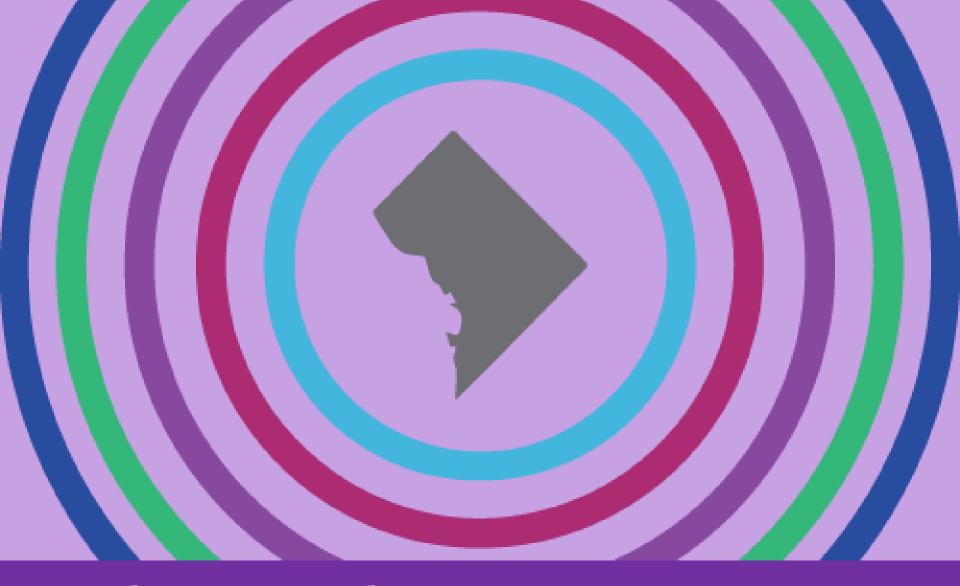


DC Supporting Families Community of Practice

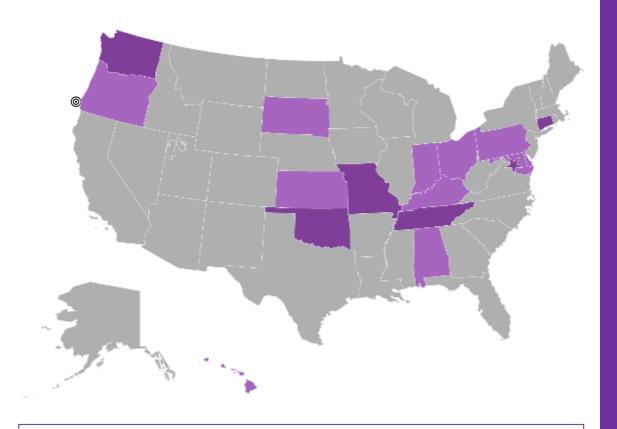




Welcome and Introduction to Day

Erin Leveton,
DC Department on
Disability Services





Project Outcome

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.

National Community of Practice for Supporting Families

Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.





All People & Their Families Have the Right to Live, Love, Work, Play & Pursue Their Life Aspirations in Their Community



DC's Supporting Families Leadership "Core" Team















Health Services for Children with Special Needs, Inc. (HSCSN)

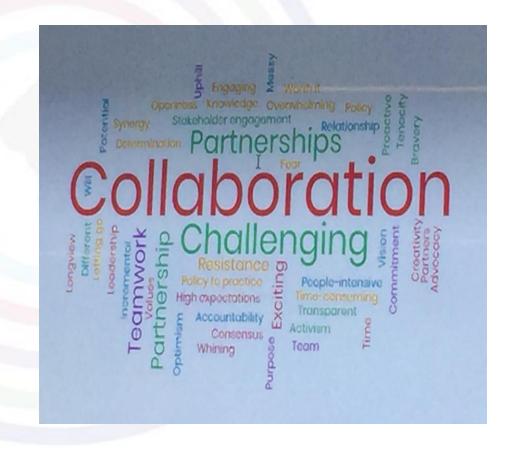


National SF CoP Evaluation





- Natalie Boonchaisri
- Diana Caldwell

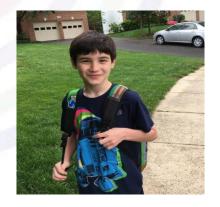


Introductions & Opening Round



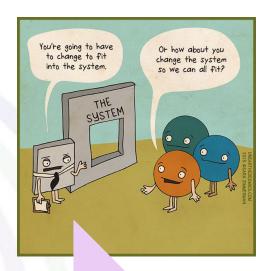
- Name
- Organization, if any
- Family member?
- 1 word on something you like/ admire about your family member or friend with an intellectual or developmental disability

- For Example:
 - * Erin Leveton
 - Department on Disability
 Services
 - * My nephew Andy
 - * I admire his creativity





Partnering for Systems Change



Community
Conversations
About
Improving
and
Expanding
DD Services

Disability
Reform
Amendment
Act of 2010
Introduced &
Stalled

2013: DC Joins National SF CoP Person &
Family
Centered
Systems
Change at
DDS

2018:
Disability
Services
Reform
Amendment
Act Signed
into Law



Disability Services Reform Amendment Act is Law



- Puts decision-making back in the hands of people with disabilities and their families by:
 - Formally recognizingSupported Decision-Making
 - Ending involuntary civil commitment
- Adds accountability
 - New formal complaint system for DDA and it's providers



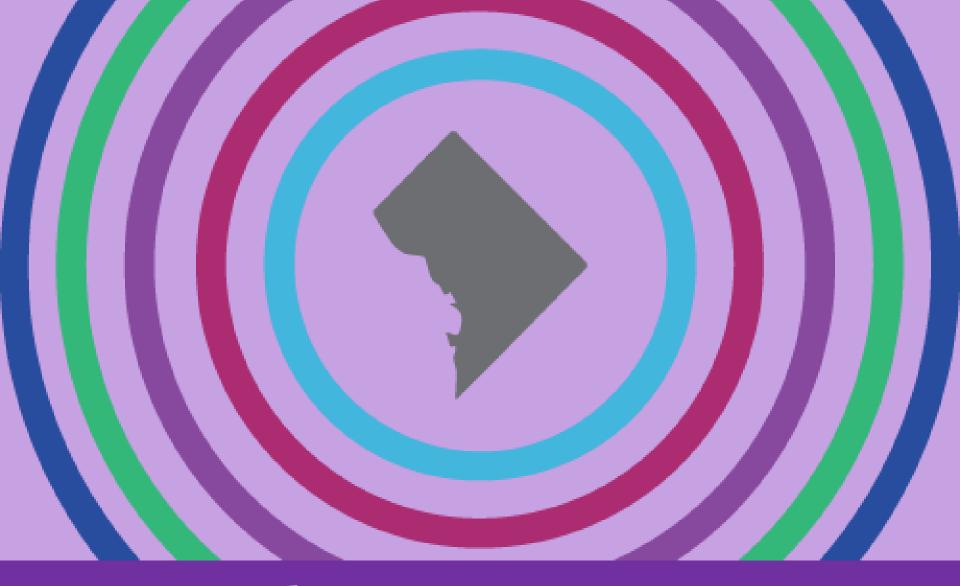


Agenda: Implementation of DSRAAA



- Learn about Supported Decision-Making
- Share ideas to help us as we create the new DDA Formal Complaint Process
- Lunch with Leadership: DDS Director Andrew Reese
 - * Note Cards for Topics/ Questions of Interest
- Understanding Changes to Civil Commitment
- © Community Announcements & Discussions
- Like/ Learn/ Change & Stipends





Supported Decision Making

Rhonda White and Morgan Whitlatch, Quality Trust



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



Icebreaker



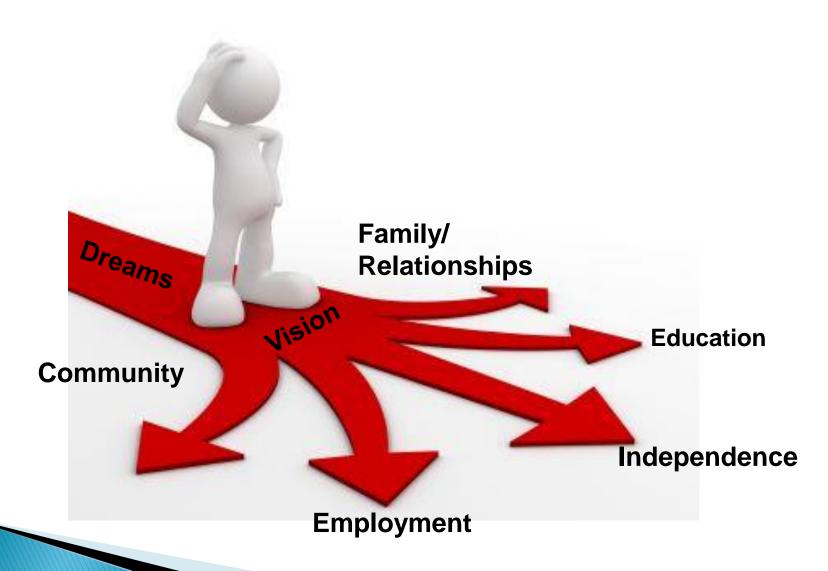




- Independent advocacy and monitoring
- Children and adults with disabilities
- Dignity, respect, and autonomy
- Rights protection and decision-making supports
- Partnering with families
- Jenny Hatch Justice Project (2013)
- National Resource Center for Supported Decision-Making (2014)



Planning: Choices & Decisions





Start with 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/



Building Healthy Adult Relationships

- Talk about respect and boundaries
- Expect differences of opinion and world view
- Make room for change
- Focus on the present and future (not the past)
- Think about how to disagree





Education for People with Disabilities

- Decision-making skills
- Rights and responsibilities
- How to run your own planning meeting
- Advocacy Skills
- How to ask for help
- Opportunities to be in community



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"



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
- 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!



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? 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/



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 selfdetermination are:

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

(Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Shwartz, 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).

Decreased Life Outcomes

Overbroad or undue guardianship can cause a "significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010, p. 354)



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

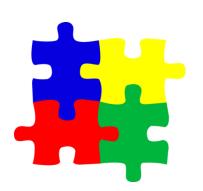
- People with intellectual and developmental disabilities who do not have a guardian are more likely to:
 - Have a paid job
 - Live independently
 - Have friends other than staff or family
 - Go on dates and socialize in the community
 - Practice the religion of their choice

(National Core Indicators, 2013-2014)



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: 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 needs assistance in decision-making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

(Dinerstein, 2012)



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-makingbrainstorming-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 Statutory Supported Decision-Making Agreement ("SSDMA"), which can be used to support a person with many kinds of life decisions; and/or
- 2. 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



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.



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 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:
 - 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 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: (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



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 lowincome D.C. residents at risk of or under overly restrictive and/or undue adult guardianships.



When Should You Contact Quality Trust's JHJP?

Is the person with a disability 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



SDM: More on How

- Quality Trust for Individuals with Disabilities
 - www.DCQualityTrust.org
- National Resource Center for Supported Decision-Making
 - 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



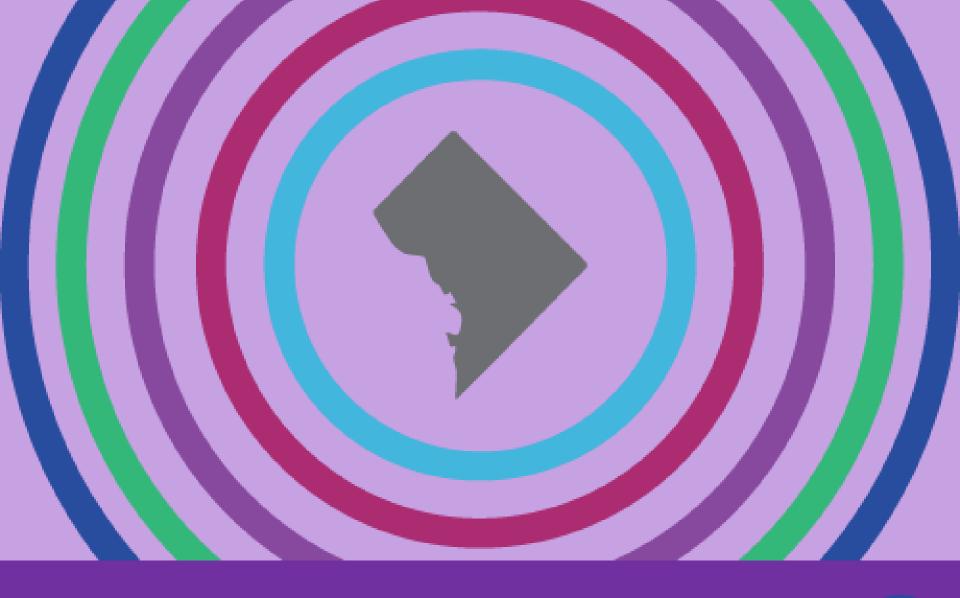
Ask Questions – Now or Later

Rhonda White, Parent Advocate and Resource Specialist rwhite@dcqualitytrust.org

Morgan K. Whitlatch, Legal Director <u>mwhitlatch@dcqualitytrust.org</u> *Licensed to practice law in D.C. and Maryland

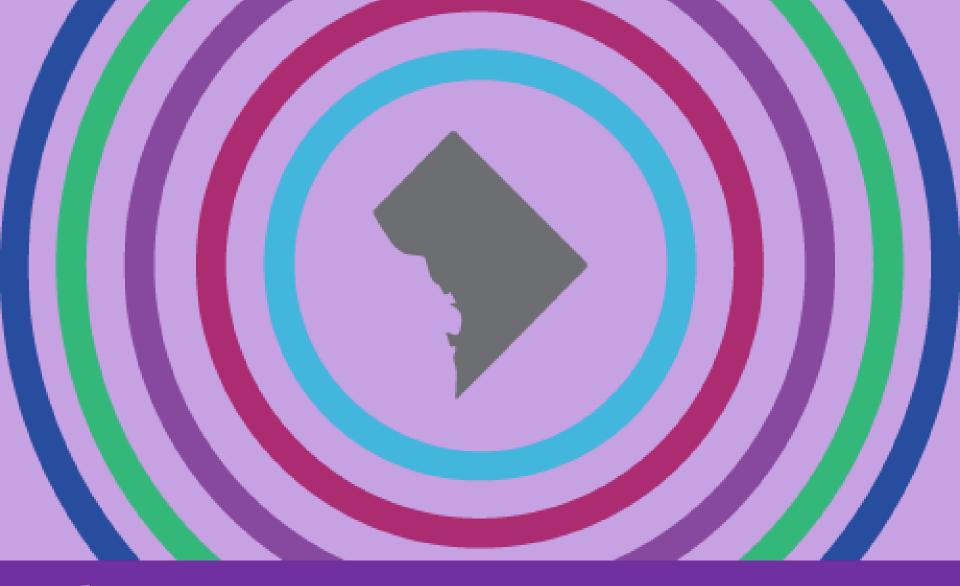
Quality Trust for Individuals with Disabilities www.DCQualityTrust.org





Break





The New DDS Complaint Process

Michelle Hawkins and Liz Seaton, DC Department on Disability Services





Complaints and Helpful Resources

DDS is committed to provide innovative high quality services that enable people with disabilities to lead meaningful and productive lives as vital members of their families, schools, workplaces and communities in every neighborhood in the District of Columbia.

DDS Customer Relations Office

To help resolve differences, challenge a decision or navigate a solution, DDS has a dedicated team in our **Customer Relations Office**.

- 1. Phone number: 202-442-8686
- 2. E-mail: dds@dc.gov
- 3. DDS Customer Service Complaint form:

https://dds.dc.gov/node/777732



Here are Ways To Bring Complaints

- Contact the DDS Customer Relations Office
- Contact DDA Service Coordinator or RSA Vocational Counselor
- © Contact Service Provider
- Contact the DDS Office of Rights and Advocacy
 Phone: 202-730-1802 (Tiffani Johnson, Rights and Advocacy
 Specialist, DDS)

Fax: 202-730-1841

Or visit DDS offices at 250 E Street SW, Washington, DC 20024

 Regarding RSA services/supports, contact the Office of Administrative Hearings (OAH)

Phone: (202) 442-9094 or visit https://oah.dc.gov/node/165292

Address: One Judiciary Square, 441 4th Street, NW

Washington, DC 20001



There's Help Available

Regarding DDS - RSA services, Clients Assistance Program (CAP) is run by Disability Rights DC at University Legal Services (ULS). CAP advocates can help solve problems with a rehabilitation services counselor or help advocate for vocational services when a person pursues legal, administrative, or other ways to protect rights.

Phone: (202) 547-0198 ext. 135 (Protection and Advocacy Intake Unit)

 Regarding issues of discrimination in employment, housing, public accommodations, and/or education you can contact DC's Office of Human Rights (OHR)

Phone: (202) 727-4559 or visit https://ohr.dc.gov/service/file-complaint

Regarding allegations of violations of the District's compliance with the Americans with Disabilities Act (ADA) and related disability rights laws, you can contact the Mayor's Office on Disability Rights (ODR).

Phone: (202) 724-5055 or visit https://odr.dc.gov



There's Help Available

Regarding protection and advocacy for people with developmental disabilities, Quality Trust for Individuals with Disabilities. QT monitors DDS and provides legal representation.

Phone: (202) 448-1450 or visit https://www.dcqualitytrust.org

Regarding protection and advocacy for people with disabilities, Disability Rights DC at University Legal Services (ULS). DRDC provides legal assistance in cases.

Phone: (202) 547-0198 or visit www.uls-dc.org

For information about peer-to-peer advocacy assistance or to learn advocacy, Project Action! PA! holds monthly meetings on Saturday mornings.

Phone: (202) 730-1700 (Rebecca Salon, DDS) or (202) 448-1450 (Phyllis Holton, Quality Trust)



Does the New Law Change Things?



Customer Relations works hard at DDS to resolve problems and informal complaints now.



NEW: FORMAL COMPLAINTS can be sent to a person who does not work for DDS, who recommends solutions to complaints to DDS Director.



NEW: Peer Support Pilot Program to assist people with intellectual disabilities throughout the process.



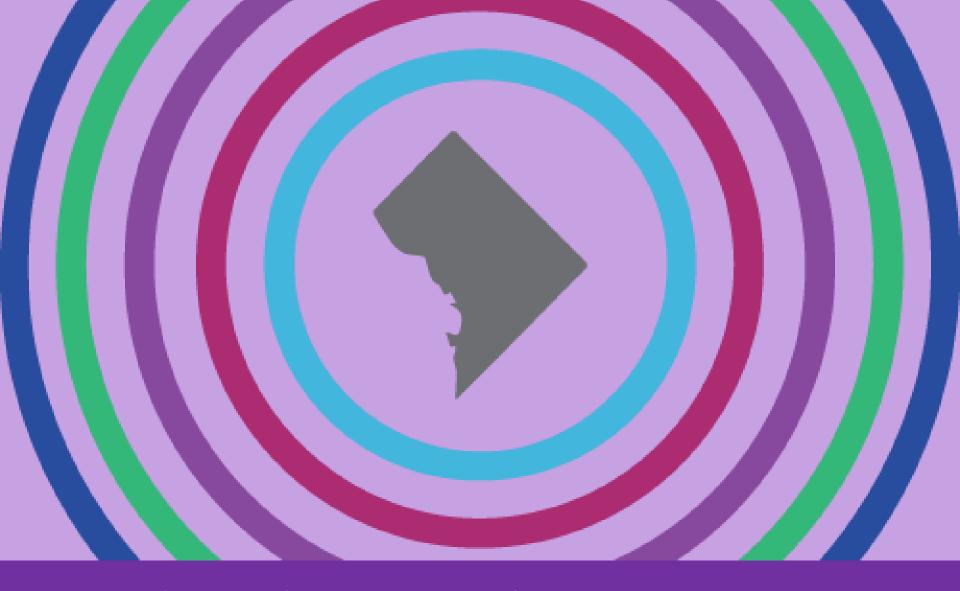
NEW: If not satisfied with solution, a person can appeal to the Office of Administrative Hearings



Part I: Activity on Upcoming DDS Complaint Process

Liz Seaton, DC DDS Alison Whyte, DD Council





Lunch, with Q&A with Director Andy Reese

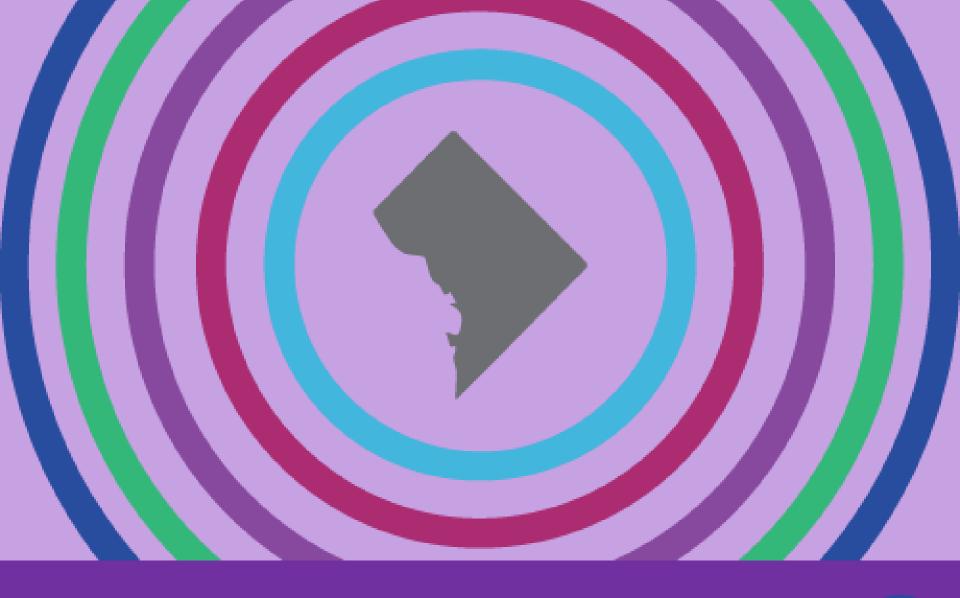




Part II: Activity on Upcoming DDS Complaint Process

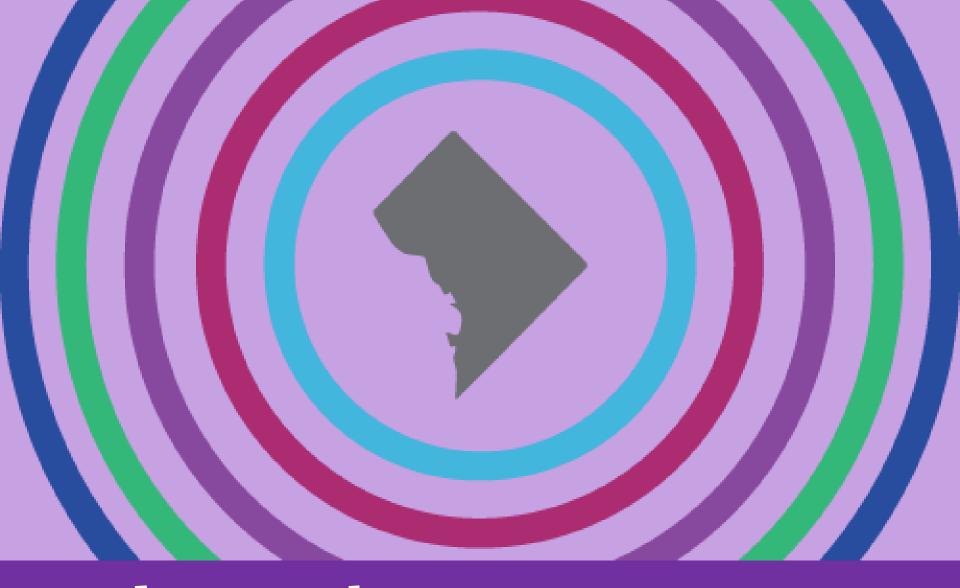
Liz Seaton, DC DDS Alison Whyte, DD Council





Break





Update on Changes in Commitment





Changes to commitment made by the Disability Services Reform Amendment Act of 2018 (D.C. Law 22-93)

Jennifer C. Mika, DDS Office of the General Counsel

DSRAA Changes Civil Commitment



- No new civil commitments.
- Currently committed persons must consent to continue commitment. If a person does not consent, then their commitment will end.
- Certain people (guardians, family) can help the person decide and/or make the decision on their behalf depending on capacity.
- No impact on criminal commitments.
- No impact on DDA services.

These changes go into effect August 3, 2018.



Ending commitment will have NO impact on the services a person receives from DDA.



Additional question at Annual Review Hearing

- In order to remain committed, the person or a substitute decision maker must agree to continue commitment.
- If the person or their substitute decision maker does not agree to continue commitment, the commitment will end.
- Commitment cannot be restarted once ended.
- As long as the person remains committed, the person must agree to continue commitment every year.



Who can serve as the substitute decision maker?

The following people can be the substitute decision maker, in order of priority:

- 1. General Guardian or Limited Guardian with specific authority
- 2. Conservator with specific authority
- 3. Spouse or domestic partner
- 4. Adult child
- 5. Parent
- 6. Adult sibling
- 7. Religious Superior
- 8. Close Friend
- Nearest-living, adult relative
- 10. Court appointed guardian ad litem

How is the decision made?



- The decision must be based on the person's expressed wishes or his/her best interests, if his/her wishes cannot be determined.
- The expectation is that the highest ranking person on the list will make the decision on behalf of the person.
- Other people on the list can challenge the decision of the highest ranked person by showing that s/he has better knowledge of the wishes of the person or is better able to demonstrate what would be in the person's best interest, if the person's wishes cannot be determined.

How will the Court know what decision has been made?

The Court has created a process for determining whether a person has capacity and if not, who should be the substitute decision maker.

- The interdisciplinary team will discuss capacity and substitute decision making at either the annual ISP meeting or a special case conference (also known as an IDT meeting) before the next annual review hearing.
- 2. 60 days before the hearing, the person's attorney will file a report indicating what was discussed at the meeting.
- 3. 30 days before the hearing, the person's substitute decision maker will file a report indicating if the person consents to or refuses continued commitment.
- 4. No less than 15 days before the hearing, any person on the list can challenge the decision of the substitute decision maker.

Copies of the Court's Directive and template forms should be available online soon.



- All involved family members and friends should receive copies of reports and notice about the annual hearing.
- If there is disagreement about capacity or who should be the substitute decision maker, the Court may hold additional hearings.
- Final decisions will be made at the annual review hearing.
- DDS cannot provide legal advice about how to complete the reports but can provide information about the process.

Questions for DDS?



Probate

Neha N. Patel Deputy General Counsel 202-679-3142 neha.patel@dc.gov

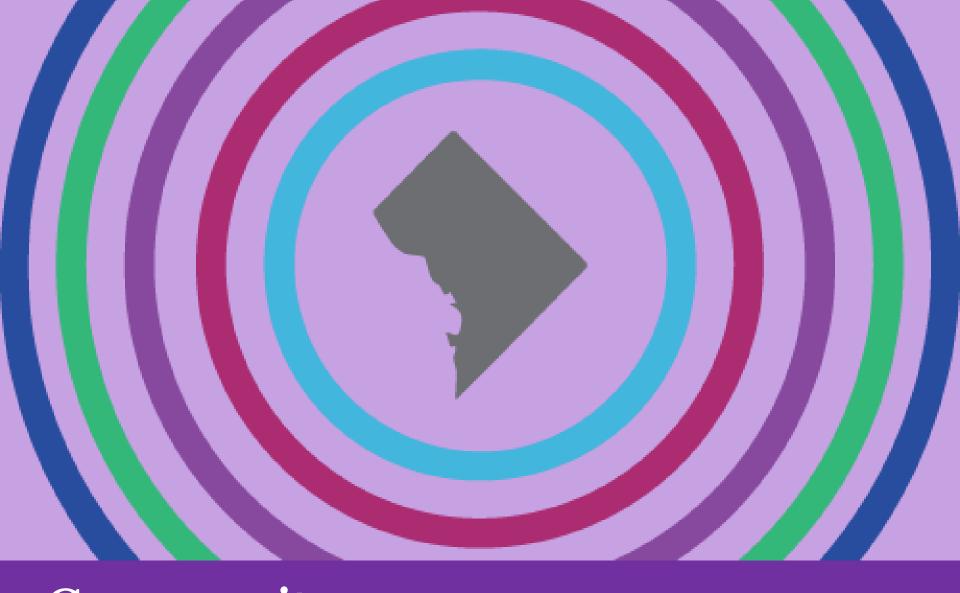
Jennifer C. Mika Assistant General Counsel 202-590-7716 jennifer.mika@dc.gov

Mental Habilitation

Richard A. Williams Assistant General Counsel 202-590-7720 richard.williams@dc.gov

Kevin C. Gardiner
Assistant General Counsel
202-730-1825
kevin.gardiner@dc.gov

Mark D. Back General Counsel 202-730-1592 mark.back@dc.gov



Community Announcements





Attendees from D.C.'s Supporting Families Community of Practice included:

Mark Agosto, DC No Wrong Door
Daisy Brown, DC Family Support Council
Joan Christopher, Georgetown UCEDD
Sudie Johnson, DC Developmental Disabilities Council
Vivian Guerra, DC No Wrong Door
Erin Leveton, DC Department on Disability Services
Emily Price, DC Department on Disability Services

Participating States:

AL, CT, DE, DC, HA, IN, KS, MD, OH, OK, OR, PA, SD, WA



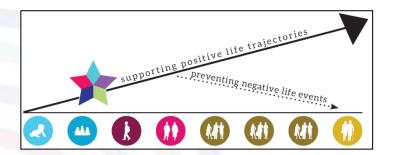




Nancy delivered a keynote address on the sexual abuse of people with developmental disabilities.

- Encouraged SF Communities of Practice to share information about ways to keep yourself or your family member safe and how to act and be an advocate when someone is assaulted
- ACL and DOJ's Office on Violence Against Women, Sexual Assault and Survivors with Disabilities, April 24, 2017: https://youtu.be/-jloD-WzZzY
- PBS News Hour, Abused and Betrayed, January 17, 2018: https://youtu.be/n_Ce-FczgWY

New Ideas



- Using a trajectory to plan our SF CoP and introduce topics at meetings
- Starting meetings with "Crappies and Happies"
- Think about what the planning team is incentivizing (e.g. SF CoP policies and leadership
- What role can SF CoP play in promoting Trauma-Informed
 Care?
- Supporting families to be leaders in CoP ("lollipop moments")
- Spread the sense of community



Innovations Work Groups:

- Policy
- Family Engagement
- Support Coordination
- Employment
- Front Door
- Cultural and Linguistic Competency

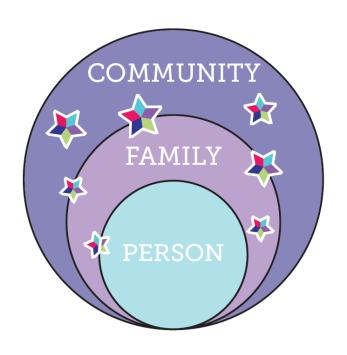
If you're interested in participating, please email emily.price@dc.gov and she will give your email to the UMKC team.

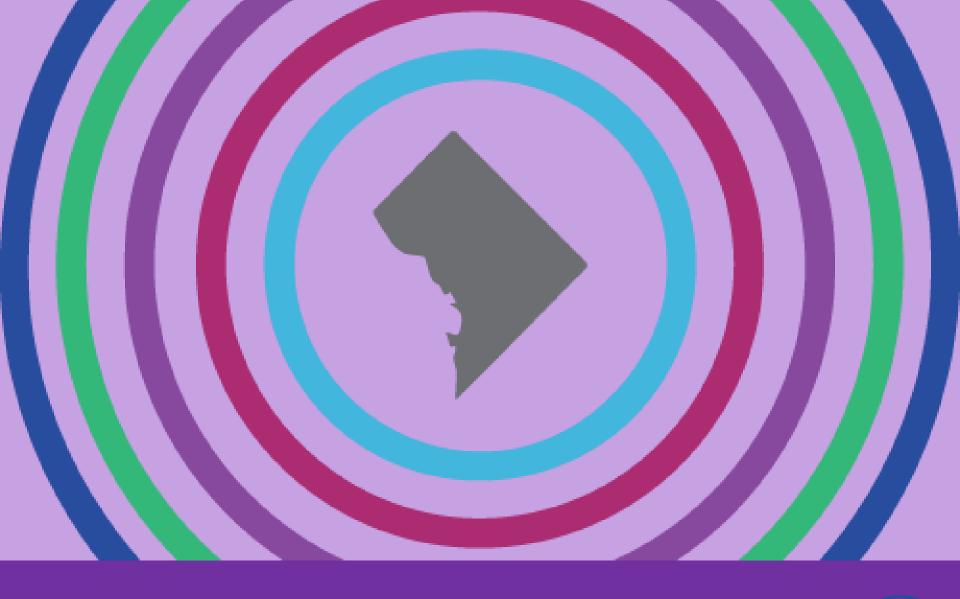




Core Planning Team Retreat

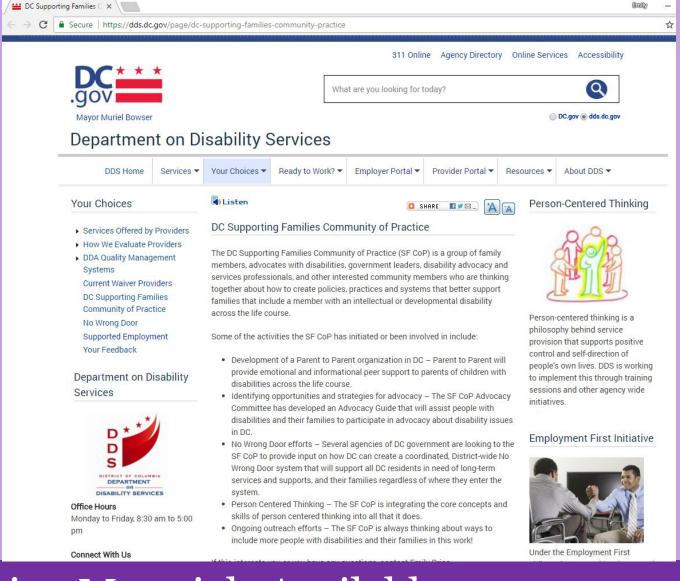
Friday, July 20, 2018





Like, Learn, Change

Please see Emily for stipend forms.



Meeting Materials Available at: https://dds.dc.gov/page/dc-supporting-families-community-practice



Questions, Comments, or Suggestions?

Contact:

Emily Price Program Development Specialist Department on Disability Services emily.price@dc.gov 202-730-1687

