

The Pragmatics of Supported Decision Making for People with Disabilities

A Guide for Self-Advocates, Family Members and Supporters



We all need help sometimes...

Supporters can:

Help explain the situation and the significance of the decision.

Assist in figuring out options and their pros and cons.

Provide emotional support in the process.

Aid us in communicating our decisions to others.





What is Supported Decision Making for People with Disabilities?

A law called AB 1663 enables people with Disabilities (PWD) to choose to use or formalize these kinds of decision-making supports for themselves in **supported decision making or SDM.**

In SDM, the person chooses supporters to help with decision-making, but the person makes the final decision (they are the **decider**).

The supporters and the types of support needed **can be written down into a supported decision-making agreement but they do have to be written down.**

Principles of SDM

- ✓ **PRESUMES COMPETENCE:** Adults with disabilities are presumed competent to make decisions regarding their day-to-day health, safety, welfare, social and financial affairs.
- ✓ **ENCOURGES PARTICIPATION:** The law holds that all adults, with supports they choose, should be able to be informed about, and participate in, the management of their affairs.
- ✓ **VOLUNTARY SUPPORT:** Adults with disabilities may use a wide range of voluntary supports to help them understand, make, and communicate their own decisions.

See AB 1663, sections 3950-3952

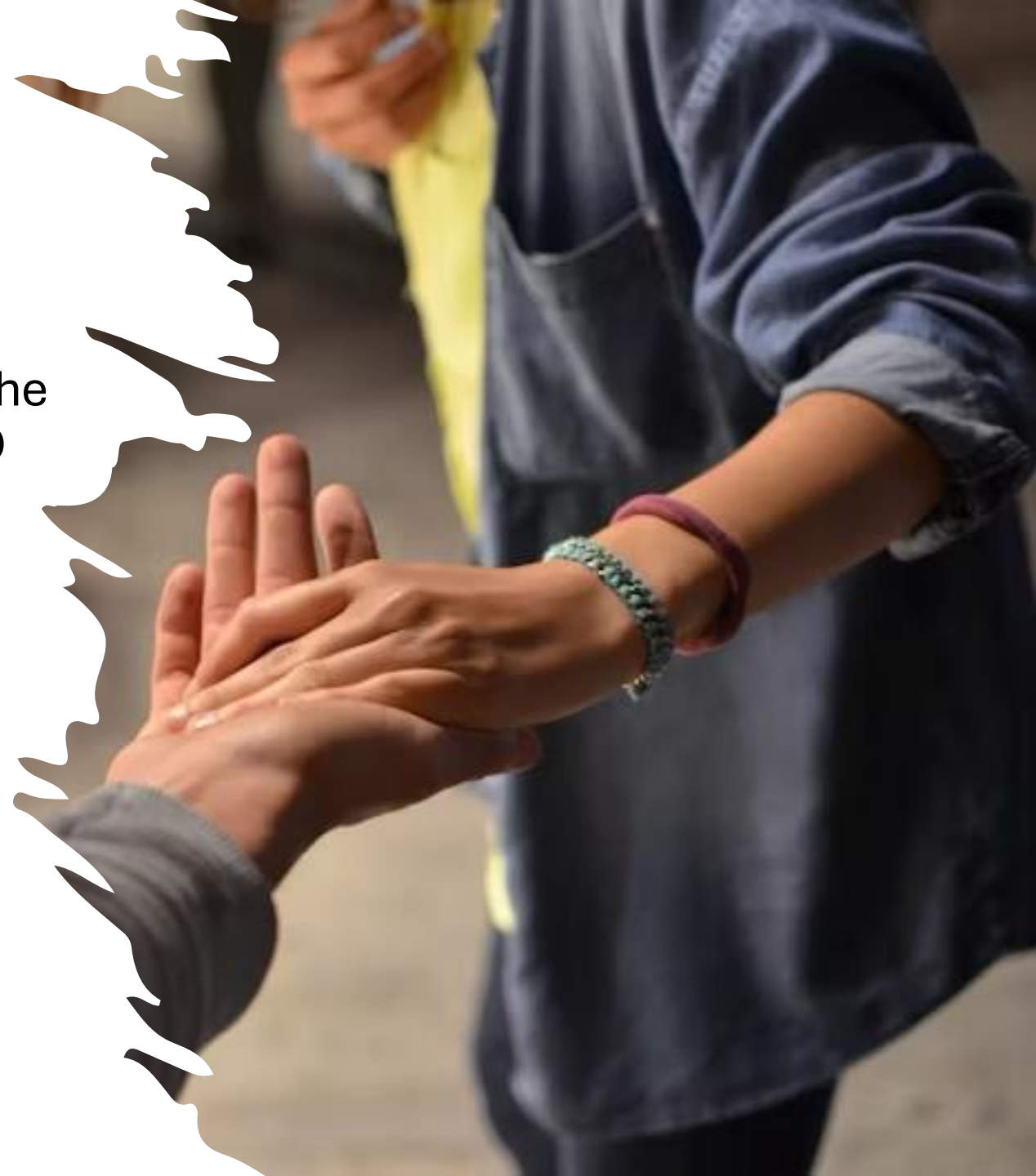
Principles of SDM

- ✓ **INDIVIDUALIZED SUPPORT:** SDM is an **individualized arrangement** in which an adult with a disability chooses one or more people they trust as supporters to help them understand, make, communicate, implement, or act on, their own choices.
- ✓ **FLEXIBLE:** Supported decision-making is one of several options available to adults with disabilities to understand, make, and communicate decisions and to express preferences, including, but not limited to, medical and financial powers of attorney, authorized representative forms, health care directives, the release of information forms, and representative payees.

Sounds great; how do you get started?

PWD can start SDM instantly by indicating the people that they want to support them – NO WRITTEN AGREEMENT NEEDED.

AB 1663 (section: 3953) is very clear that adults can have supporters in any meeting or communication concerning, but not limited to: Individual Education Plans, Individual Program Plan, a service planning meeting, medical care plan or hospital discharge, financial planning, communication or meeting with bank or other financial institution, an employment planning meeting, or a medical appointment.





All communication is valid in SDM

An adult with a disability may indicate that they wish to have the other adult or adults attend a meeting by oral statement, gesture, or any augmentative or alternative communication method used by the adult with a disability.

Or a PWD may prefer a written Support Decision Making Agreement (SDMA)

Think about decisions that you want support with...

Think about when you want that help...

Think about how you want them to help...



NO WRITTEN AGREEMENT IS REQUIRED!

BUT IF A WRITTEN SUPPORTED DECISION AGREEMENT IT IS DESIRED, IT SHOULD:

- Use easy-to-understand language.
- Include the name of the PWD, and names/contact information for the supporters.
- List the areas in which the adult with a disability requests support from one or more supporters.
- Include acknowledgments by each supporter that they agree to:
 - Provide information as requested by the adult with a disability.
 - Support the adult with a disability in good faith and to the best of their abilities.
 - Respect that the final decision shall be made by the adult with a disability and not the supporter.
 - Not coerce or manipulate the adult with a disability into making any decision.

A POPULAR TEMPLATE FOR SDM:

Many people use the ACLU Form, which you can access with this QR code.

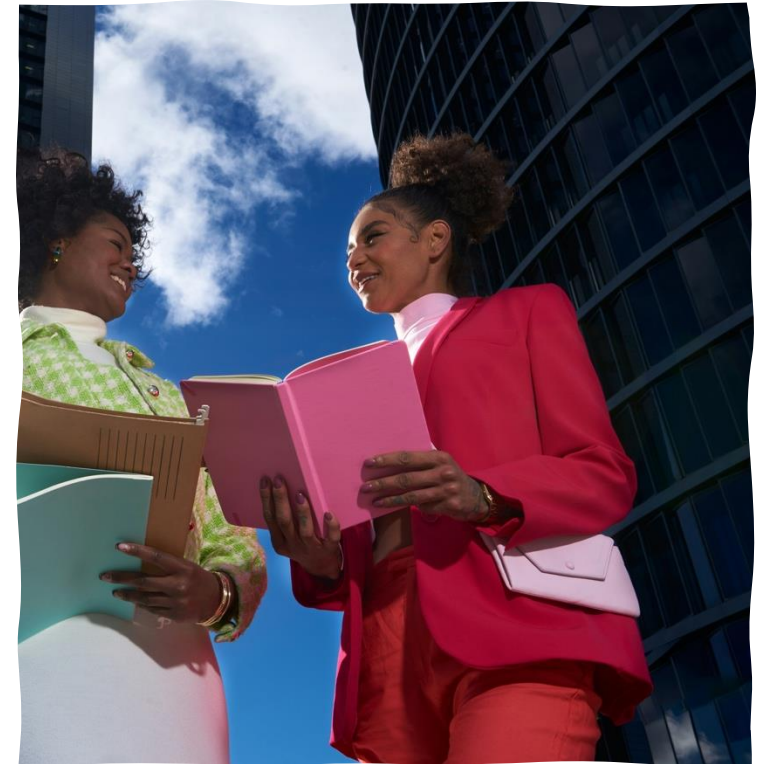


While **not mandatory**, documenting the SDM arrangement in writing can provide clarity and prevent disputes.

Written agreements can be notarized (this can be challenging depending on how the person communicates) **OR**

Witnessed by two people who verify that the PWD communicated this in their presence.

Using Supported Decision Making



SDM and Education



Parents hold educational decision making rights until a person is 18 years of age. Colleges and universities will only speak to family if they hold decision making rights or have a signed permission to exchange information.



At 18, education rights revert to the adult, in less there has been legal action about this.



This should be discussed as part of transition services under IDEA, which are intended to help transition the student to post school educational activities, work activities and living arrangements.

PWD can use Supported Decision Making in the IEP Process

Manual on Supported Decision Making for
Special Education (PEATC/Virginia)



IEPs and Preparing for SDM

Decision making, advocacy and agency do not suddenly appear at 18.

For some people, these are skills that should be covered in IEPs in an age and skill appropriate way to develop these capacities.



Examples: Advocacy and Decision Making Goals In the IEP

The District of Columbia Public Schools (DCPS) teaches students as young as three to use Supported Decision-Making and “build networks of support . . . to ensure that they are familiar with the process and utilize it in day-to-day activities.”

Practice by stressing age/developmentally appropriate choices.

Encourage the students to identify any person(s) that they want to help them.



Examples: Advocacy and Decision Making Goals In the IEP



Targeted self-advocacy IEP goals to address communication can help students voice their needs confidently; eventually, they engage more fully in their education and build a foundation for lifelong self-advocacy.

Self-advocacy IEP goals can help students gain the confidence to discuss their unique needs with teachers and ensure they receive the necessary support in the classroom.

Participating in their IEP meetings enables students with special needs to voice their opinions, share their strengths and challenges, and actively set their educational goals.

School Staff May Be Unaware of SDM and Recommend Conservatorship

Educate school staff! Cal State East Bay, Center for Disability Justice Research and DREDF are building online training on SDM and how to encourage its use by students (See <https://www.csueastbay.edu/cdjr/supported-decision-making-outreach-team.html>)

Consider alternatives to conservatorship! Like SDM or Assignment of Decision Making Authority for California (click on the QR code for the form) to a parent or friend.

For college age, see if the college or university had a form.



SDM and Healthcare



Supported Decision-making is used in healthcare settings all the time.



Healthcare is complex, and decisions may be needed for providers, insurance companies and hospitals (some may insist on specific forms).



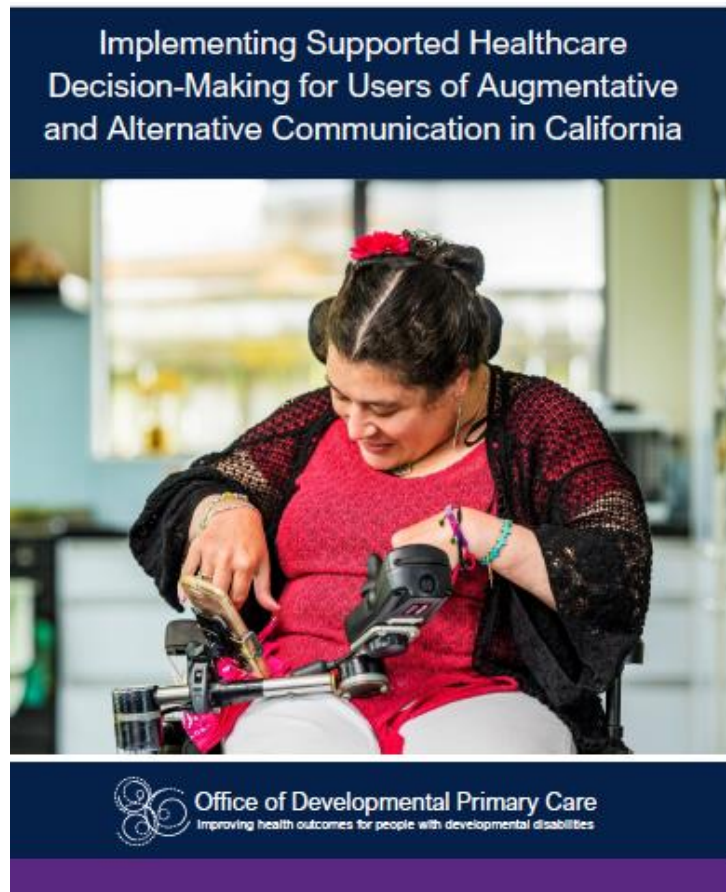
PWD and their supporters may be concerned about emergency situations where SDM is not easily accessible,

Supporters Can:

- communicate with clinicians
- help with remembering to take medication or follow up
- translate complex medical concepts into plain language
- weigh treatment options
- make and prepare for medical appointments
- transport to appointments
- take notes during appointments
- provide clinicians with a medical history and other information
- obtain medical and insurance information
- assist with physical tasks such as dressing or transferring onto exam tables
- pick up prescriptions or medical supplies

Partners in Health: Implementing Supported Healthcare Decision-Making for Users of Augmentative and Alternative Communication, Office of Primary Care, UCSF

Manual on Supported Decision Making for PWD with a Focus on AAC Users



Companion Documents

- Authorized representative: An authorized representative may act for you on all or some duties related to your medical eligibility and enrollment. This form is often specific to a hospital, clinician, or insurer.
- Advanced Care Directive: An Advance Directive provides a way for people to direct their own healthcare even when they are in a coma, have dementia or are mentally incapacitated or unable to communicate. A person can use an Advance Directive to spell out their wishes regarding physical and mental healthcare and to select someone to make healthcare decisions when they are unable to do so. (See QR code for fillable CA form and <https://www.disabilityrightsca.org/publications/advance-health-care-directives>)



Both usually require notarization or the signature of two witnesses

SDM and Regional Center



SDM can be used by PWD with Regional Centers



The new Individual Program Plan template explicitly covers who the PWN wants support with and from whom (including legally appointed decision makers).



The IPP should also document methods and preferences of communication used by the individual, what others need to know to communicate with the individual, supports or devices needed for communication and other information to share about how the individual communicates/understands.



New Individual Program Plan Template

SDM and Financial Matters



Supported decision-making can be used to help make decisions about all kinds of things, including money and finances if needed.



More than most other areas of decision-making, there is a potential for conflicts of interest when using SDM for finances.



The best practice is to plan ahead to address these conflicts before they happen. Many SDM templates include a separate role for financial monitoring.

Companion Agreements/Arrangements

- **Representative Payee:** SSI/SSDI payments go directly to the representative payee. The representative payee is then responsible for paying the individual's bills, saving money, etc. The representative payee must provide information to the Social Security Administration about how the individual's money has been spent.
- **Power of Attorney:** Giving someone power of attorney means they have the ability to make financial and other business decisions on your behalf. Some people will set this up as an addition to their SDM agreement.



Companion Agreements/Arrangements

- **Joint Bank Accounts:** Some parents set up joint accounts for their PWD. As joint account holders, they can both make financial decisions and monitor how funds are used.
- **CalABLE/Authorized Representative:** CalABLE accounts allow individuals living with disabilities to save and invest money without losing eligibility for certain public benefits programs, like Medicaid or Supplemental Security Income (SSI). An authorized representative is someone who is allowed under state and federal law to make decisions for the CalABLE account beneficiary.



Companion Agreements/Arrangements

- **Special Needs Trusts:** Special Needs Trust (SNT) allows for a disabled person to maintain his or her eligibility for public assistance benefits despite having assets that would otherwise make the person ineligible for those benefits. A trustee holds, administers, and distributes all property allocated to the trust for the benefit of the disabled person during his or her lifetime.





Many people with disabilities need and want assistance making decisions about health care, life choices, and financial matters, but they do not necessarily need a guardian to make those decisions on their behalf. When individuals with disabilities direct their own decision-making process, they gain confidence and become better self-advocates. By expressing their preferences and exercising their right to decide, individuals with disabilities get the chance to interact with people in their community — shopkeepers, landlords, bankers, and doctors. This allows people with disabilities to make the social connections that define community life.



QUESTIONS ?



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