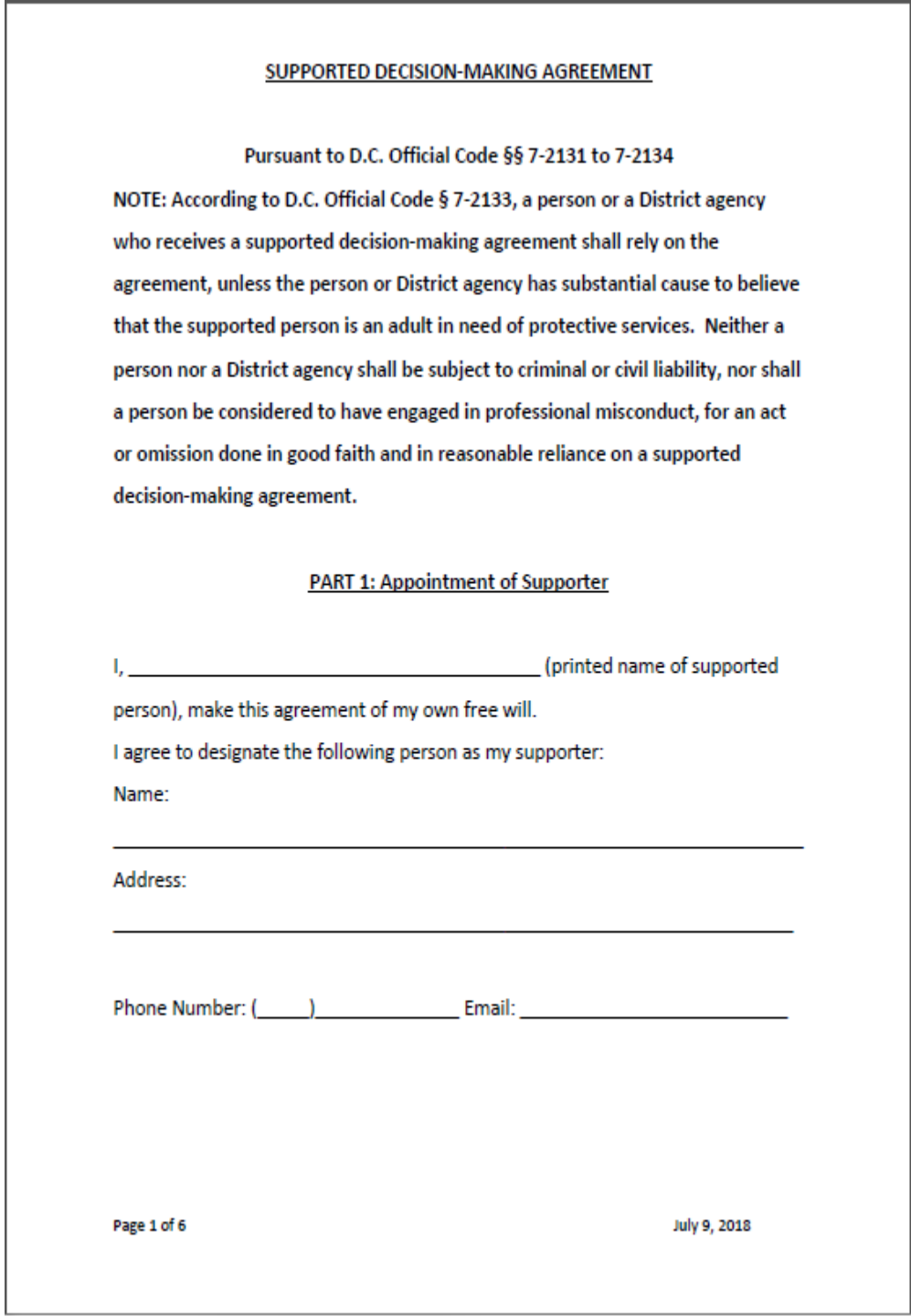
Name:	Relationship to me:
Address:	Phone number(s):
	Email address, if applicable:

810 First St. NE, Ninth Floor, Washington, DC 20002 • Phone: (202) 727-6436 TTY: 711 • osse.dc.gov

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: _____

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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

Continued- Who Cannot Be a Formal Supporter under an SSDMA?

- A formal supporter **CANNOT**:
  - Provide or own/operate any entities that provide **healthcare or disability services** to the supported person; or
  - Work for any **government agencies** that are **financially responsible** for the supported person's care

  UNLESS they are the person's **relative**

- D.C. Law 22-93 indicates that this restriction is applicable to DCPS and OSSE SDM Forms, too

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; **OR**
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**

Who Should Be a Formal Supporter under an SSDMA?

- A formal supporter should be an adult who:
  - The **person trusts**
  - The **person chooses**
  - **Wants the person to make their own decisions**
  - **Wants to be** the person's **formal supporter,**
  - Will be **reliable**
  - 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**

How is the Statutory SDM Agreement Completed?

- **DC Statutory SDM Agreement** - Read the Instructions!
  1) Who can use the form
  2) Who can be a formal supporter
  3) How the form is signed
  4) What to attach to the form
  5) How the form is cancelled

- The SSDMA form requires the person to list **who** the former supporter will be, **which** kind of choices will be supported, **how** the supporter can help, and **when** the SDM is effective.

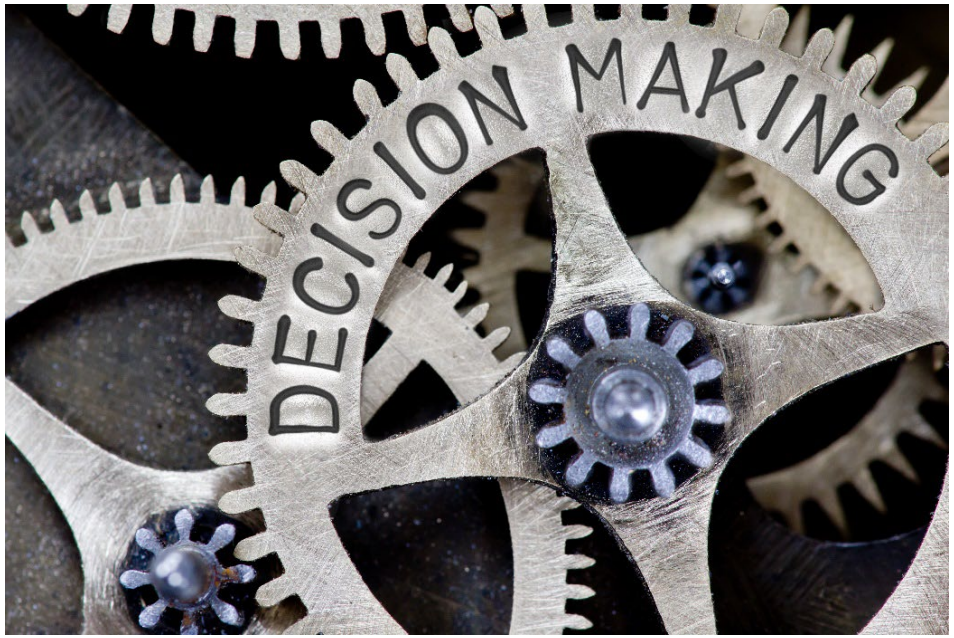
- **Release-of-information forms** should be attached to the SSDMA form
  - **Health Care – HIPAA Release Form**
  - **Education – FERPA Release Form**

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

Everyone Has the "Right to Make Choices"

- **Support people to build capacity** to make decisions over time.
- **Explore less restrictive alternatives** to decision-making support before thinking about guardianship.



Ask Questions Now or Later

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Quality Trust for Individuals with Disabilities
www.dcqualitytrust.org

National Resource Center for Supported Decision-Making
www.SupportedDecisionMaking.org