

National Resource Center for Supported
Decision-Making Symposium
June 10, 2019
Washington, DC

Exploring Opportunities and Barriers to Supported Decision- Making in the District of Columbia

How the District of Columbia developed a year-long discussion and pathway to implementing Supported Decision Making by working intentionally with families, community partners, District agencies and self-advocates.

Our Presenters

- ▣ **Joan Christopher**, Director of Community Services, Georgetown University Center for Excellence in Developmental Disabilities, Washington DC, jj485@georgetown.edu
- ▣ **L. Thomas Mangrum, Jr.**, Co-Chair of Project ACTION!, Washington DC
- ▣ **Molly Whalen**, Executive Director, DC Association for Special Education, Washington, DC mwhalen@dcase.org
- ▣ **Liz Seaton**, Legislative and Policy Analyst, Department of Disability Services. Washington DC, liz.seaton@dc.gov

What We Will Share Today:

- How stories from family members and self-advocates who have implemented and used supported decision making efforts and agreements are influencing the rollout of our new law and expected training of staff and agencies.
- DC's Family Support Council leadership on a Supported Decision Making Project (with help from the state grant coalition) allowed us to create two focus group sessions with agencies, families, self-advocates and community members.
- How these efforts spawned various other efforts, including a day-long Supporting Families Community of Practice meeting focused solely on SDM and which organizers created other learning tools such as hypothetical case studies.
- Highlight some of the “Ah-has” that emerged from our stakeholder discussions, and the breadth of how “deep” our community needs to go to really support understanding and implementation of supported decision making concepts.

Outreach and Talking to Stakeholders

- From 2017 to date – many, many presentations were made by the Quality Trust for Individuals with Disabilities to stakeholders in the community to explain SDM and the many misconceptions:
 - Parents, students and staff of DCPS and the Office of the State Superintendent of Schools, including the
 - The Family Support Council, which led to the convening of two world café discussions
 - Meetings of the Community of Practice for Supporting Families

Table Discussion at a Community of Practice-Supporting Families meeting with Families about “Denice and Hallie” ...

- ▣ Summary of the fact pattern
- ▣ Table discussion questions
- ▣ Purpose was to identify issues where (or where not) SDM would be helpful with resolving issues

An example of informal SDM

- ▣ “Can anyone here take my blood pressure?”
- ▣ After discussion, how was this resolved?

Remarks by Thomas Mangrum,
Co-Chair of:



Let Our Voices Be Heard
DC's Self-Advocacy Coalition

Please see Mr. Mangrum's biography in the Symposium Materials

Family Support Council - Supported Decision Making Project: Building Ideas and Content for Trainings for DDS & DC Agencies

- The Family Support Council convened two sessions for all stakeholders to give broad input into opportunities and perceived barriers to Supported Decision Making in DC, so that everyone: youth, adults, elders with disabilities, family members, service providers and agency staff will play a significant role in designing trainings and SDM rollout at key agencies in DC.
- Each session had over 35 participants.

First Session: World Café Designed Discussions

- World-café small group discussion format with three rounds of discussion, including topics:
 - what do you know about SDM, what questions do you have, what do you think/feel and worry about with SDM?
 - Collateral deep dive – where we shared resources from the state programs in the NSDM group and asked participants to share their thoughts on them.
 - Dream It! Describe your ideal scenario for supported decision making systems AND trainings.
- Lesson Learned: Using small group discussion and “world café” type format and supportive facilitators provides for accessible conversations and input from both self-advocates and professionals. We are very pleased with the collection of input we gathered from the first session.

First Session: World Café Designed Discussions

- With support from Quality Trust for Individuals with Disabilities, Morgan Whitlatch primed the group with a presentation about the elements of SDM, and a timeline showing the progression of SDM in DC and where we are now.

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!



- Timeline of the progression of SDM in DC and where we are now. (courtesy of Quality Trust)

Supported Decision-Making:



The District of Columbia's Path So Far

2013

August

DCPS

Revises its Transfer of Rights Guidelines to recognize SDM; Creates an SDM Form; Begins introducing SDM in schools, starting in pre-K

2014

October

Special Education Student Rights Act

Passes the DC Council and affirms adult student in special education can use SDM

2015

September

Mayor's Bill 21-0385

1st DC bill on SDMA is introduced
Later, it dies in Committee

2016

July

OSSE

Adopts updated transfer-of-rights regulations recognizing SDM; issues a model SDM form

2016

October

In re R.K.

First court case in DC to terminate a guardianship in favor of SDM

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Supported Decision-Making



The District of Columbia's Path So Far

2017

March

Mayor's Bill 22-0154

2nd DC bill on SDMA is introduced.

Becomes the DSRAA

2018

May

Disability Services Reform Amendment Act

DC becomes the 4th jurisdiction in the U.S. to codify SDMA

2018

June

"Dolores"

First DC court case to terminate the guardianship of a senior in favor of SDM

2018

August

SDMA Instructions

DDS and QT develop instructions to accompany DC SDMA form

2018

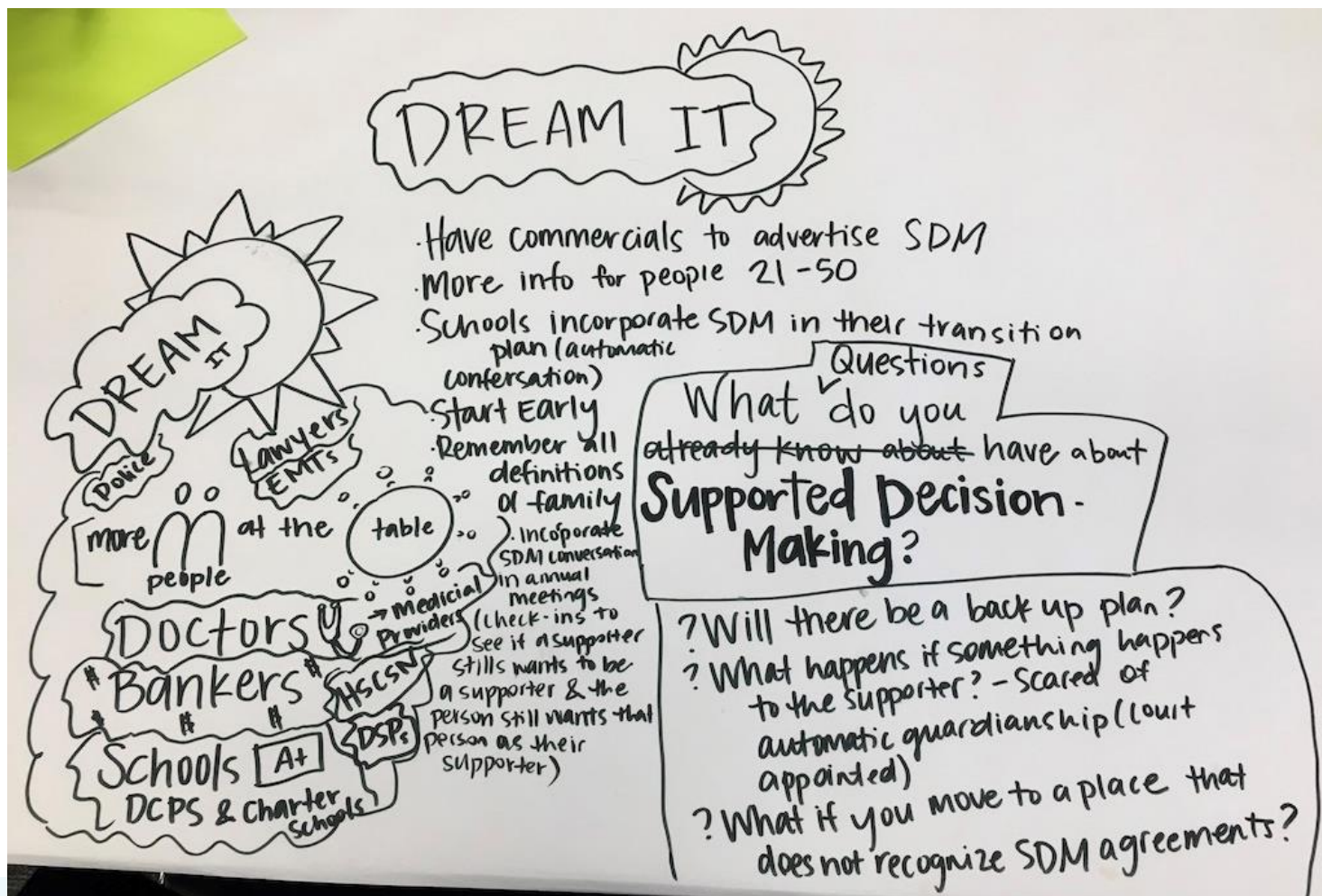
October

DC FSC

Joins (through DCASE) the NRC-SDM State Program Community of Practice

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First Session: The World Café Discussions



First Session: The World Café Discussions



Second Session: Small Group Discussions & Video Conversations

- The second session built on the conversations and input from our World Café session.
- The attendees reviewed the summary of results from our first discussion session on Supported Decision Making
- We had small group discussions to “deep dive” into key questions that emerged about SDM in DC to build out the key elements and outlines for future trainings at all DC agencies.

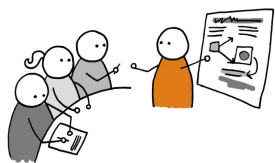
Second Session: Small Group Discussions & Video Conversations

- Participants viewed videos available nationally on SDM to provide ideas, resources and concepts; and had an engaging commentary on their “ah-ha’s”:
 - [Making Healthcare Choices: Perspectives of People with Disabilities](#) (on SDM and healthcare choices)
 - [Supported Decision Making - Gabby's story](#)
 - [Delaware Supported Decision-Making: Your Support, My Decisions](#) (features families, people with a range of disabilities)
 - [Supported Decision-Making: What Supported Decision-Making is and Why It Matters](#)
 - [Ryan on Inclusion and Decision Making](#)

Recommendations from DC Family Support Council

- Based on the reports and discussions from the two focus group sessions, the Family Support Council made the following recommendations:
 1. DDS should design a “train the trainer” Supported Decision Making module in collaboration with key agencies in DC in the next 12 months, and the training should utilize the stakeholder questions and discussion from the FSC-Supported Decision Making Project focus group sessions, the Power Point presentation developed by Quality Trust from the January 24th group session (with author credit to Quality Trust for reference) and utilize stakeholders as possible trainers.
 2. DDS should develop a plan for annual marketing/communications with various groups about Supported Decision Making – to include: DC agencies, financial institutions, medical facilities/providers, and other community organizations.
 3. DDS should provide periodic reports to the Family Support Council about the implementation of recommendations #1-2 through June 2020.

Department on Disability Services: Leadership on SDM and SDM Training



- The D.C. Department on Disability Services honors SDM, and did before Disability Services Reform Amendment Act became law.
- June 14, 2018, Quality Trust presented on SDM at the Supporting Families Community of Practice, DDS presented on other titles of the new law.
- June-July 2018, DDS partnered with Quality Trust to develop an information and instruction packet to accompany the new SDM Agreement form. We engaged Project ACTION! and the Family Support Council to review for content and accessibility.

Initial SDM Training of D.C. Agencies

- July 19, 2018, DDS presented a webinar training on the new law and SDM for Human Services cluster agencies: Department on Aging and Community Living, Department of Behavioral Health, Department of Health, Office of the State Superintendent of Education, and Health Services for Children with Special Needs.
- July 26, 2018, a Family Support Council SDM-focused meeting/webinar, included these agencies plus D.C. Public Schools.

Updated DDS Website (August 2018)

Search: *DC DDS Decision Making Rights*

- **DDS Decision Making Rights | Forms & Resources**
- [Home](#) | [Supported Decision Making](#) | [Commitment](#) | [Forms & Resources](#)
- Here are the forms, reports, tools and resources to help you understand and manage the process regarding the DDS Decision Making Rights for People with Disabilities. Click to view the attachment(s) below.
- [View the Supported Decision Making Agreement Form](#)

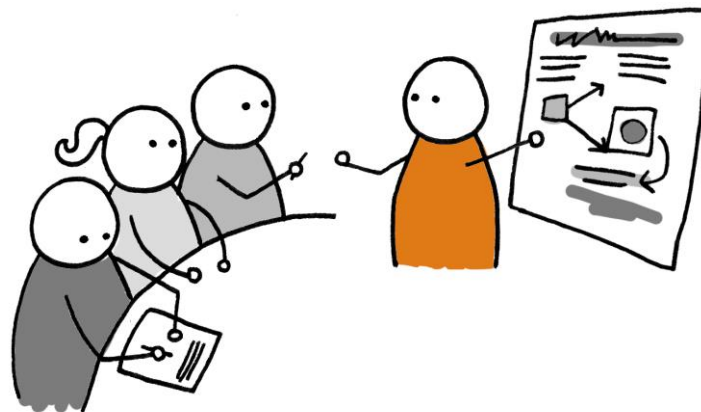
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Department on Disability Services on SDM and SDM Training

Presently DDS is developing

- An in-depth training for all three administrations to build knowledge of and competencies in SDM.
- A Train the Trainers Curriculum for other D.C. Agencies, especially in the Human Services Cluster
- All will end with practice scenarios to cement learnings



DDS's Training Content

DDS's SDM Trainings will be informed by:

- ▣ Family Support Council Focus Group Final Report
- ▣ Quality Trust's trainings and other content
- ▣ DDS's experiences holding trainings to date
- ▣ The needs of the agencies' staff

Future trainings will conclude with Practical Training Problems, designed so participants have the opportunity to apply the SDM principles learned.

Preliminary Findings - Focus Groups

- ▣ Several key findings, presently in draft form
- ▣ Incorporating in Trainings
- ▣ Handout

Our “Ah-Ha” Moments Regarding SDM in DC

