2. Are there any other areas to consider? If yes, please specify.

- Accessing public benefits (Medicare, Medicaid, SSI, CalFresh, health insurance)

- Accessing to affordable housing

- Attorneys

- Business ownership/employment

- Contracts

- Dementia

- DMV

- Education for elected officials

- Emergency preparedness

- Emergency services (5150, police, EMT, fire department)

- Everyday life (home, friends, church, recreation, where to live, social/sexual relationships, marriage and children)

- Family planning

- Future planning

- Hayward school district

- Healthy relationships/sexuality/abuse prevention/self-advocacy skills

- Housing

- IHSS

- Insurance services

- Language

- Marriage

- Minority community outreach (Ex: churches offer mediation training and dispute resolution, could also offer SDM training and services)

- Need something in place so consumers with no relatives will be released to mortuary after death to be cremated or buried as planned

- Physical fitness

- Prenatal care

- Provision of attorneys to represent people "threatened" with conservatorship or those trying to exit conservatorship

- Spiritual settings

- Support for regional centers

- Teaching SDM in youth

- Trainings for families about SDM as an alternative to conservatorship

- Travel

- Voting rights

3. We know community members continue to encounter systemic resistance or barriers when they use SDM. With this in mind, what specific barriers do individuals encounter when using SDM?

- Agencies want a form (like POA or advanced healthcare directive) to limit liability issues

- all staff (personal care, ILS, day, residential...), parents and others make assumptions or reinforce "learned helplessness"

- Being told it's only for "high functioning individuals"

- Create standardized training that is required for employees at school, hospital, legal, and financial settings/have standard forms so documents are recognized statewide. Also for supporters and individuals interested in SDM

- Discrimination

- Finding legal representation (need SDM centers inside courts)—automatic referral to SDM professional when conservatorship is filed

- Front office/admissions/scheduling staff in healthcare settings are not well informed about SDM and refuse to speak w/ parents of an individual with IDD if they don't have a conservatorship on file. Medi-Cal managed care plans also have made this a barrier and private insurance as well. Schools/IEP teams continue to tell parents they can't attend an IEP/speak to the school after the student turns 18 unless they get a conservatorship

- Health care settings are unfamiliar with SDM and have a bias toward conservatorship

- Inaccurate information

- Individuals don't know what questions to ask or what their rights are

- Individuals not given a chance to make their own decisions

- Lack of access to communication devices

- Lack of accountability and responsiveness

- Lack of awareness and understanding, legal and policy barriers, stigma and discrimination, resource constraints, communication challenges, cultural and diversity factors, resistance from caregivers or family members, complex decision-making situations

- lack of awareness

- Lack of community acceptance/providers not taking SDM seriously

- Lack of knowledge

- lack of receptive understanding supports and choices

- Lack of understanding and advocacy

- Language and financial barriers

- Language barriers/cultural differences

- Legal and healthcare systems "default" to non-SDM models

- limited financial resources, limited access or little knowledge as to how to use electronics, e-mail, signing electronic documents. Information not at level where clients can understand their options or choices

- Multiple barriers in healthcare settings when individual is non-verbal (especially with Tri-Care benefits)

- Need consistent strategies of how to break down the info, allow time for professionals to explain services to individuals utilizing SDM

- No clear guidance—need more support staff trained and legal guidance regarding liability

- no support in getting started

- not allowing a "companion" in medical procedures, etc during COVID

- Not enough staff to help guide, supervise, and accommodate SDM

- Parents/family members opposing client choices

- People unaware of SDM and not sure how to ask for help

- Providers ignore SDM agreements (even when notarized) (bank didn't know what to do with the document)

- Racial discrimination

- RC not providing accurate information/SCs not knowing

- Refusal to implement already existing laws (FERPA, HIPAA, IDEA)

- SDM being too "squishy or conceptual" as opposed to legally concrete notions of conservatorship or POA

- Skepticism about working with a person with disabilities with supporter (general bias)

- Someone to ask for advice on SDM paperwork

- Support person influencing individual to make decisions to the advantage of support person

- Supporters being told that providers need to speak with the individual, not the supporter

- The process should always be collaborative and look at the consumer with a holistic perspective, but the feeling is not always as such.

- Using plain language to explain options to individuals

- Very little education on SDM/not knowing what it is, who is applies to, etc.

- "Self-advocacy-Support group" model used by People First

- "People assume that the person does not have the ability to make a decision, especially with regards to medical and financial. People do not understand even remotely what SDP is, it is very much industry specific jargon. This has to begin with medical and financial institutions embracing the concept and the rest will follow."

- "The biggest barrier is lack of access to chosen direct support services and expertise for direct training and opportunities to practice skills. People with disabilities and their SDM Team members need the support of a functioning and supportive system. Businesses, healthcare providers, banks and agencies need to practice widespread acceptance of powers of attorney and SDM agreements. Stronger legislative protections for Powers of Attorney that are available in other states need to be in place."

4. The SDM-TAP will create a publicly accessible webpage for SDM related materials and resources. The SDM-TAP will also create a 'warmline' support phone number to provide community members and professionals with technical assistance for SDM. These functions will be funded by SDM-TAP administration dollars and not grant dollars. What other specific functions should be supported by administration dollars?

- Accessibility for technology communications

- Accountability for professionals who do not respect SDM

- After hours support for legal/medical emergencies when providers aren't supporting SDM (crisis support)

- An official 'identification' card of sorts that people could print that includes the info for the decision-partners and the website for reference

- Awareness campaign directed at families/loved ones of individuals with disabilities assisting in amplifying the existence of SDM models and SDM resources. The campaign and resources should also be accessible/available to Spanish-speaking families

- Background/reference checks on supporters

- Classes for individuals/supporters of transition age (so they can take it together to understand their roles)

- Create app for SDM

- Data on the type of calls/support needed through warmline to know where to focus money and efforts

- Direct support in addition to warmline, including in person access for those with technology barriers

- Easy access to resources/spreading the word about resources and where to access

- Email or online chat instead of phone

- Email/zoom/text/chat support

- Grassroots efforts, such a paper materials and in person information sharing

- IEP advocate help

- Individuals/supporters

- Information cards to provide to anyone to explain SDM, law, why it matters, etc.

- Information specifically for individuals with severe autism

- Language translation/communication support

- Legal advocacy

- On going support

- On site trainings for medical professionals, police, EMTs, fire departments, mental health professionals, colleges (for students in social work, psychology, medical, nursing, education, etc. programs)

- Online and in person trainings

- Paper copies of web resources

- Resource page with contact information for local area resources

- SDM centers inside all California Courts

- SDM forms to share with doctors/etc. (access to forms via mail for families who don't have computer or skills to download—maybe in public libraries, community centers, elementary schools)

- Social media

- Social networks to keep people informed

- TA provided in the home

- There needs to be clear guidance on what will be provided by SDMTAP and what cannot due to legal and professional reasons. What will the limits be when dealing with an organization that is out of compliance with SDM and other laws?

- Trainings/webinars for SDM professionals/families/individuals/supporters

- Translation of forms/resources/warmline in languages other than English

- Videos or video modeling of SDM; learning rights and responsibilities

- You-tube videos with step-by-step instructions (peer reviewed videos)

5. SDM-TAP should expand and strengthen the use of SDM in California. What measurable outcomes would you like to see from the SDM-TAP grants? For example, changing hospital protocols to welcome supporters for individuals in all appointments or increasing the number of individuals who understand SDM.

- Adding SDM to the Judicial Council forms that list alternatives to conservatorship. A reduction in the number of conservatorships granted each year or at least a reduction in the year-to-year increases.

- Advocate for IHSS to allow time for caregivers to help with SDM

- Change insurance protocols

- Changing insurance protocols to allow a supporter or a physician-designated surrogate to provide support to the individual in handling medical insurance matters without needing to pursue conservatorship

- Changing legal proceedings to allow for supporters of individuals in all hearings and meetings, including those regarding employment. Offer supportive persons when planning finances, doing taxes, filing for SSI, etc.

- Culture shift away from conservatorship to least restrictive alternatives (See DVU SDM CAP Principles)

- Curriculum in secondary and 18-22 year old programs addressing SDM

- Decreasing the number of RC clients who are conserved.

- Develop "champions" who have expertise

- Facilitating HIPPA compliant communication between supporters and health care providers when the client is asking for support communicating with medical team in cases of very complicated medical care

- Have specific areas to receive patients with disabilities so that they do not have to wait long and that 2 people enter with them

- Hospitals and jails allowing supporters to visit

- I would like for all services, hospitals, doctors, and service providers to be officially notified of the rights of the disabled to use supportive decision-making without having to carry around paperwork.

- Increase number of individuals who understand SDM

- Increase number of organizations that support use of SDM/have specific SDM initiatives

- Long term vs. short term tracking to measure progress/outcomes

- Make sure supporters are qualified: no criminal background, review every 6 months, interview individual without supporter to ensure they are happy with their supporter

- Measurable numbers of people served and the amount spent to serve them.
- Medical professionals asking if an individual uses SDM, rather than asking if they are conserved; data regarding the number of conservatorships implemented each year (and an eventual decrease in the number of conservatorships implemented); SDM resources reaching more diverse individuals and families (on the basis of race, class, national origin, sexual orientation, age, and language proficiency); and changing hospital protocols to welcome supporters for individuals in all appointments.
- Number of appointments attended etc.

- Measurable outcomes should include info on catchment areas on who uses them and what for, did using SDM-TAP make a difference in serving the needs and there should also be a way to facilitate measurable outcomes aimed at ongoing continuous quality improvement so that the systems and information will improve and change as information, change, needs and technology changes occur.

- Number of current staff who have received the SDM training/certification, families who were supported to ensure they understand SDM, number of resources provided and in what language, types of resources provided

- One measurable outcome is PENALTY and Fines directed at individuals or organizations that received federal and state funds but abuse the intent of the funds for their own interest. The judicial system needs to penalize such individuals and fine them as written in the Lanterman Act. The Legislature needs to pass laws that criminalize these individuals and organizations that act against the fundable laws that create these organizations to help and not to harm the I/DD clients.

- Oversight audits starting at the director level down to line staff which includes records of their trainings, number of visits per month supporting individuals and families, meetings minutes of trainings

- Oversight of supporters to ensure fidelity

- protocols for state and federal benefits, like Medicaid, Medicare and Social Security.

- Providing mandatory posted flyers (like they do for CAL OSHA / Labor/Employment Laws)

- Trainings: By 2025 SDM will offer 25 Zoom trainings & tailor trainings to specifics fields outlines in #1. (With handouts so they can take it back & share with peers)

- "Number of new hires in all settings who take the SDM training and fully understand the process.

- "Medical insurance providers not recognizing SDM as a legitimate alternative to conservatorship. Educational professionals not understanding SDM and encouraging, or threatening, parents to petition for conservatorship or lose their ability to participate in educational planning. Courts looking at SDM as a specific type of plan, similar to POA, without understanding that SDM may look different for different individuals based on their specific preferences, wants, and needs."

6. Are there specific communities who need the most help to use SDM in California? If so, please specify. For example, Vietnamese speakers, disadvantaged communities, foster parents, or self-advocates with co-occurring health needs.

- AAPI, BIPOC, disability and disorders

- African American communities

- African Americans and Hispanics with children with disabilities—for cultural reasons, they often do not ask for help for their children's needs

- aging adults with I/DD whose parents may be conservators but don't have someone who is "succeeding" them and the adult's parents always made their decision

- Aging

- Alzheimer/dementia patients

- Chinese

- Clients who do not have involved families or who have no family

- Community centers/homeless population

- Conserved individuals

- DD parents/mentally ill

- Families at or below poverty level

- Fetal alcohol spectrum disorders

- Focus on delivery settings (social services, healthcare, etc.)

- Foster/adoptive parents

- Group home and day program staff/other caregivers

- Hispanic

- Hmong

- Homeless

- Households with more than 1 person with a disability

- Incarcerated individuals

- Individuals living in board and care homes

- Individuals who don't have someone who cares for them

- Individuals with co-occurring health needs

- Khmer (Cambodian)

- Korean

- Laotian community in SF bay area

- Mothers of girls who are worried about unconserved women being taken advantage of

- Non-readers, those using assistive technology

- Parents of children with IEP/504

- parents of intellectually disabled youth ages 16-18 to prevent conservatorships from happening in the first place

- Parents/caregivers who are not digitally literate

- People with low academic levels

- RC employees

- Rural areas in Central valley (Tulare, Kings, Fresno counties)

- Rural/minority where primary language is not English

- Self-advocates

- Severe autism

- Single parent families

- Spanish speaking

- Those with significant communication needs (using AAC devices)

- Vietnamese

7. What do you feel are the greatest barriers to successful implementation of SDM in California?

- Acceptance by the general public and professionals

- Access to the technology

- Accountability

- Confusing systems, lack of consistent access to resources

- Cost

- Cultural understanding

- Difficulty getting information about SDM to people who could use it/trouble finding supporters

- Disability discrimination

- Education and legal assistance

- Education

- Gate-keeping behaviors at the agency level

- Getting people to services (transportation)

- Higher compensation for support workers

- Lack of knowledge about the value of SDM

- Lack of providers (partly due to low pay and burnout)

- Lack of training/awareness/education/understanding of SDM among general public, legal, healthcare systems

- Lack of understanding about conservatorship works in practice

- Limits to healthcare visit times do no allow time to fully use SDM

- Misinformation, fear, not knowing the program exists, not knowing one's rights

- More information and knowledge about the process

- Not enough listening

- Not enough protection against misuse by supporters

- Not knowing what the program is and what it offers to whom

- Parents who want to maintain control of their adult children

- People questioning the legality of SDM

- People's attitudes/community acceptance/stigma/bias

- Politics/limited funding

- Regional center (lack of staff, lack of training/understanding)

- Requiring documentation is a barrier—providers refusing to accept SDM without it

- Slow roll out

- "Information, Knowledge and the need is increasing faster than we can get people to meet it. Systems change is slow. We need change for our loved ones yesterday. Most of all mindset. There are still more non- believers than there are courageous individuals who are willing to change and give people who may have different needs an opportunity to live their best life."

- "institutional lethargy"--failure to find and serve the target population, communication and education to the target population and helping professionals

- "Not enough awareness among community, bureaucracy and cumbersome procedures of implementation that take too much time and effort."

- 1:1 support for individuals