SDM-TAP/AB 1663 Coalition Meeting
8/31/2023
Breakout Session Notes

All Breakout Session groups had the same 3 questions. Here are the questions they were presented with:

Question #1

The grants program ($3 million) will assist implementation of SDM and systemic change so that SDM is accepted and supported within the primary areas of focus below. Think about what areas of focus have the greatest needs when it comes to Supported Decision-Making (SDM). Please rank the areas in order of need from greatest to least. Are there any other focus areas to consider? If yes, please specify.

- SDM in education settings
- SDM in legal or judicial settings
- SDM in medical or healthcare settings
- SDM in I/DD services
- SDM in financial settings

Question #2

SDM-TAP should expand and strengthen the use of Supported Decision-Making in California. What measurable outcomes would you like to see from the SDM-TAP grants?

Question #3

Are there specific communities that need the most help to use SDM in California? If so, please specify.

Breakout Session Group Responses

Group One

1) Question One Discussion

a) The financial area should be its own focus area, separate from the judicial area and could include car dealerships, banks, credit cards, identity theft, being taken advantage of financially by friends/family who share accounts, etc.

b) The judicial focus area needs to make sure the courts are on board and using SDM as an alternative to conservatorships of all sorts. SDM needs to be used in crisis supports, mental health, LPS, diversion, criminal and family law systems (including in marriages/divorces). Many people come out of the criminal justice system conserved. Judicial settings do not always align with the "public safety" world (law enforcement, etc). SDM-TAP should coordinate with judicial council (who also received money through

AB 1663) on the training materials they use to make sure they are consistent.
   c) Employment may need to be considered as an area of focus as employers can insist there be a conservatorship before speaking with anyone regarding the employee (possibly reach out to Chambers of Commerce).
   d) Judicial is the highest priority with education next, then I/DD services, then medical.

2) Question Two Discussion
   a) Reduce the number of conservatorships in the state
   b) Have more families educated on SDM by regional centers
   c) SDM can be informal, which makes it difficult to measure
   d) How do we ensure informal SDM becomes "normal" and a part of everyday conversations
   e) Get results from other efforts on SDM (Texas) and national SDM projects
   f) Google/media trends as a measure for individuals seeeking information on SDM

3) Question Three Discussion
   a) I/DD
   b) Judicial
   c) Focus on communities that are unaware of SDM
   d) Aging
   e) Behavioral health
   f) News as a way to spread information and raise interest
   g) It's all important!

Group Two
1) Question One Discussion
   a) Institutional vs Grassroots Actors
   b) The four areas of focus encompass a lot of the places where people encounter challenges, where the rubber hits the road. For example, schools, courts, healthcare settings, etc. So at first glance, these areas of focus seem best directed towards institutional actors in those sectors.
   c) Need to prioritize grassroots too, like orgs run by people with disabilities or CBOs. Those applications likely may not fall into these 4 areas of focus and will likely focus on things like educating others, workshopping SDM agreements, etc; things that transcend a particular category or sector.
   d) When only focus on community-based organizations, that leads to outcomes like training and education. Which are all good things. But those things aren't well suited to systems change and culture change in systems.
   e) On the other hand, you can't just give money to institutional actors alone and expect things will suddenly change for people. We really want institutional actors to work in concert with grassroots. For there to be a partnership, from the beginning of the grantmaking process.

f) So if we move in the direction of these categories, we need to be explicit that sectors that get this money *must* partner with disabled people and grassroots orgs.
g) Also, folks come to the IDD system already conserved. We need to focus on the education system. That's where the pipeline starts. If there's an IDD system focus, let's look at the folks that serve children, not adults.
h) Other missing areas: We should also think more broadly to IHSS systems because how good they are at training the provider community.
i) For the purpose of rank ordering, financial and judicial doesn't always neatly tie together. The connection should be clear, or they could be separated out. Also, change "judicial" to "legal" because it's just more plain language.
j) In case of a tie, look at existing grant criteria and then select one area where the score for that area is the tie breaker (e.g. sustainability or other criteria). So it's not about "the sector" and more about "the impact."

2) Question Two Discussion
a) The outcomes seem pretty clear: fewer people in conservatorships, more people using SDM, more people *recognizing* the use of SDM. But the data is so bad. For example, we don't even know how many people are in conservatorship today. In other words, these things are measurable but not measured.
b) Programs typically measure things that are easy to measure: inputs, not outcomes. For example, the number of SDM trainings, the number of people trained, etc. We need to be intentional about developing proxies for outcomes about which we don't have data. This means coming up with a solid theory of change that we can measure and then can use as a yardstick by which to measure grantees.
c) One proxy might be changing the default option. For example, people get caught in conservatorships because that is just what. you. do. It's first on the list. Changing the default to SDM is measurable and potentially a good proxy.
d) Operational definitions are really important in all of this, and they should be consistent across all grantees.

3) Question Three Discussion
a) Ran out of time for discussion

Group Three
1) Question One Discussion
a) Highest priority – Judicial; Second – Medical and Education; Third – I/DD Services
   i) There is a point of no return with the judicial system. Once conservatorship happens it is permanent and can be hard to change. May also be the most resistant to change system. Help people know

that SDM can take care of things without having to go to conservatorship is most pressing need because it can become less of a choice after conservatorship.

   ii) Medical and Education settings are also entry point (and so is HSS). Schools indicate to parents and caregivers that they have to get conservatorship so education about SDM is critical.

   iii) Conservatorship can start in Medical settings and this can get in the way of medical treatment. Healthcare settings may require conservatorship to honor informed consent.

   iv) Caseworkers are also an entry point.

b) Legal /judicial and healthcare have high priority (medical #1) – so many decision points in healthcare settings every year for most people. Many decisions in a short time span. Fewer decisions in legal settings as an individual. Judicial usually longer term decisions and less frequent.

c) Are we informing caseworkers for in home services about SDM; they often bring up conservatorship; HSS as the largest agency needs education in this area. This is important for all the settings.

d) Consider prioritizing entry points in all those service systems – education to the people in each system who are currently recommending conservatorship.

   i) Who do we need to engage with to make sure people are educated about SDM - where do people start learning about SDM? E.g., Caseworker

e) Families often don't know what it means to conserve their loved one. Need education on what it means and the fact that it is very hard to reverse.

f) All critical areas. I/DD services may be top priority as that may have the highest proportion of individuals who might be considered for conservatorship.

g) Elderlaw conference annually with different tracks (for attorneys). Plenary session on SDM this year. Two areas where it comes in. 1. Drafting SDM agreements or facilitating them. And identifying for whom they might be useful. 2. Someone has an SDM agreement – issues related to confidentiality if supporters are in the room. Who needs to sign off etc. This is a big area to educate on.

h) How to train lawyers on SDM when they are being compensated for conservatorship? They need education on this in the judicial system. Conservatorship can be more lucrative because it is more complicated. Need more safety nets in the system to ensure all options are considered. (Small % that will do it for the money). The small number that are financially motivated tend to be appointed. In that case, education may not be enough. Goal may be to change the culture so more attorneys know what should be done. We may find resistance that requires cultural change.

i) Financial incentives in medical settings if a patient needs to be discharged.

2) Question Two Discussion

a) Number of conservatorship applications go down (but we don't have those data)
b) SDM registry? Track the number that are submitted. (don't have yet either); needs funding
c) Surveys of stakeholders to learn what people know about SDM (hospital staff; physicians; school administrators etc.); establish a baseline and then revisit to see if there are changes.
d) Work with the state to establish a data system that actually works
e) Number of petitions to terminate conservatorship should increase. How many of those are actually terminated?
f) Demographics (including race and gender), regional data etc. to measure where this is happening and who is getting access to SDM support to ensure equity.
g) Grantees can report back on number of people who receive training; SDM process changes; could go to courthouse and look in their county to see how many conservatorship applications are submitted and if that changes over the grant period.

3) Question Three Discussion
a) AAC community – because of myths about their ability to understand and independently communicate.
b) Low-income communities
c) Spanish speaking community and any non-native English speakers

Group Four
1) Question One Discussion
a) TAP needs to work with all communities, including aging, people with physical disabilities, incarcerated, mental health. People with communication challenges
b) Importance of youth, families in transition, etc as change agents
c) Coordinate with other groups that are using conservatorship/SDM (Care Court, etc). There us anxiety that other groups are diverging in SDM approaches
d) Implementing 1663 is difficult. How do you make reporting to APS accessible? How do you create medical forms in line with SDM….next to kin law is simpler than SDM approach
e) SDM is opportunity to get families on board with thinking about how to help loved ones make decisions early in life
f) Caution against having multiple grantees creating structure (medical forms)
g) Parents are key. Parent to parent information peer support
h) Need to reach probate/special needs trust attorneys
i) Ranking
   i) Caution about determining the most important right to protect
   ii) Parents

  iii) Teachers

  iv) Need to provide simple, 1 page referral information to teachers and medical staff. These professionals are not informed enough to support/guide

2) Question Two Discussion

 a) Cannot measure reduction in number of conservatorships

 b) How many people came to trainings….project provided support to (DVU asked parents if thought about conservatorship, planned to) measured whether families shifted in plans

 c) Trusted partners doing peer to peer outreach and support

 d) Self-advocates training professionals within all major systems

 e) Warmline: can that provide specific TA to parents or professionals or is that role to provide general outreach and connect to grantee sites

 f) Measure the people served by all grantee sites that they feel competent and can implement SDM

 g) Warmline: People need support when they are at the doctor, meeting with service providers etc to resolve barriers that people are facing in the moment. Question…is that a warmline or a specific project assisting families.

3) Question Three Discussion

 a) Ran out of time for discussion