

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

Purpose: 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.

Based on the reports and discussions from these two sessions, the Family Support Council is making the following recommendations:

1. DDS should design a “train the trainer” Supported Decision Making module in collaboration with pertinent key agencies in DC (to include: DC Health, Department of Health Care Finance, Child and Family Services Agency, District of Columbia Public Schools, Department of Behavioral Health, and District of Columbia Office on Aging, Aging and Disability Resource Center) 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 PowerPoint 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.

EXECUTIVE SUMMARY Supported Decision Making Focus Group Session #1 January 24, 2019

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- How is consent withdrawn?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
- 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’s for Quality Assurance
 - Conflict resolution when there’s tension between supporter and family
 - Training with law enforcement, first responders
 - Situations-real life stories about
 - Supporters experiences
 - Supported person’s experiences
 - 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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EXECUTIVE SUMMARY
Supported Decision Making Focus Group Session #2
March 28, 2019

Round 1 – Questions:

1) How often should an SDM agreement need to be signed, reviewed, or re-assessed? How should that work?

- Whenever a person is dissatisfied, though people should have access to a mediator too. Not all supporters are going to be “yes” people, so agreements should not automatically be eliminated just because there is a disagreement.
- Whenever circumstances change
- SDMA’s are a legal agreement, and should be signed, witnessed, notarized, etc.
- SDM agreements should include protocols about when it will be reviewed and how it will be reviewed
- Ask, why do you want to change your supporter?
- How is this person supporting you?
- How does your family communicate/get along?
- When the individual changes their mind and feels that it needs to be changed
- Changed yearly with options to review with life events
- Important to know what the person wants
- The person needs a greater understanding so they can decide how often they want to review
- If someone in DDA supports, maybe there is a question asked annually at an ISP meeting if the person wants to review the SDM
- It should always be emphasized that a person can make a new one when they want – but there should be clear understanding that it is a legal document and it should be a thoughtful process
- SDM agreements should not just be a piece of paper to sign at an ISP meeting and should not have an automatic expiration date. ISP meetings are a place where discussions about SDMA can occur – but don’t need to be.
- If the SDMA includes an expiration or review date in the original language

2) How would we incorporate the use of a “team” of people as supporters (i.e., a group of siblings)?

- Supporters should not be paid
- How can case managers raise red flags? Who has oversight over supporters? Would that oversight person be on the team of supporters?
- Could supporters choose areas of expertise? Financial? Medical? Living arrangements? Legal? Travel? Dealing with family? Educational? This should be allowed. Everyone should sign the agreement and some will have to commit to more frequent support than others.
- For safety, have backup supporters, or others who know what’s going on.

- Relationships mapping and identifying a team (maybe during ISP)
- Use communication styles with different teams
- Consider supporters outside of direct family - parents don't necessarily need to be part of the team
- What are the roles of the team if this is used?
- Perhaps a team based on topic or issue (i.e., one for medical, one for housing)
- Consider location (local or out of state)
- Each person should be able to decide how many supporters they want
- There has to be one agreement for each supporter – so if the person with a disability chooses a team approach – there still has to be an SDMA for each person involved.

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

- For businesses – we should approach the Better Business Bureau, Chamber of Commerce, etc. and inform/educate them
- Public Awareness Campaign – PBS stations, PSA's,
- Peer to peer communication within different communities – doctors, bankers, translate materials into different languages
- Professional conventions, associations – connect with them to see how we can make this make sense to them – table at events?
- Approach religious organizations, disability ministries to educate about SDM
- Incorporate SDM into person centered thinking – talk about these as complimentary practices – “realize you're working for the person”
- Model the Person Centered Training program
- Training should involve people with disabilities and community involvement
- Survey banks, agencies, etc. to promote training
- Webinar series of trainings
- Public campaign to train staff at agencies to medical community to services and companies
- Share with all DC Communities of Practice (i.e., COP-Secondary Transition, Supporting Families, Cultural Competency, School Based Mental Health, etc.)

Comments/Clarifications Regarding the SDM Law on the Discussion Points/Questions #1-3:

- SDM is a legal agreement, so if a person is dissatisfied, the form should not be automatically pulled out and re-filled out – a person should be referred to an advocate or attorney
- It should be made clear that the SDM form is not a mandatory form to be filled out every ISP – it should not be the responsibility of the Service Coordinator
- An SDM agreement is powerful in the hands of the person that it's about – that person takes charge of getting it completed and decides how it's used

- There needs to be a separate SDM agreement with each supporter: There has to be one agreement for each supporter – so if the person with a disability chooses a team approach – there still has to be an SDMA for each person involved.
- A the person with a disability may have an SDMA and power of attorney (it is not either/or)
- Comments on mediation: changes to a SDMA happen when the person with a disability wants it, a designated supporter wants a change, and if there was any expiration date on the original SDMA; it is appropriate to offer mediation as a tool if the person with a disability and their supporter are at odds – but the decision does lie with the person with a disability. And, agencies should be making the person with a disability aware of organizations who can help with advocacy (i.e., Disability Rights DC, Quality Trust, AJE)
- Even if supporters are dissatisfied with the outcome of mediation or whatever discussion happens when a person is dissatisfied, the person is still in charge and the agreement can still be revoked
- A person with a disability cannot be “forced” to go through mediation when they say they want to change their decision maker, but this could be encouraged and made available.
- Law says you have to have one agreement per supporter
- Training supporters is important – they should know their role – they do not make the decisions for the person
- Coordination of supporters – each person decides how they want coordination to happen
- If there are multiple facilitators, can there be one coordinator? Suggestions can be made about best practices regarding number of supporters
- Have people with disabilities meeting with doctors, lawyers, in person explaining SDM
- SDM Hotline phone number to call with questions
- Use one-page profiles!
- SDM Ambassadors at DC agencies: DBH, DC Health, DACL, ODR, OHR, DDS, Ofc Aging
- Create a “Best Practices” resource that could provide advice to agencies and community such as, 1) always talk directly to the person with a disability, not the supporter, 2) Use relationship mapping to determine a supporter or team of supporters
- There can be both formal and information supported decision making relationships

Round 2 – Questions:

4) What are ways we could deal with family concerns: i.e., fear for adult child, lack of supporters, fear of letting go, understanding the “logistics” of SDM

5) How do we support people who may be choosing something that may not be healthy for them?

- Enlist other people who are trusted friends.

- Find a peer group for them to share pros and cons

6) Create a list of characteristics to consider in choosing a good supporter

- Committed, Honest, Dependable, Understanding, Caring, Patient, Empathetic, Sensitive, Curious
- Trusting – the person must trust their supporter, do you trust this person?
- Someone with emotional intelligence
- Someone who understands the DC community – resources, materials, laws, local issues
- Creative thinking/problem solver
- Someone who has integrity, is trustworthy, open to researching options for the person with a disability
- Find a contemporary, age-wise or otherwise
- Someone you already know and you know they respect you
- Someone who values your opinion on your life
- Someone with good judgment, and someone who respects the person with a disability's autonomy
- Someone who is ready to be a supporter, not the decision maker
- Age-appropriate when important to the person
- Someone who can plan for the future
- Good listener and good communicator and someone who understands how the person with a disability communicates (i.e., consider non-verbal communication, extended time to communicate, etc.)
- Family member
- Someone who understands the person with a disability's family dynamics
- Not afraid of taking risks, or stepping back to let someone make and learn from their own mistakes, someone open-minded
- Someone who knows specifics about things that are important to the person (e.g., traveling to Paris)
- Tech savvy
- Knowledgeable about assistive technology, banking, financial, housing, etc.
- Knowledgeable about field of disability
- Knowledgeable about the laws, and the rights of the person with the disability
- Effective communicator
- Someone who respects the person with a disability and understands they are a supporter, NOT the person who decides; someone who has confidence in the person with a disability and communicates that to everyone in the process
- Diplomatic and patient with the person with a disability
- Someone who is available to be present when needed
- SDM should allow the person with a disability to have positive experience and support their self-esteem – it is important for the person with a disability to not become “invisible”

- Someone who makes the person with a disability feel good; believes in, pays attention to and values the person with a disability; someone who knows the values and preferences of the person with a disability,