

# Supported Decision-Making, Conservatorship, and Alternatives

## An Overview for Self-Advocates, Family Members and Supporters



**SUPPORT FOR FAMILIES**  
EDUCATION • EMPOWERMENT • EQUITY



# Agenda

- Overview:
  - Types of Decisions
  - Conservatorship
  - Supported Decision Making (SDM)
  - Alternatives to Conservatorship/  
Companion Documents
  - Legal
- SDM in Practice
  - where to start
  - SDM in Education
  - SDM in Health Care
  - SDM in Finance Matters
- Questions/ Feedback

# Age of Majority

When a person turns 18, all rights under state and federal law will transfer from the parent/guardian to the young adult.



## Health Care

Choosing a medical plan  
Choosing doctors/therapists  
Medical Treatment Decisions  
(understanding the pros and cons)  
Accessing Healthcare  
Grievances and Advocacy



## Financial Matters

Personal Budget  
Bank Accounts  
Credits Cards



## Education

Special Education or 504  
plans in schools  
Access to records (college or  
K-12)  
Disability Services in college  
or university setting



## Personal Decisions

Living arrangements  
Personal  
relationships  
Activities



## Legal

Sharing your information  
Applying for services  
(i.e. Regional Center,  
CalFresh or MediCal)  
Signing Contracts  
Voting

# How do people make decisions if they need help?

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Individuals may have others make decisions for them, in this model one person fills in or **substitutes** for the individual.

Individuals may make their decisions themselves, with some or a lot of **support** from others.

There are options for adults with disabilities and their families in this range.



# Conservatorship

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A conservatorship is a court process where a judge decides whether you can care for your own health, food, clothing, shelter, finances, or personal needs.

With a conservatorship, the judge can choose another person to make some (limited conservatorship) or all of these decisions for you.

**CONSERVATORSHIP**



**SUBSTITUTION**

**SUPPORT**

# Conservatorships and People with Intellectual and Developmental Disabilities

- **Limited conservatorships are generally those used for people with intellectual and developmental disabilities.**

The conservator may handle just the care of the person or may also manage the person's finances.

- If they're responsible for a person's care and protection, it's called a **conservatorship of the person.**
- If they handle finances, it's called **conservatorship of the estate.**

# 7 powers that can be restricted in a limited conservatorship

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Residence	Decide where the person lives.
Records	Access the person's confidential records and papers.
Marriage	Consent required for the person to marry.
Contracts	Decide whether to enter into a contract.

# 7 powers that can be restricted in a limited conservatorship

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## Medical

Give or withhold medical consent on their behalf.

## Relationships

Exercise or limit their right to control social engagement, family planning and relationships.

## Education

Make decisions about education.

# Positives and Negatives of Conservatorships

## Positives

- There is one document, and parents/conservators can find it more straightforward.
- Some parents feel this is the best way to protect the legal and financial interests of their family member with a disability.
- There is a clear legal process to follow that is widely recognized.

## Negatives

- ***Most restrictive*** means of helping a person with a developmental disability.
- Conservatorships are expensive and can require the help of an attorney. ***(After AB 1663, if the conservator and the conservatee agree, the court can terminate a conservatorship without a hearing.)***
- Courts make the decisions about conservators, not the family.
- People who are conserved are not safe from abuse, or arrest or financial scams.

# Supported Decision Making (SDM)

Supported Decision-Making (SDM) is a person with a disability (PWD) making their own decisions with the assistance of a trusted team that they choose.

The team can be family members, co-workers, friends, and past or present providers. The individual should select supporters who know and respect his or her preferences and who will honor the choices and decisions the PWD makes.

**SUPPORTED DECISION MAKING (SDM)**



**SUBSTITUTION**

**SUPPORT**

# Supported Decision Making (SDM)

Team	A person with a disability (PWD) chooses a team of supported to help understand, analyze and express choices.
Flexible	PWD can decide on a written agreement for SDM or just choose the supporters for any decision or any length of time.
Tailored	PWD chooses how and when they want support.
Adaptable	PWD may rely on known supports other than a written supported decision-making agreement
Decider	PWD maintains agency and control over their choices.

# Positives and Negatives of Supported Decision Making

## Positives

- Maximizes agency and independence for the PWD.
- Free to use or try, and easily changed or terminated at any time.
- It may reduce stigma and increase self esteem for the PWD by allowing the 'dignity of risk'.
- Some studies show a reduction in risk of abuse when the PWD has a team of supporters.

## Negatives

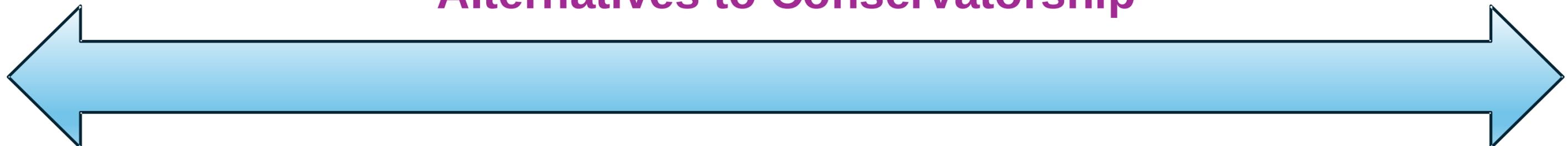
- SDM is not widely known and may encounter resistance from professionals.
- Even supporters who aren't guardians can hinder autonomy or clash with the PWD over decisions.
- In some instances, PWD may not be acknowledged (or treated) as the decision maker, the focus may be on the supporter(s).

# Alternatives to Conservatorship/ Companion Documents

Alternatives to Conservatorship/Companion Documents refer to legal tools and strategies that can be used as less restrictive options to support individuals with disabilities without resorting to a conservatorship.

PWDs use alternatives to conservatorship, which usually consist of written agreement(s) between them and someone helping them. These documents can be stand-alone, or they can be used with a supported decision-making process.

**Alternatives to Conservatorship**



**SUBSTITUTION**

**SUPPORT**

# Common Alternatives to Conservatorship

<b>Durable Power of Attorney</b>	This gives someone else the ability to make decisions for the PWD. Some of these cover some types of decisions, like medical or financial, but some cover both.
<b>Authorized Representative</b>	A term used heavily in healthcare. An authorized representative may act for a PWD on any medical issue, or the PWD may limit what the authorized representative can decide on. The PWD may cancel or change this appointment at any time.
<b>Advanced Care Directives</b>	For medical care, an advanced directive allows a PWD to designate a health agent to make decisions when they are ill and allows the PWD to make decisions in advance on health care.
<b>Representative Payee</b>	Appointed by Social Security to provide benefit payment management. PWD can contact Social Security to change or dismiss a representative payee.
<b>Joint bank accounts, Special Needs Trusts and CalAble</b>	PWDs can set up joint accounts with trusted friends or family members. With a special needs trust, the trustee manages the funds. The PWD selects an authorized representative for CalAble for assistance with financial management of these funds.

# Positives and Negatives of Alternatives to Conservatorship

## Positives

- Like with SDM, PWD can decide who helps with what areas.
- Agreements are voluntary and can be ended by the PWD.
- Can be low cost.
- Recognized legal process.

## Negatives

- Can be the most complicated alternative with many different agreements that need periodic renewal.
- Many of these documents need to be notarized and this can be challenging if communication is challenging for the PWD.
- Helpers can substitute their choices for the PWD, as these allow for both support and substitution.

# Using Supported Decision Making

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**Most of us get support when making decisions.**

Supporters/ Helpers:

- 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.



# Supported Decision Making in Practice 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 PWD maintains their decision-making power, chooses supporters to help with decision-making, and makes the final decision.

# 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.
- **ENCOURAGES PARTICIPATION:** The law hold 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.
- **INDIVIDUALIZED SUPPORT:** SDM is an individualized arrangement in which an adult with a disability chooses one or more people they trust as supporters.
- **FLEXIBLE:** SDM 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.

Note: 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.



# NO WRITTEN AGREEMENT IS REQUIRED!

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

- Be in 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.

# **Support Decision Making Agreement (SDMA)**

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

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

# A POPULAR TEMPLATE FOR SDM:

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



CLICK  
HERE

# Using Supported Decision Making

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**Education**



**Health  
Care**



**Finance  
Matters**

# SDM and Education

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Parents hold educational decision-making rights until a person is 18 years of age.



At that time, education rights revert to the adult, unless 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.

# IEPs and Preparing for SDM

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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.



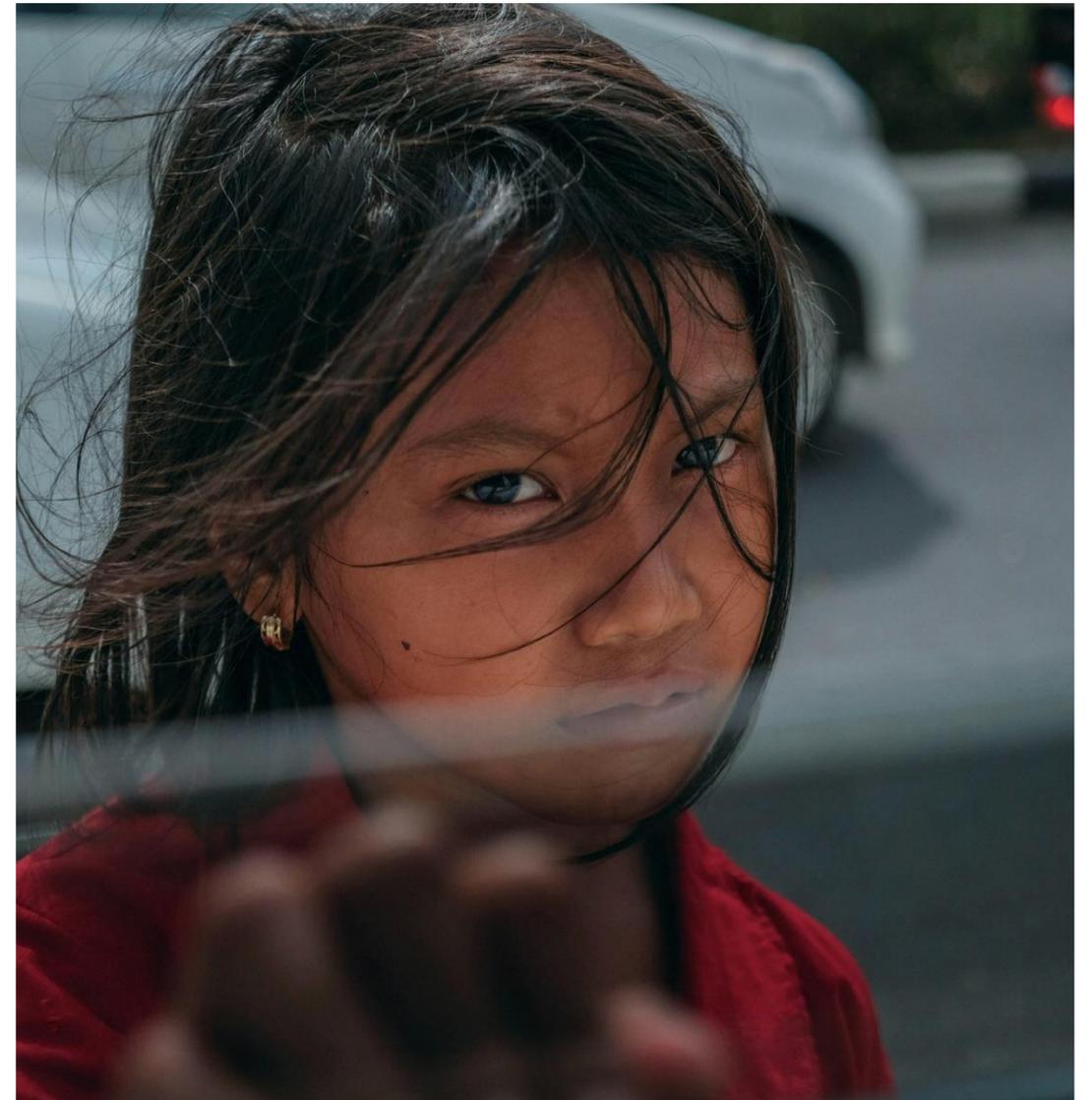
# Examples: Advocacy and Decision Making Goals In the IEP

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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.”

Student can develop this skill through practice (at home and at school) for age/developmentally appropriate choices.

Students can be encouraged to identify any person(s) that they want to help them with decisions throughout their school career.



# Examples: Advocacy and Decision-Making Goals In the IEP

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**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

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## **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 Education for California (click on the QR code for the form from Disability Rights California) to a parent or a supporter.



# SDM and Healthcare



Supported Decision-making is used in healthcare settings all the time as most of us need help making these decisions.



Healthcare is complex, and decisions (and release of information) may be needed for providers, insurance companies and hospitals.



PWD and their supporters may be most concerned about emergency situations where SDM is not easily accessible because of illness.

# 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

# SDM and Healthcare/ Companion Documents

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- **Authorized Representative:** An authorized representative may act for you on all or some duties related to your medical eligibility and enrollment. This is often a form 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>)



These may require notarization or the signature of two witnesses

# SDM and Financial Matters



Supported decision-making can help make decisions about all kinds of things, including money and finances.



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



Supporters should take proactive steps to prevent real, perceived, or potential conflicts of interest.



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

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- **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.
- **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

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- **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.
- **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.
- **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.



# 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  
(IPP) Template



# QUESTIONS ?



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# Please Fill Out Our Feedback Form!



## Thank You!

This work is made possible through a grant from SCDD and SDM-TAP