

SDM-TAP Community Conversations

Summary Notes from Breakout Sessions

Community Conversation Date: 10/25/23

Community Conversation Area of Focus: SDM in Legal Settings

Note from participant for future meetings: To help with these sessions and generally - Would be wonderful if we could provide questions ahead of time so people who use AAC can prepare responses.

1. Self-Advocate Experiences

Megan: Has had mostly good experiences with supported decision making.

Sandra: The guests in the room may not have any experience with SDM so they don't know how to answer this question.

Lourdes: Not a self-advocate so cannot share on this question.

Andrea: This question does not apply to her but works with many families with family members with I/DD who have no idea on SDM. Many comments from the school district not allowing family members to share/be involved in their planning and the SD are not aware of the SDM. Any ideas on how to make SDM more effective.

Laura: Experience of 22 years as a parent advocate and has served on committee in schools, and supported families in the work with IEP. Helping families understand they can request documents in Spanish, if they do not agree they do not have to sign, etc. SCDD should work with SD and start curriculum in Spanish and various languages for families/parents. After the pandemic, we have more access to technology and using that to spread the word and information. Sometimes schools just check boxes and do not assure families are indeed understanding the information provided, creating a catalog for families/parents and assuring it is accessible. Also making sure parents are prepared for this moment of age of majority and not just reaching the age of 18 and being told you can no longer be involved in decision making for your child. Put a poster with QR code on finding more information on SDM all over schools, etc.

Ivon: Just had an IEP, and asking him about his personal life such as where to live, jobs, etc. using pictures/images on this however she did not find this appropriate for her child being asked to live outside of the family home.

2. How do we reach the communities who need the most support with SDM?

Megan: Education; word of mouth; brochures; presentations to various groups; Autism Society of San Diego.

Zach: Through Facebook or media websites; have self-advocates do presentations on SDM to other organizations. Information about SDM in plain language on the SCDD website. Linked in; court systems; share the information with DDS and ask them to put it on their website.

Sofia: Local churches, community center, public benefits offices; connect with parent support groups or parent leaders in these communities.

Jeanne: Present at groups for people with mental health concerns and groups for family members; NAMI – nonprofit for people with mental illness

Ale: TV commercials, YouTube ads; advocates.

Reva: Is information getting to attorneys who are helping people with conservatorship, so they know about AB1663. Is there energy going into educating people who do conservatorship?

Miny: San Diego County Public Defender office; they have a special unit to serve mental health and juvenile court matters.

Tony: Educating service providers, such as teachers, doctors, caregivers, lawyers, and bankers so they can raise SDM to their clients/consumers as a possible decision-making tool.

Lourdes: I am an IF in a rural area, and everything is based on trust and who they feel comfortable with. It is not about money, it is about an authentic communication and noble heart. When it is about that you get more families that trust you and have connection with them. If families do not have the connection with services/agencies, they will not feel comfortable working with or reaching out to them.

Laura: Obtaining respect and trust from agencies/workers/services providers. Credibility. Especially with the immigrant community. Barrier of Spanish speaking families and illiterate. Providing more visuals and videos for those who cannot read or write. Training video or training in general that is designed for people in urban areas and do not include or consider people that live in rural areas.

3. What challenges have you faced within legal or judicial settings when trying to utilize SDM?

Sandra: There may be such a lack of information that there is no way to answer this question because professionals don't have experience. Family member is content with what he has in place, but he does have the ability to make his own decisions. There is nothing set in place for him to have a team and there is no formal process to create a team, and information about this isn't there even with a regional center in place. No one has been able to provide direction or support on this. Doesn't want him to be solely dependent on parents and need to get something in place so he can be prepared for the future.

Valerie: How much is fatigue from learning new concepts when the old ones have not been learned yet?

Sandra: Attended overuse and abuse of conservatorship webinar with panel from American bar association. Conservatorship has a role to play where it is needed, but we need to reframe our thinking around this so people have the ability to make choices. The ability to make choices should be a disqualifier to conservatorship.

Elizabeth: My biggest fear is not having people set up to help my daughter when I die. Her father is not in the picture. I have no young family members. What happens if she is left without support?

Matoya: Son is turning 18 in high school. An NPR broadcast on conservatorship had speakers discussing challenges and obstacles. That was the first-time hearing about limited conservatorship.

Sandra: Concern about law enforcement; they rely on competence, and we don't have great mechanisms to evaluate someone's competence. There needs to be a process that establishes the person's competence in areas they are not conserved. IQ testing is not reliable for this.

Lourdes: This type of support requires an attorney/ public notary. In Mexico there are different meaning for notary/attorneys who are specialized in specific areas and a public notary who are authorized to sign a legal document and they only require a 6 hours class to be this notary. Very different and especially in prices and process. So this can be a scary process when mentioned to Spanish speaking families. This will need to explained Spanish speaking families in detail.

Laura: Shared how some parents truly do not know the rights of their children.

4. What steps have you taken to overcome those obstacles? Did they work? If not, what else needs to be done?

Megan: Having a supportive family is helpful for using SDM. She is able to use it well with her families help.

Melinda: Communication partner for a nonverbal 24 year old adult. Also a nurse practitioner so she sees other families. She things a lot families are not aware of SDM. Could work through the court social workers so they can speak with families about SDM. Conservatorship is a series of responsibilities and so the two systems can work together for areas where a person needs more support and those where they don't. About this process: Would be wonderful if we could provide questions ahead of time so people who use AAC can prepare responses.

First group that need to be educated are people that work in psychiatric emergency services as they are often called on a consult to the ER as people come through. This is the population that may be conserved. Even that population of health care workers is uneducated about SDM and they should be practicing it as a communication method with everyone.

Tony: Maintaining attorney-client privilege is a challenge when a client has supporters involved in attorney conversations. Attorney-client rules may need to be revised to address this challenge.

Sharon: Since learning of SDM one of the things that continues to cause dismay for me is that since this is law and we have these Attorneys working on conservatorships, and judges granting the conservatorships.... Why is SDM not being discussed when the petitions are being filed with the courts. Chris with State Council mentioned the other day that when this information was presented to those on the legal side they said it was great information and wanted the information shared to relieve them of some of their cases.... If an attorney is representing families or even in the generic resources we use (Law Library) where conservatorships are discussed, why is not SDM not a priority for discussion as this is the start of the process. Maybe touching base with those generic resources could assist with spreading the word also regarding SDM.

Cecelia: She was told conservatorship was the only option. She stopped everything after talking with a MIND. She had already paid an attorney and lost money. She discovered there were options before conservatorship. She found out about SDM through her regional center social worker – told her about a Spanish language presentation at the MIND about conservatorship and SDM. Learning about SDM now.

Ale: Is SDM a document? Hospital, for example, will say an adult can make their own decisions – how does SDM work in the hospital or another legal situation?

Facilitator: Talked about some documentation and that this is not part of the legislation. SDM agreements have been used successfully and for some they are not honored. We are aware this is a barrier.

Carmine: I know this session is not focused on the school districts, but my experience is that parents are often told by district personnel that their soon to be adult child needs to be conserved. He is from regional center and hears from families that schools are encouraging conservatorship. SDM is new for legal teams and regional centers. Make parents feel that if they do not have conservatorship they are not allowed to have an opinion about their child's care. He thinks having powers of attorney or some documentation to support the use of SDM and that the person being serviced is on board with that decision. The adult person may not want their parent involved all the time and may want them other times. It is hard to know that when you are the professional without documentation.

Melinda: The medical system is expensive to ensure providers – in the absence of a legal document such as power of attorney (recognized by medical institutions) many medical orgs may not get insurance to operate or to cover their providers. There has to be a legal entity that protects providers. Medications are complex and have multiple side effects at times. The discourse now between the neurodiverse community of 'high functioning' individuals who are targeting technology and other professions and that needed for people who have higher support needs is disjointed. As a provider, SDM will not be an alternative to power of attorney unless it is encoded in law. Concern is that if she is going to prescribe a medication (e.g., an antipsychotic) for autism, she wants to know who the legal person to make that decision is – otherwise if there is not legal person and it is the individual making the decision she is asked to determine competency herself then she can't get malpractice insurance. Melinda sees SDM as an adjunct to conservatorship – should use SDM as a method not as a legal standing because she is not clear it has a legal standing. Melina wants to know more about how the law works.

Megan: Agrees with most of what is being said but not all of it. Melinda has an excellent point but also she needs to understand people are different. Its sad when family members think conservatorship must be the only option. You can't just group people.....*cutting out*....individuals with disabilities are individuals; you can't herd them all together. You have to look at people as individuals and you can't herd them together and stereotype.

Catherine: Can Client Rights Advocates employed/contracted by Regional Center's hold meetings to begin grassroots in the community and zoom?

Sandra: Son has experienced school getting him to send mom out of the room and then trying to convince him to decline the tools and supports he needs just to "try not using them". When pointing out to them that the accommodations were put in place because he needs them, they are not receptive to that.

Valerie: If people don't believe the need is there, or don't see the need clearly, there is still stigma and resistance to even provide the help.

Lourdes: It is important that POA, Limited conservatorship, etc. Clients from RC have to go through unjust decisions due to having to leave their day to day activities to go authorize their parents to sign /meet etc. Doctors are scared of attorneys & HIPPA law so it gets very complicated when they do not know about documents that give authorization to parents/families. All people need a circle of support when making big decision especially in medical settings/ legal decisions and usually those have to be made fast and in the moment and this causes problems for those who cannot have their circle of support their due to not having the appropriate documentation or these institutions not having the knowledge of SDM.

Laura: Having accessible resources, and trainings especially on age of majority. Providing the information also directly to the SA on their decision making and supports that they can access once at the age of majority.