

SDM-TAP Community Conversations

Summary Notes from Breakout Sessions

Community Conversation Date: 10/24/23

Community Conversation Area of Focus: SDM in I/DD Services Settings

1. Self-Advocate Experiences

Megan: Has been able to use SDM in her life because she has a supportive family. Specific example—she graduated with a high school diploma and wanted to go to college. Started an online college program and earned a Bachelor's in Sociology and a Masters in special education.

Erika: Is a family advocate her son is 26/28? Speaking on SDM in the hospital settings/medical settings, there is no respect for this document, they treat it like it is just a piece of paper. SDM is not accepted/valid in hospital settings. (para área médica, no hay respeto de este documento/papel cualquiera. Este documento no es válido en el hospital.)

Yudy: What is SDM and the difference compared to conservatorship. What about Regional Centers (RC), do they know about SDM? Is SDM a law and why doesn't everybody know about it? Facilitator responded and explained the purpose of these community conversations. Participant suggested writing a letter to all families to inform them of SDM, the law, and legitimacy of this new process. Facilitator explained that all RCs' case managers are different in what info they provide to families however all RCs did receive the directive of the SDM and are aware of SDM. Participant requested a copy of the SDM in law.

Lulu: Commented in chat that recording the breakout room does not give the privacy and allow participants to share their personal experiences.

Gricelda: Asked if this was written in law and if all institutions/systems are supposed to accept SDM. Facilitator responded and explained that they are aware and should accept otherwise this is what these calls are for or let SCDD know for future issues as well.

Yudy: What is SCDD's role is in SDM? Facilitator responded that our role is to notify systems and these community conversations will help with the focus of grants.

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

Megan: Suggests "just starting the conversation."

Bridget: She has 2 children and will need to use the self-determination program for her kids. Facilitator clarified SDP is different than SDM but the two are compatible.

Sandra: Transition programs often cut families out of communication. Also, families are often directed to conservatorships without knowing the implications. Question: what are we doing to reach out to family law attorneys and estate planners who are encouraging conservatorships simply because they are unaware of SDM. Families seek these services when planning for the future and these professionals often lack alternatives.

Chris: Recently presented to the LA Bar Association and conservatorship attorneys. A lot of them said that they are overwhelmed by people wanting conservatorship and would like to reduce their workload....changing the culture of attorneys may be easier than we think.

Megan: Is a member of People 1st and suggests reaching out to People 1st and other self-advocacy groups would be helpful. Social media, Facebook and Youtube, etc are also important. It is important to get accurate information out rather than relying on people to spread the information that may not be complete or accurate.

Melissa: Is a parent of a regional center client and an Independent Facilitator. Most parents have never heard of SDM and believe conservatorship is the only option. Melissa is well informed but not to the point that she knows where to direct people for enough information to implement. She doesn't know what is required to use SDM and inform regional center, medical staff, etc that they are using SDM. Melissa has never had any issue with her current regional center staff or medical providers but has concerns what would happen in an emergency situation with unknown providers, Believes she needs some document to show using SDM but unsure what that is.

Yudy: Inform others and let them know of SDM, as well as SCDD informing others in committee's/mesas directivas of this. What is SCDD doing to get the word out, such as trainings, etc.

Lourdes: I work with rural areas. Got in with a mom. She shared information with her neighbors, and they shared and establishing trust is important. It is just doing the work in that area. When one person in the Community knows and shares, Word of mouth Works. Personal Connection helps with building groups and organizations that Support communities. We need hospitals, attorneys, law schools, teaching this is the best option.

Peter: When you have connections with Community based organizations, make sure we are reaching out to those entities and know the culture of the Community.

Mike: Grant information needs to be shared broadly enough that those who need it know about the grants. That is a different kind of spreading the Word. Ed Roberts Center knows a lot about AAC providers.

Peter: shared organizations AAC.

3. What challenges have you faced within I/DD settings when trying to utilize SDM?

Jody: Daughter is 19 and when she went to the hospital, Jody printed out a power of attorney to use during the hospitalization. She is concerned what she needs to do to show they are using SDM. A neuro-psych eval recommended she have a limited conservatorship. Can SDM and conservatorship be used together? Regarding how to reach underserved populations, reach out to community services and providers (schools, therapies, parent groups, churches).

Rachel: She has encouraged families to use supported decision making agreements has been helpful to develop empowerment.

Sandra: It has been important to have community conversations with different cultural groups to have discussion about how SDM works within each culture. Important to have community leaders be the ones to present to the community to translate the concept of SDM rather than simply translating materials and resources.

Lori: Will there be a connection with the CDE so that SDM is integrated into the IEP structure. Lori also mentioned a mother told her she got conservatorship based on recommendations of professionals and was heartbroken because they had always used SDM and conservatorship was not needed. She wanted to end the conservatorship but learned that was a difficult process.

Ale: She came from Mexico over 20 years ago. She got conservatorship because when her child transferred from pediatric to adult medicine the pediatrician said the adult providers needed it. She is now questioning what will happen with the conservatorship when she and her husband die?

Noelle (Director of Devereux): Said there are many avenues to disseminate this information. Existing agencies and services have newsletters and family meetings and would be happy to disseminate information about SDM to their families and people they serve.

Rachel: Said at her RC they have alternative to conservatorship workshop that they do with OCRA.

Sandra: Families with children with complex medical needs are directed to conservatorship.

Rachel: People who don't speak can communicate with AAC charts/devices.

Gricelda: SA face challenges in all settings, e.x. even in a restaurant when we want to eat and being told our son is too loud due to sensory stimulations/etc. that should also be a conversation with public settings or the public in general. Others do not know people with I/DD might not understand the personal space, executive functioning, drooling, farting, etc. and want them excluded or isolated in public settings. How can SDM support people with I/DD in this area?

Lourdes: Clients are over 30. Many were conserved. They did not have options. People get intimidated about filling out the paperwork. Very few people are aware of the resources that help them navigate. Parent Network Groups can help each other with what to do and where to go for help. We need to help educate parents through these networks and help get them connected so they are not intimidated by the system. Having something that takes them step by step will help. Costs can also be intimidating when people don't know what the costs are. A list of trustworthy notaries would help.

Mike: SDM is not really around at all. There are pockets of its presence but overall, people are not familiar with it. There are people who are conserved who never knew of this and unraveling conservatorships is not easy. It is not a replacement of conservatorship; it is a tool to help someone make decisions. The challenge is, there is still a large percentage of those who have an archaic view, and there is also those who dismiss it because they don't see it as a viable option. It is a cultural shift that needs to happen.

Peter: I was told the (having trouble understanding), used SDM to help make decisions during this time and it was helpful. Sometimes in medical settings there is an ableist attitude. Wanted to be listened to and didn't have access to AAC to help communicate.

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

Lourdes: Medical doctors and providers often minimize/discourage family involvement when the patient is an adult. Need to teach doctors that involvement is important. Gave an example where a doctor initially refused family input but when they showed the doctor the 1663 legislation and said she would talk to the manager if doctor refused, the doctor agreed to allow family input.

Megan: Regardless of how informed people are about SDM, there is always something else to learn.

Alexis: Works with the San Diego RC and service coordinators and professionals need a lot more education, training and information about SDM and the need to first try less restrictive options before rushing into conservatorship.

Monica: Works with people who are elderly who don't have family to help support. They can often make decisions when people take time to explain information. Doctors want to have a quick, high level conversation and an immediate decision and push to have a decision-maker who can operate on their timeframe. It is important to slow the process and force the doctor to involve the patient. Monica has also had doctors tell her she is not allowed to simplify or have conversation or even tell her she must leave the room. Even when she provides identification shares her role, they sometimes refuse to work with her. She often asks the doctors and RNs to send in a nurse practitioner who can take more time to explain and then allow the patient to make an informed decision.

Sandra: The theme cuts across the professionals working with the elderly, in schools and medical providers seem to think they can dictate who they believe should be conserved based on what would be easier for their needs. Parents and families seem to be very supportive and believe their loved ones are more capable than professionals.

Megan: Has had situations where professionals wanted to exclude her supporters and she has had to refuse to cooperate with them until her supporters are allowed to be involved. Anxiety has a profound impact on her and many other people....support can have an important calming effect.

Ale: Is conservatorship necessary. She has found that getting medical records for her adult children can be difficult even with a conservatorship.

Monica: She often schedules an appointment with a nurse practitioner prior to the medical appointment to explain the needs and abilities of the patient and role of the supporter and ask that the information be entered into the medical records. Not all nurses will do it, but when they do, she has found the medical team has been much more supportive and understanding.

Bridgette: She has had bad experiences going into the community with her child with a disability. She is looking for a number to call, bracelet or other means to stay safe when she is in the community with her child.

Yudy: Many agencies do not apply the agency mission and vision like they say they do or assure their workers carry the mission through their work. It would be great to assure that agencies are kept in check.

Gricelda: Do not minimize the clients. Comment on agencies being the same people who deny and make it harder for families at time and the injustice of this towards families with I/DD. Receiving the same feedback and suggestions to families, e.x. remember to follow up on all

services, IEP, IPP, CM, Therapy, etc. families are tired and have so much to deal with, in general still accepting this diagnosis, etc. it is all too much.

Lulu: This would be a great spot to share tools and documents from this process to strengthen our skills for this new SDM law/process, specifically in each of the areas that we are invited to talk in. The issue with judicial/forensic and people w/ I/DD may not know their rights and does not have the appropriate defense/representation and family cannot be involved due to a legal dox. Jail is a terrible place for them and have no support/low quality life.

Zema: A challenge that people/families of people w/ I/DD face are not knowing the employees of agencies (public and private) or agencies in general for people with I/DD. We need those employees to receive appropriate trainings. A few days ago I completed a survey re: immigration/for immigrants, on the survey there was no question re: people with I/DD. Me and a group of parents had a meeting with the board and made the complaint and requested a revision of the survey to include people with disabilities.

Lourdes: Tell people the terminology and empower them to use it. Now we have better information that is evidence based, help them understand it. Combination of education, history, and empowerment. If people don't know the steps, they don't know what to do. It has to go hand in hand, you can only go so far.

Peter: It has to be both. If I go in as a patient, they only listen to a point. When I go in as an SCDD employee, they listen more. There should be a class for all social workers that is required to teach this. Since we have to change hearts and minds, it needs to be a multi-pronged approach.

Mike: Our system is extremely siloed. We need to engage the silos simultaneously. Anywhere people receive access to federal or state assistance should be engaged so people will have the resources available to them when they reach out to these places for help. Regional centers are the conduit and should be used to spread information.

Lourdes: AJCC information. She used to work there. American Job Center of California.