

Family Support Council - Supported Decision Making Focus Group
Session #1 World Cafe
Supported Decision Making in DC: Come & Ask, Come & Learn, Come & Develop
*Thursday, January 24, 2019, 12:30-2:30pm at OSSE, 1st Floor, Eleanor Holmes Norton
Conference Room II, 1050 First Street, NE*

Purpose: The FSC is convening two sessions in a focus group format (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) will play a significant role in designing trainings and SDM rollout at key agencies in DC.

EXECUTIVE SUMMARY of Group Discussions

Round 1 – Questions:

- 1) “Based on what you heard this morning from the presentation on SDM or what you already know, what questions do you have about SDM?”
- 2) “What do you personally think/feel about SDM?”
- 3) “What worries do you have about SDM?”

Key Themes from discussions:

- How often does SDM agreement need to be signed, reviewed, reassessed, how do we incorporate use of a “team” of people
- How is consent withdrawn? How do you replace or change a supporter (for preference, or because a supporter moved or is incapacitated)
- Need training to show the difference between SDM, POAs, guardianships – explaining ALL the options
- 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
- Family concerns: fear, lack of supporters, letting go, understanding the “logistics” of SDM
- What are the protection levels to eliminate abuse? I.e., How do we support people who may be choosing something that may not be healthy for them?
- Ensuring real self-advocacy – and not allowing the supporter to be making the decision
- How do we train self-advocates to have the confidence to make decisions?
- Do we need materials prepared in various developmental/age appropriate levels
- [What would be the parameters of an SDM Agreement
- Create a list of characteristics in choosing a good supporter
- Logistics of using the form – do you carry it with you, do you have it on file at doctor’s office, etc. do you file with an agency?
- Do we create an annual training program? For families, schools, agencies?
- Create a list of resources, organizations and advocates who can provide SDM information and understanding
- Information toolkit showing where to get SDMA forms plus an additional into regarding supported decision making
- Understand with that will be a cultural shift with families and communities to make SDM the default instead of guardianship, i.e., Guardianship was a threat...”If you want services you need guardianship”

- Shift in schools and in hospitals because all they have and all they know is guardianship
- More outreach to the “core people” about SDM instead of only families and service care providers (schools, hospitals)
- Trainings at schools, agencies, community organizations, medical community, financial institutions, faith-based organizations

Round 2 Question:

Notes: each table group had 4 different items/resources used by other states in their SDM marketing and training – in this round- the goal is to get the reactions of the small groups to these resources and what resonates with the participants and what might be used for DC

“Look at each of these 3 pieces of collateral (handouts, resources, etc.) used in other states for SDM, for each one, what do you like about it, what do you not like about it? “

(Top 7 Things from Indiana)

- Need accessible language, need more infographics and visuals
- Have different tools for different audiences (parents, self-advocates, agencies, banks, etc.)
- Can be reference sheet after training a “take-away”

(Scenarios)

- Like the scenarios, maybe one per life stage, provide answers or directions, provide more definitions of key words, concepts, include scenarios for when a person doesn’t support your decision, add a “what would you do” element to discussing the scenarios
- “Alternatives to guardianship” and “set a plan for success” are good language
- References/highlighting on “mentoring” are helpful

(Flyers from SC)

- “Straight to the point”
- More of a marketing piece (not a training piece)
- Develop different materials targeted to audience
- Students, families/parents, government agencies (break it down)

(General comments on training materials)

- Use video more! Or an interactive tool/online guidance?
- Answer these questions with materials:
 - What’s it going to do?
 - How’s it going to work?
 - What is the impact on me and my family?
 - Is it a good thing?
 - Recognize it’s a change?
 - How to get to a place that is comfortable
 - Being clear that person can make their own decisions
 - Across audiences
- Need technical Q&A for those expected to honor SDM and SDMA’s

- Clarify SDM as concept not just agreement
- Differentiate use of SDMA in school and after school (graduation)
- Highlight key points: A person may need SDMA and POA, More clarity needed-different tools (SDMA, POA, guardianship)-how get, how to revoke
- Add contact List i.e., primary agency contact list
- Have diverse photos
- Add Q&A section
- Where do you start? Where do you get forms, how do you process, etc.

Round 3:

“Dream It! Describe your ideal scenario for supported decision making systems AND trainings.”

- A SDM Training for every SPED coordinator in DC
- Schools incorporate SDM in their transition plan-make that an automatic conversation
- General understanding that SDM is a civil right issue, and we need to allow individuals with disabilities to make decisions (and mistakes!) on their own volition
- Create a Community of Practice for supporters to understand their role, and find resources and learn the difference between being a supporter and being the decision maker
- Organize an “expert group” on SDM to be available for questions
- What do we do about people who don’t have a personal connection to a supporter? Create a pool of volunteer supporters?
- Make trainings and curriculum for medical students, teachers, therapists, lawyers, finance professionals.
- Full translation of materials, and interpretation for all communities
- Training at transition age especially w/ whole team facilitated by an expert on SDM
- What should a self-advocate cover with their supporter? Is there a “get to know me process”, should we add person-centered resources to this role-out?
- Create a set review period of SDMA for Quality Assurance
- Conflict resolution when there’s tension between supporter and family
- Training with law enforcement, first responders
- Situations-real life stories about
 - o Supporters experiences
 - o Supported person’s experiences
 - o Reframe as experiences and learning opportunities
- Have commercials to advertise SDM or videos on lots of different platforms
- Create a video series about SDM in DC
- Start practicing with young adults to be to help them understand about supported decision making
- Present supported decision making during professional development in DC schools
- Incorporate self-advocates into all training – possibly a self-advocate video message?
- Reminding everyone involved that SDM is flexible!
- Start early with SDM language!

- Make sure trainings cover how to make SDM accessible, and also working with all kinds of self-advocates and disabilities; i.e., resources for non-verbal advocates
- Create timeline example (first do forms, check in at 3 months, etc.)

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FACILITATOR instructions and Notetaking pages

Agenda

		Notes
12:30-12:55pm	Set-Up, Lunch Boxes & Welcome (Molly & Daisy) SDM presentation (Morgan Whitlatch)	As attendees arrive - they should sign in and take some food and find seating at one of the 7-8 table groupings. Molly & Daisy will welcome everyone and review the purpose of the session, and introduce Morgan Morgan will have a powerpoint and present the basis of SDM and outline of the new DC law.
12:55-1:00pm	World Cafe instructions (Molly)	Each table needs one Facilitator: Chioma, Emily, Montrel, Joan, Rhonda, Carol, Alison Molly will explain how the discussions and rotations will work and timing. Facilitators should encourage their table attendees to use the paper at their tables to write notes, draw pictures, highlight their thoughts. <i>Facilitator notes: You should plan to take notes of the conversation at your tables or assign a volunteer at the table to take <u>notes ON the notetaking pages provided</u>. These will be used during the harvest section of the session. Facilitators should try to allow space for everyone at their table to share, talk or write on their paper based on the questions for each round.</i>
1:00-1:20pm	Round 1	Questions to ask your table: 1) Based on what you heard this morning from Morgan or what you already know, what Questions do you have about SDM? 2) What do you personally think/feel about SDM? 3) What worries do you have about SDM?

1:20-1:25pm	Everyone will be encouraged to move to a new table (or some can stay where they are - as long as there is a "new" group for each round	
1:25-1:45pm	Round 2	<p><i>Facilitator notes: each table will have a handout collection with 4 different items used by other states in their SDM marketing and training - in this round- the goal is to get the reactions of your table to these resources and what resonates with the table participants and what might be used for DC</i></p> <p>Question to ask your table:</p> <ol style="list-style-type: none"> 1) Look at each of these 3 pieces of collateral (handouts, resources, etc.) used in other states for SDM, for each one, what do you like about it, what do you not like about it?
1:45-1:50pm	Everyone will be encouraged to move to a new table (or some can stay where they are - as long as there is a "new" group for each round	
1:50-2:10pm	Round 3	<p>Question to ask your table:</p> <ol style="list-style-type: none"> 1) Dream It! Describe your ideal scenario for supported decision making systems AND training in DC.
2:10-2:30pm	Harvest/Next Steps	<p><i>Facilitator notes: Participants will have a 5 minute break while the facilitators gave to go over the collection of your notes; we will highlight common themes from each round. These will be presented to the larger group in our last 15 minutes, for their response and to plan the topics for Session #2 on March 28, 2019</i></p>

Facilitator Name: _____

Round #1 1:00-1:20pm	Questions to ask your table: <ol style="list-style-type: none">1) Based on what you heard this morning from Morgan or what you already know, what Questions do you have about SDM?2) What do you personally think/feel about SDM?3) What worries do you have about SDM?
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Notes:

Facilitator Name: _____

<p>Round #2 1:25-1:45pm</p>	<p><i>Facilitator notes: each table will have a handout collection with 4 different items used by other states in their SDM marketing and training - in this round- the goal is to get the reactions of your table to these resources and what resonates with the table participants and what might be used for DC</i></p> <p>Question to ask your table:</p> <ol style="list-style-type: none">1) Look at each of these 3 pieces of collateral (handouts, resources, etc.) used in other states for SDM, for each one, what do you like about it, what do you not like about it?
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Notes:

Facilitator Name: _____

Round #3 1:50-2:10pm	Question to ask your table: 1) Dream It! Describe your ideal scenario for supported decision making systems AND training in DC.
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