

# SDM-TAP Community Conversations

## Summary Notes from Breakout Sessions

**Community Conversation Date:** 10/26/23

**Community Conversation Area of Focus:** SDM in Medical Settings

### 1. Self-Advocate Experiences (15 minutes)

No self-advocates wanted to share.

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

Make sure that outreach is culturally appropriate.

Maureen: Clinical SW at UCI Autism Center – working on transition to adulthood – using MIND institute and ACLU SDM materials. That is where she is starting from. She thinks that one of the things almost all of their patients that would benefit from an SDM model have an IEP at school. There was a report earlier this year that families are being told to seek conservatorship disproportionately by school teams. So outreach around the special education arena may be a really good place to provide information and technical assistance. Hoping that we can push for something to happen in that space. Not that schools need to provide the training but that is a place where you could reach a lot of people. Here is the link to the report she mentioned: <https://www.dds.ca.gov/wp-content/uploads/2023/03/ExpertPanelFinalReportMarch2023.pdf>

Melissa: Education to medical and healthcare providers. Educate those individuals that would be faced with working with that SDM process with the individual because as much education as we want to give to individuals we support and their families if they are unable to have SDM recognized it just becomes very frustrating for those families and starts it off in a very adversarial way when they are ignored.

Carole: It terms of districts or IEP teams sharing that the parents can't be part of the IEP process unless the child is conserved she knows that is discussed. There isn't a second layer about the fact that supported decision making can be discussed or that there are things a child can sign that will allow parents to continue to participate. There is a fear in parents that they are going to be shut out of the meeting. SDM will be a heavy lift for families and SDM users. It is hard enough to get someone to recognize a person who has an I/DD has a voice. She loves SDM but she is also a person who has refused to talk to her totally verbal child about symptoms. You need to have an ally that has trust equity who can get us into the rooms and communities of those who are hard to connect with.

Alex: Home and community based services final rule is a new law where institutions can't function in the same way. He is going to provide a link to resources about this new law and what a person's new rights are under this rule. There are easy read and plain language versions of this law. <https://autisticadvocacy.org/policy/toolkits/hcbsrule-2/>

Melissa: Start having discussions about SDM early on and training and preparation for an individual to be ready for that. If a discussion of SDM could be a part of the teaching and instruction for Special Ed teachers because they would have that education in the beginning and take that into their classrooms.

Maureen: Thinking statewide and specific populations in health care there are also issues with insurance like DHCS, managed care plans, etc. There seems to be a lot of variation county by county. Sometimes their health plan is more understanding than other situations. The CalAIM effort that included ECM for I/DD individuals it would seem like if we can get info to the MediCal and managed care plans and the ECM programs so that they can understand and suggest SDM. There are supposed to be promotores tied to ECM that could address some of the specific language and cultural needs as well.

Alex: Want to encourage people to check out the resource he provided about the HCBS final rule. He isn't an expert on HCBS but he knows that if a client is told what their rights should be and there is a place not meeting those rights but the client still chooses to live there that is an informed choice. <https://autisticadvocacy.org/policy/toolkits/hcbsrule-2/>

Carole: Is there any guidance from the American Academy of Family Practice on SDM that guides medical professionals. How will they know what to do if there isn't guidance or information for them? When she thinks about SDM all the other decisions are important but medical stuff is SUPER important. Maybe that is something that could be worked on – guidance for the folks that need to honor SDM agreements. So they can honor their legal obligations so they can do the right thing. They also need to protect themselves too. She is all in and is on this journey with us. She hopes and wishes for the day that they can use this for making decisions. When she first looked into this there was literally nothing. It was so bare bones. She is grateful we are talking about more engagement and really activating this great practice.

Maria L: Has a son with severe/high support needs Autism, he has had a good experience with supportive decision making in hospital settings, everyone has been patient thank god. I am here to be more informed on the topic.

Maria C: Has also had a good experience so far since her son is a minor and she can still accompany him still. Also here to know more about SDM.

Ralph: Through public services, schools, community centers, and can market things in other languages. Churches as well. Supermarkets that serve other cultures. Rely on post office to help get the word out. Banks, small community grocery stores, fire departments, police departments, especially in rural areas. Tribal directors/leaders for native American communities.

Jordan: More access to education and public events. Social Media groups can help spread the word. Health fairs and other resource fairs.

Jillian: Information accessibility on websites. Having disability specific information include this information. Working with organizations like Kaiser to have specific pages focused on knowing your rights.

### **3. What challenges have you faced within medical or healthcare settings when trying to utilize SDM?**

Reva: Plug for person centered thinking. They used that one page profile that she can use when she goes into a medical appointment, especially when seeing a new doctor, it gives her

positive control. They found that getting that one-pager into the doctor in advance of the appointment and if they honored it she had positive control.

Maureen: She is in the healthcare setting and one of the things that they have noted with their own patients. Sometimes at the provider level there is understanding of SDM and they are on board with it but the 5 people who the family had to deal with before the provider were the problem (front office staff, insurance people, etc). There are needs for training in their job and understanding of policies. The other issue is that there are large health care centers and small health care centers – when you're dealing with a larger system they don't necessarily know your situation. Sometimes the smaller health care centers are easier because they know you well and understand your needs. When providers get training the risk management folks also need to know about the changes so they can support the providers. Continuing education might be something that we can use so that legal professionals in risk management positions with hospitals. DHCS/MediCal in terms of having a role with regards to large healthcare and hospital systems to embed education in those entities. Focus groups for risk management folks.

Ralph: lack of understanding. Educate medical personnel (all levels) so they understand HIPAA better. Don't let HIPAA be a barrier. Reach out to a specific person in a hospital and encourage education through that person.

Jillian: Effective communication with deaf individuals' presentation; COVID protocols made it difficult to have more than one person in the room, limiting effective communication. Lack of knowledge about how to use certain tech that would allow support to be present. Can be problems with providers to know how to bring interpreters into meetings. **Tara Lagu study:** There is a big hesitancy among providers to take the additional time to sit with an interpreter or talk through making decisions, doctors feel the need to move quickly. ['I Am Not The Doctor For You': Physicians' Attitudes About Caring For People With Disabilities \(healthaffairs.org\)](https://www.healthaffairs.org/content/policy-analysis/20190919) Maybe it is also important to educate the users of SDM on the positives/negatives for having a specific person on the team. Develop education on how to build the team that can help make the decision best for you.

Jordan: I see a pattern where healthcare providers don't always believe it if they have not seen it before. We have a lot of people who are addicted to drugs, sometimes doctors get a superhero mentality to get this patient off drugs and the patients are not willing to do what they need to do or get off the drugs. The doctors are not meeting them where they are at. Patients may not be willing to open up. Someone in the room who had lived experience can be more effective when trying to get someone to open up and SDM can help with that.

Valerie: Implicit bias, when doctors are dismissing the issues brought forth because they are assuming one thing. People may need help with changing doctors in order to be listened to.

Jillian: [Physicians' Perceptions Of People With Disability And Their Health Care - PMC \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/31411111/)

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

Maureen: They have been doing family education around this and developed multi-lingual plain language consent forms and medical power of attorney so that they can practice in their office and then use it when they have to see other medical providers. There is a need for practice

and demonstration. And going through the forms line by line. Literally go section by section to show them how to complete the form. They are based off of the ACLU SDM toolkit but the family may not have seen this so family members really need to understand it so they can work on it with their loved one. You can't hand it out and hope people understand. You have to do it in a demonstration way. They learned about SDM because they are transitioning to a larger adult population that needs to transition to adult care and so they used these other materials. They are setting themselves up to further support their community. Hopefully there won't be as much push back towards SDM. SDM should be the natural "try this first" pathway. Hopefully it will be easier as there is more education for everyone. Link to the tools they rebranded in their healthcare setting: <https://www.aclu.org/documents/supported-decision-making-resource-library>

Reva: Can you use the SDM for Request of Information? Or to overcome the fear of HIPAA violations with supporters in medical appointments?

Jillian: (agreed with Ralph), educate providers and work on ensuring that their training is more focused on care for people with disabilities, and ensuring that people can benefit from SDM by having that info at their fingertips. There is not a lot of information breaking it down, so having it be more specific would help. Show how it interacts with guardian/conservatorship. There is legal advocacy. Promote specific cases with outcomes. Providers asking if someone is using SDM and asking if they would like to use it, or know what it is, offering info on how to start that process. How to pull a team together on short notice and establish the team. Info referral. Planned Parenthood would be great to have on board with this and ensuring people have this as a tool so they are making informed choices.

Jordan: Education/exposure to information for providers, law enforcement, etc.

Ralph: Education to overcome stigma, the way a client may be looked at or treated, and encourage empathy.

Sheraden: We have under 20 medical schools in California...how do we ensure they have SDM training before they get to their residency? Trainings with crisis response workers. Give ER doctors a quick tool kit that they can give to those in crisis.

Valerie: Institution resource fairs (for their staff) if we could table at those events and use that opportunity to educate staff.