

NRC-SDM State Community of Practice DC Project: Final Report
August 30, 2019

The DC Family Support Council (FSC) led this Supported Decision Making (SDM) project by convening focus groups (including all stakeholders) to get broad input into opportunities and perceived barriers to SDM, so that everyone (youth, adults, elders with disabilities, family members, service providers and state staff) could play a significant role in designing trainings and SDM rollout. The focus groups included sharing national best practices and questions pertained to the design of SDM training for both community members and agency staff. The DC Family Support Council used SDM technical assistance provided by the National Resource Center for Supported Decision-Making State Community of Practice (NRC-SDM CoP) for support in: creating a plan for introducing SDM and developing a replicable structure; designing training key points; developing guiding conversations to engage organizations and partners (i.e., banks, health care providers, etc.); and how to talk to stakeholders about SDM, how to choose supporters and how to inform “gatekeepers” in the community.

Some of the key aspects that have emerged from this year-long project are:

- Stories from family members and self-advocates who have used supported decision making and formal SDM agreements influenced the rollout of DC’s new law and expected training of staff and agencies.
- Community interest in SDM, 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.
- Stakeholder discussions assist with understanding challenges families and people with disabilities face in using SDM, and reveal the breadth of how “deep” our community needs to go to really support universal understanding and implementation of supported decision making concepts.

The key element of this project was the convening of two focus groups on Jan 24, 2019 and Mar 28, 2019 that coincided with regularly scheduled FSC meetings. The FSC is a group of 11 family members of people with disabilities and people with disabilities themselves who are appointed by the Department on Disability Services (DDS) Director to assist, advise, and provide recommendations to DDS and sister agencies on developing person- and family-centered supports, which includes self-determination and support for making informed choices.

The first focus group, entitled: “Supported Decision Making in DC: Come & Ask, Come & Learn, Come & Develop” was a two hour session and attracted over 35 participants, including self-advocates, family members, agency staff and community based organizations. The meeting was held in a “World Café” small group discussion format with three rounds of discussion, including topics: 1) what do you know about SDM, what questions do you have, what do you think/feel and worry

about with SDM? 2) Collateral deep dive – taking a look at shared resources from the state programs in the NRC-SDM CoP and asked participants to share feedback.. 3) Dream It! Describe your ideal scenario for supported decision-making systems and trainings.

Using small group discussion and “world café” type format and supportive facilitators provides for accessible conversations and input from both self-advocates and professionals. The Project facilitator prepared a full report and executive summary of the discussions, comments, suggestions and ideas from the first Focus Group session and shared with team members in order to use in planning for the second session. Overall it was a constant challenge was attracting service agency staff to participate in group sessions and dialogues at a consistent level.

The second SDM focus group was held on March 28, 2019 in conjunction with DC’s Family Support Council. Entitled: “Supported Decision Making in DC: Next Steps - Building Ideas and Content for Trainings for DDS And DC Agencies” this two-hour session attracted over 30 participants, including self-advocates, family members, agency staff and community based organizations. Small group discussions were had to encourage the attendees to answer a series of questions that arose in the first focus session including: 1) How often should an SDM agreement need to be signed, reviewed, or reassessed? How should that work? 2) How would we incorporate the use of a “team” of people as supporters (i.e., a group of siblings) 3) How do we make sure all agencies and public service organizations understand SDM? How do we ensure community understands SDM? i.e., banks, medical community, companies, and 4) Create a list of characteristics to consider in choosing a good supporter. Attendees were also shown a selection of SDM videos created by other states and polled the group for comments.

Using small group discussions and guided questions, again yielded accessible conversations and input from both self-advocates and professionals. The project team was pleased with the full collection of input we gathered from the two sessions, which ranged from practical nuts and bolts use of informal and formal SDM considerations to wide-ranging recommendations about the breadth of information-sharing, training and marketing of SDM needed in the District of Columbia.

The project team collected a wide-range of thought-provoking comments and perspectives from both focus groups, and in turn submitted a recommendation that the comments were used by district government agencies to develop the “core” of the SDM training. The DDS State Office of Policy, Planning and Innovation is utilizing these comments and perspectives in developing a Train-the-Trainers curriculum for the agency, sister agencies in the Human Services cluster, and more.

Using the reports from both focus sessions and working with the Family Support Council, two additional recommendations to DDS were shared regarding the development of the SDM training and rollout. These recommendations received a unanimous vote by the members of the Family Support Council. The recommendations are as follows:

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.

In addition to the work on the two focus groups; the efforts from this project created these ancillary actions:

- DDS worked with DC Health, the District’s health department, on draft proposed regulations for group homes (includes residential habilitation and ICFs). DC Health is a non-voting member of the FSC and learned more about the importance of SDM to community members from the FSC discussions and this project. DOH added language to recognize supported decision-makers in draft regulations prior to this work.
- DDS specified in Proposed Rulemaking for the upcoming DDA Formal Complaint System mandated by the Disability Services Reform Amendment Act of 2018 (DSRAA), that a person who files a formal complaint may choose to have an informal supporter or a formal supporter under the DSRAA’s Supported Decision Making Agreement, and has similarly included those options in a draft policy and draft procedures for the complaint system, which will become operational after revised Final Rules are published.
- The DC team was accepted to present the results of this project at the National Resource Center for Supported Decision-Making Symposium on June 10-11 in Washington DC.

DDS has reported to the Family Support Council that they are presently developing

- An in-depth training for the Rehabilitation Services Administration, Developmental Disabilities Administration, and Disability Determination Division to build knowledge of and competencies in SDM.
- A Train the Trainers Curriculum for other district agencies especially in the Human Services Cluster

- Practice scenarios for these trainings to enable participants to take a hands-on approach to learning about SDM and its relevance to the work of the relative administration/division

A continuing goal from the community for this effort is to ensure that the training and rollout of SDM in DC continues to utilize a community-based approach and that the recommendations and discussion/suggestions from this project are utilized effectively. There is an expectation that SDM trainings will be informed by:

- Family Support Council Focus Group Final Report
- Quality Trust's National Resource Center on Supported Decision-Making trainings and the organization's other available content
- DDS's experiences holding SDM trainings to date
- The needs of Human Services Cluster District agencies' staff

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

***Note:** The DC Project did not receive funding for this project from NRC-SDM, only involvement with the CoP thus no budget is provided in this final report.*

Attached Products:

SDM Focus Group Session #1 Executive Summary

SDM Focus Group Session #2 Executive Summary

SDM Focus Group Session #1 Agenda and Facilitator notes

SDM Focus Group Session #2 Agenda and Facilitator notes

National SDM Conference DC presentation

DC Project Synopsis and Quarterly Reports

DC DDS Key Findings on SDM