

# Supported Decision-Making & D.C. Law 22-93



# 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
- ▶ Partnering with families
- ▶ Jenny Hatch Justice Project (2013)
- ▶ National Resource Center for Supported Decision-Making (2014)



# Today's Topics

1. Overview of Supported Decision Making (SDM)  
What? Why? How?
2. Exercise: What Makes a Good Supporter?
3. Statutory Supported Decision-Making Agreement (SSDMA)
4. Exercise: Who Do You Choose as a Formal Supporter?
5. Commonly Used Areas for a Statutory Supported Decision Making Agreement



# Decision-Making Steps

- ▶ Clarifying the issue, problem or choice
- ▶ Assessing the options
- ▶ Evaluating the “goodness” or “fit” of different options.
- ▶ Making a “decision”



# 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, 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”



# Questions

- ▶ **What is Supported Decision-Making to you?**
- ▶ **Can you think of a time when you used Supported Decision-Making to make a decision or to help someone else make a decision?**
- ▶ **What have you found from your experience with Supported Decision-Making?**
- ▶ **Have there been any barriers or challenges?**



# D.C. Continuum of Decision-Making Supports

## Supported Decision-Making

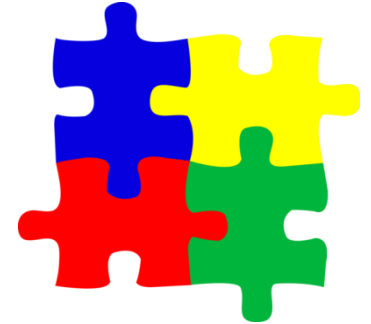
- ▶ **Advance Directive &/or Power of Attorney**
- ▶ **Educational Representative**, appointed by OSSE
- ▶ **Substitute Health Care Decision-Maker** under DC Code §21-2210
- ▶ **Representative payee**, appointed by SSA
- ▶ **Court-appointed Guardian or Conservator**
  - ▶ Time-limited Emergency or Health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



# Explore Options



- ▶ **Finding the Right Support:**
  - What **kind of decision** needs to be made?
  - How much **risk** is involved?
  - How hard would it be to **undo** the decision?
  - Has the person made a **decision like this** before?
  - Is the decision likely to be **challenged**?
  
- ▶ **Ask:** What is the **least restrictive** support that might work?
  
- ▶ **Remember:** Use the Right **Tool**, for the Right **Decision**, at and for the Right **Time**

# Supported Decision-Making: Why? 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: Why?

## Dolores's Story



“It makes you feel **powerful** to be in charge of your own life. You can have a lot of help everywhere, but **you are your own boss.**”

– Dolores

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



# And it also makes sense!

## ▶ **Self-Determination**

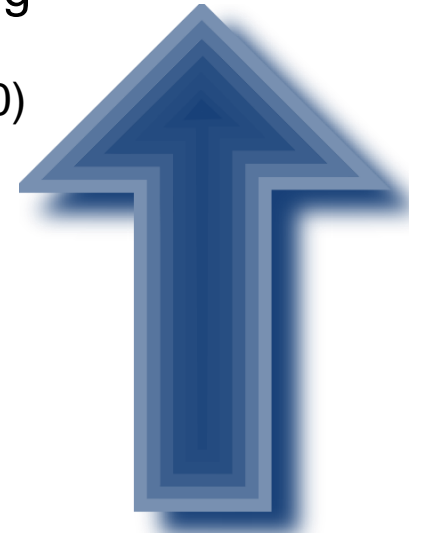
- ▶ **Life control** — People's ability and opportunity to be "causal agents . . . Actors in their lives instead of being acted upon"

(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

## ▶ **People with disabilities with greater self-determination are:**

- ▶ More **independent**
- ▶ More **integrated** into their communities
- ▶ **Healthier**
- ▶ Better able to **recognize and resist abuse**

(Powers *et al.*, 2012; Shogren, Wehmeyer, Palmer, Rifenshield, & Little 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)



# More evidence

- ▶ **When denied self-determination**, people can:
  - ▶ “[F]eel **helpless, hopeless, and self-critical**” (Deci, 1975, p. 208).
  - ▶ Experience “**low self-esteem**, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick 1995, p. 21).



# More evidence

- ▶ Students who have self-determination skills are **more likely to successfully make the transition to adulthood**, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997)
- ▶ Promoting self-determination is a **special educational “best practice”** (Wehmeyer & Hughes, 1998).
- ▶ Schools should focus on **improving students’ ability to set goals, solve problems, make decisions and advocate for themselves** and, just as importantly, to give students the opportunity to exercise these skills (Wehmeyer & Gragoudas, 2004).



# More evidence

- ▶ **People with intellectual and developmental disabilities** who do not have a guardian are more likely to:
  - Have a paid **job**
  - **Live independently**
  - Have **friends** other than staff or family
  - Go on dates and **socialize** in the community
  - Practice the **religion of their choice**

(National Core Indicators, 2013-2014)



# 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?”**





# Common Considerations

- All forms of SDM recognize:
  - The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others;
  - That **a person can take part in a decision-making process** that does not remove his or her decision-making rights; and
  - **People will often need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein, 2012)



# Exercise: What Makes a Good Supporter?



# 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**



# 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](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: \_\_\_\_\_



# Who Can Use the SSDMA Form?

- ▶ **General Rule:** Adults (  $\geq 18$  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 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?

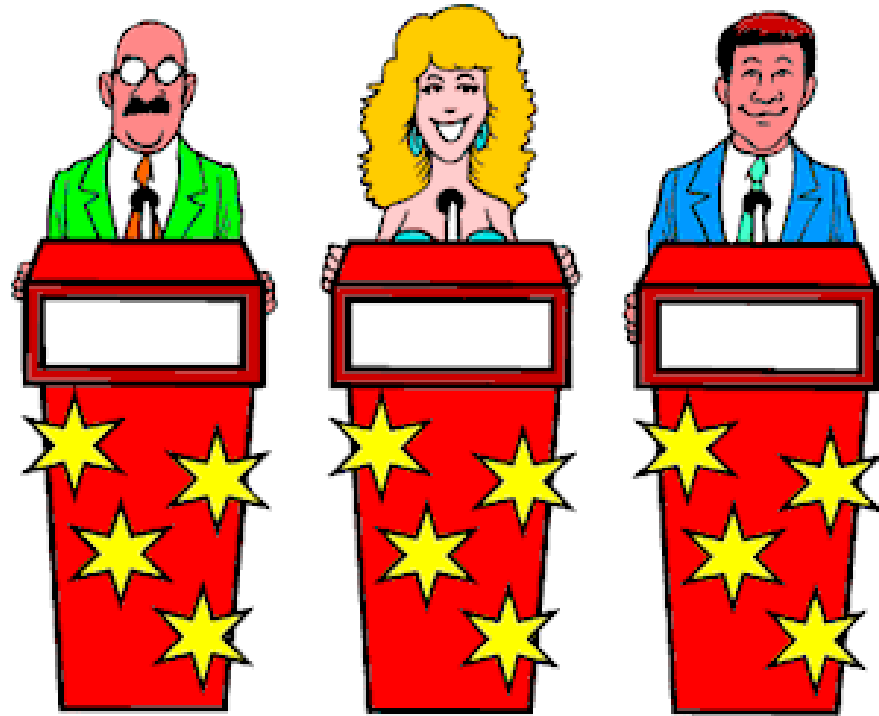
- ▶ Even if they are your relative, a formal supporter **CANNOT**:
  1. have been **found by a government agency** to have **abused, neglected, or exploited** the supported person or **inflicted harm** upon a child, older adult, or person with a disability; and
  2. have, **within the last 7 years, been 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**





# Exercise: Who to Choose?



# How is the SSDMA Form Completed?

- ▶ **Unless it covers only educational decisions**, an SDM Agreement must **substantially follow the SSDMA form** found in the statute.
- ▶ **How to Use the SSDMA Form**
  - ▶ Identify **formal supporter**
  - ▶ Pick with **which kinds of choices** the person wants help
  - ▶ Pick **how the supporter can help**
  - ▶ State whether or not there are signed **release-of-information forms** and attach them to the SSDMA form
    - ▶ **Health Care – HIPAA Release Form** (example available at: <https://dbh.dc.gov/page/dbh-hipaa-privacy-forms-1-and-3-english-version>)
    - ▶ **Education – FERPA Release Form** (example available at: <https://osse.dc.gov/publication/accessing-student-education-records>)
  - ▶ List **when the SSDMA is “effective”** (dates the SSDMA starts and ends)



# 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



# Other Examples of SDM

- ▶ Education
- ▶ Finances
- ▶ Health Care
- ▶ Housing



# 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 with Finances

- ▶ **Completing an SSDMA**
- ▶ **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**





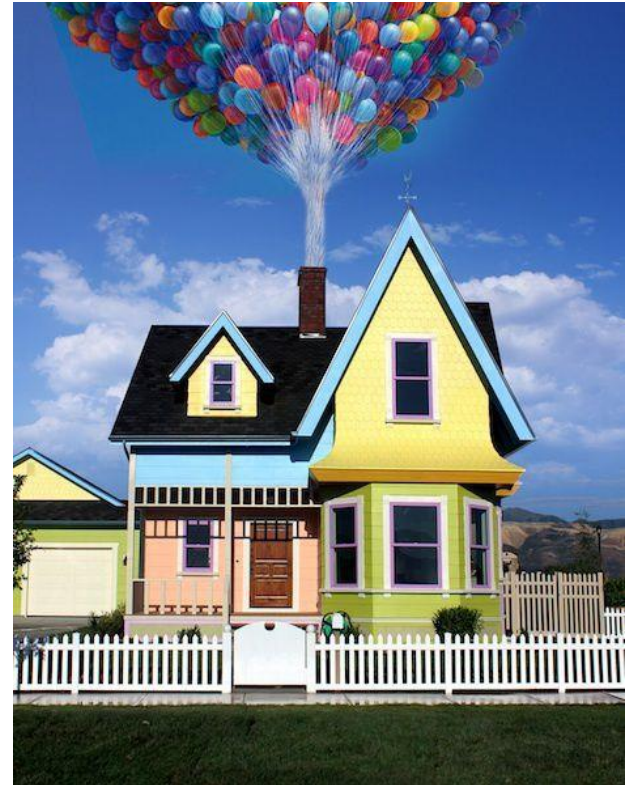
# Supported Decision-Making in Health Care

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



# Supported Decision-Making in Housing

- Completing an **SSDMA**
- **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



# Other Common Terms ≠ “Supported Decision-Making”

- ▶ Shared Decision-Making
  - When a doctor and patient make medical decisions through consensus
- ▶ Person-Centered Planning
  - When a group of people focus on a person’s preferences to plan for his or her future
- ▶ Substitute Decision-Making
  - When a person is authorized under the law to make some or all decisions for another person.



# 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.



# 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](mailto:jbronson@dcqualitytrust.org)



# SDM: More on How

- ▶ **Quality Trust for Individuals with Disabilities**
  - ▶ [www.DCQualityTrust.org](http://www.DCQualityTrust.org)
- ▶ **National Resource Center for Supported Decision-Making**
  - ▶ [www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)
- ▶ **NRC-SDM 2016 “From Theory to Practice” Webinar Series**
  - ▶ Archived webinar topics include implementing SDM in education, community based supports, and with financial decisions.
  - ▶ Available at: <http://www.supporteddecisionmaking.org/events>
- ▶ **“Supported Decision-Making Teams: Setting the Wheels in Motion”**
  - ▶ Parents guide available at: <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>



# 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](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>



# Resources for Planning

- ▶ Life Course Toolkit:

<http://www.lifecoursetools.com/planning/>

- ▶ Maps and Paths:

<http://www.inclusion.com/bkpcpmapsandpath.html>

- ▶ Essential Lifestyle Plans/Person Centered Thinking:

<http://sdaus.com/resources/>

- ▶ The Arc Center for Future Planning:

<https://futureplanning.thearc.org>

- ▶ Got Transition/Center for Health Care Transition Improvement

[www.gottransition.org](http://www.gottransition.org)





# Ask Questions – Now or Later

Rhonda White, Parent Advocate and Research Specialist

[rwhite@dcqualitytrust.org](mailto:rwhite@dcqualitytrust.org)

Jessica Bronson, Staff Attorney

[jbronson@dcqualitytrust.org](mailto:jbronson@dcqualitytrust.org)

\*Licensed to practice law in D.C. and Maryland

Quality Trust for Individuals with Disabilities

[www.DCQualityTrust.org](http://www.DCQualityTrust.org)

