

SDM-TAP Community Conversations

Summary Notes from Breakout Sessions

Community Conversation Date: 10/23/23

Community Conversation Area of Focus: SDM in Education Settings

1. Self-Advocate Experiences

Suggestion for future meetings: Need to submit the questions beforehand because it takes a long time for people who do not use speech to communicate to tee up their answers.

Communication partner for a person with a disability explains: Individual they support never by the educational system to provide feedback about decisions made about that person. Our systems do not do a good job explaining all the support options available to people. Speech and language professionals do not endorse the use of letterboards, which is also a barrier to communication.

Self-Advocate: Have not been able to find help. Lives by themselves, in a house, and gets overwhelmed with decision-making. Does not know where to get support.

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

Program manager at regional center: Getting info out there about supported decision-making is needed *across the board* and not necessarily targeted to underserved or specific communities. Families are getting messages from schools and doctors from the earliest ages that they should explore conservatorship. This means: more publicly available information, sample forms, additional trainings, etc. Trainings are needed for regional center staff too, since service coordinators are often suggesting conservatorships.

Everyone assumes there is a conveyor belt to a conservatorship system. And even when families try alternatives (like POAs or SDM), schools and medical professionals don't recognize those alternatives. So education about SDM needs to go to systems and institutions (education and medical) *in addition* to people served and their families.

They should offer information about SDM at IEP meetings when the age of majority.

Family networks are critical to reaching AAC users and/or families at or below the poverty level.

Family resource centers are already doing a lot of this work. Many families are never going to go through the courthouse and through conservatorship. Need to go through community leaders figure out how to reach those communities in a way that makes sense as to both the words and the meanings behind those words.

I was expecting to learn more through the regional center. Supported decision making was mentioned and we were asked if we were interested but we needed to be educated on what it is and how to begin.

I'm a parent of a 17 year old. I'm bringing up SDM with all her physicians in advance, while she's still in pediatric care. So far, her pediatrician already knows about SDM, but my daughter

will be able to stay with her pediatrician until she's 22. As she transitions to adult care/specialists, I'm hoping ped specialists can help them inform re: SDM.

“Grand rounds” can be used in the context of education or medical to help educate professionals in the system about SDM.

Courts have social workers that come into homes to investigate conservatorships. Consider educating the court social workers about alternatives to conservatorship like supported decision-making.

Regional center employee and family member: Lawyers who do conservatorships talk to parent groups and join meetings and use fear based practices to create a pipeline for their business. Need to provide education and outreach to wherever parents are gathering to provide a different perspective.

It seems that there are no thoughts about seniors who are isolated with mental challenges and need support. Work through university and college level nursing programs, or IHSS or other agencies that work with seniors. Mailers, churches, community activity centers, senior homes as word of mouth. I'm thinking the local senior centers could have someone come in to discuss SDM. Also the Department of Aging, WISE Senior Services. Estate planning and end-of-life planning firms.

Multi-media formats about SDM.

Yudy: Is SDM for RC client's only or for the general public? How to navigate when Service Coordinators say due to HIPAA they cannot disclose info without a conservatorship on file – also mentioned when doctors do this how should one navigate such situation.

Zemar PHP: What can you do when someone only speaks Spanish or if someone cannot verbally speak due to their diagnosis, how to navigate SDM. Would like for this to be a program that is personalized and to have adequate training and obligated training for those who are in the support team of the person trying to be a part of SDM. They should have background checks for those who are on someone's support team, are trained, and are knowledgeable on the person's dx.

Yudy: This program should get help from RCs and other agencies to promote these trainings, to create flyers/share flyers informing people that SDM is an option, present this to support groups as well would be helpful.

Zemar PHP: Teachers and SpEd teachers should also be educated on SDM and this program so they can better support students and families and to know there are other options outside of conservatorship.

Brainstormed Ideas:

- DSS and DDS – should call
- Relating to students and adults—FRCs and RECs and SELPAs
- Parent w a conservatorship: Even with that, it is very difficult for behavioral health folks to communicate w me. That's the biggest barrier for me. (Son w limited conservatorship).
- Outreach to families will be tough, especially to Spanish language families. Need trusted partners / go where those folks go and feel safe.
- Regional centers.
- Autism Societies and other community partners.

Network w other training conferences.
Transition Fairs.
HCBS trainings should include SDM.
County Public Health Depts.
Social media outlets
Colleges
Zach Hill (SA) offered to help w trainings.
DSPS programs at colleges
Online learning platforms like Teachable, In-Flight Academy, etc. getting it in their content. [Adjoin - Inflight \(talentlms.com\)](https://www.talentlms.com)

At what age is SCDD targeting/attempting to roll out Supported Decision Making? Although it is not a necessarily a replacement for Conservatorship (but can be), that process usually doesn't get initiated until the Age of Consent is processed in the IEP process for transition age students.

Education Professionals also need to continue the evolving approach to have Student Led IEPs... transition age is rife with a lot of movement for families.

I would think that the notion of Supported Decision Making should be launched EARLIER...

Parent: For this to work, you cannot wait until transition age. It's got to start very young. It will be an uphill battle. Families aren't getting the training early on, so they are not often in a position to adapt to this. Elementary school age. Making decisions that are workable at that age to ensure there is practice for students and families early on. We have not prepared kids and families for this model.

Professional: (The parent) is correct... the skills of Self-Advocacy are not emphasized or cultivated within the school system and the support community.

Professional: Local cultural communities- Tribal communities, health and education entities that are intersectional in nature

3. What challenges have you faced within today's area of focus when trying to utilize SDM?

Program manager at regional center: Concept of SDM has been around a long time, but is still new to the people who need to use it. Have heard from school psychologists that they believe conservatorship is mandatory. Even the concept of including people in their own meetings hasn't gained traction, including working through how to make those meetings accessible to the person. Schools often get nervous about documents that get signed by an individual who isn't conserved using SDM because they are afraid of liability if they act on those decisions.

Mother of 19-year-old daughter. Daughter submitted a letter stating that she wants her parents involved in educational decisions. Psychologist urged her to get a conservatorship.

Important to emphasize decision-making through the IEP process because once a student turns 18 and someone suggests its time they practice making decisions, it's too late. Teachers need to be taught about how to involve the students.

Yudy: When her son WAS in school, the school just looks at age. Once they turn 18 years of age they think they are an adult and can make their own decisions and no longer give parents

a chance to be involved unless they have conservatorship. The schools don't take into account cognitive age. How will the program ensure that the SA selected the person supporting them through SDM? Particularly those SA's who are non-verbal? Who can parents turn to to educate themselves on this topic and to find support if they are not well versed on this topic or unable to be the one to provide SDM to their loved one, where can they find help to find someone else.

Ed environments and pros push people into conservatorship as the student gets close to transition age.

Parent: IEPs are driven to the decisions to the direction the entity wants to see for that student (regardless of what the student and family wants). Very problematic. If the student or family shares something else that is on the contrary, they may be met w Qs about conservatorship. Whoever is saying the thing that the IEP wants to do will be given the weight.

Professional: Lack of awareness of Supported Decision Making, since it is a relatively newer concept/ idea shared broadly (even though it is NOT new in reality), and the recent legislation basically legitimized it... from my perspective, districts will share conservatorship because it is known. Truthfully, the notion of Person-Centered Planning in transition age programming is not very well known either.

Families don't know of their rights in IEP so they don't even know how to stand up for their and their student's decisions, much less guiding SDP in IEPs... the challenge with utilizing the IEP process as a forum to have Supported Decision Making as a process, is not just the fact that IEPs are run similar to what Ms. Baird stated, but the fact that IEPs do not have student power over their parents and professionals is not legally recognized until 18 or the Age of Consent

Self-Advocate: I think SDM needs to be promoted in areas that have a high risk of experiencing emergency so promoting this information to the first responders would be a great idea

Karina: I believe more workshops for SDM would be helpful. Especially how to write one up. My child is in a transition program, and they didn't even take it seriously when I told them that I wanted to use SDM during her IEP. I provided them a copy of Assignment of Educational Decision-Making Authority California Education Code Section 56041.5. They just wanted to confirm that she was not conserved. The administrator even stated she didn't have too much information on SDM.

Wayne: Schools are used to having parents make decisions and they want to keep it that way. Needs a whole attitude shift. Schools don't like to consider that students are becoming adults and don't want them to make decisions—don't think they are capable. Ed professionals don't have enough info to support SDM.

Other areas to promote SDM would be with Educational Advocates, SLPs, Special Ed attorneys, Judges and Administrators currently dealing with Conservatorships.

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

CDE's website should be updated to include information about alternatives to conservatorships because that's often a go-to resource for people seeking information.

Grants should go to organizations not affiliated with school districts. Schools have already determined what services they're willing to offer. They could be more helpful in sending information and notifications to families about supported decision making on a routine basis, but they don't need grants for this. Need to cultivate groups outside of schools. This is also a particular issue for people with speech related disabilities since speech and language professionals have refused to endorse the use of letterboards as a way to obtain communication access.

Regional centers can help be a voice for an individual and help educate families, schools, and individuals about SDM.

Use of trusted messengers, like one school district sharing good practices with another. Or students and families sharing info with each other. Statewide self-advocacy conferences or transition conferences are good forums for this.

Use of outside experts or assessments about the person's communication needs and decision-making capacity can help convince others.

Yudy: Getting conservatorship for her loved one was an easy process, but she does believe the agencies working with people with IDD need to have more empathy.

Regional Center: we put together a presentation for schools about alternatives for conservatorship and do it a few times a year. Professional communities like medical settings it is not well received. Still dealing w this issue even after 1663 passed. Work w local Federally Qualified Health Center and other health care centers and oversight entities.

Professional: I have been personally and professionally promoting Supported Decision Making with individual families with the after-school programs that my organization runs, and with the leadership and families of the Transition Program of my organization. The school district is not quite up to speed on this subject just yet. Noted that CDE- Secretary Thurmond- who has a background with the disability community.

SELPA level first- top down and simultaneously bottom up (Ala Costa Centers in Berkeley- we have both After School Programs and we contract with Berkeley Unified to provider Transition Age Programming).

I believe the IEP has a section to check if the individual is Conserved or not. It would be nice to have a SDM section.

Yasmin V. Parent of adult who is conserved: When her student was getting to transitional age, considering medical involvement that's when conservatorship. I want to educate therapists and others that serve our kids. This is a civil rights movement.

Gabriela heard of families getting push back and not having their SDM supported in medical and ed settings.