

Decision Making for People with Disabilities

An Overview for Self-Advocates, Family Members and Supporters



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.





What kind of decisions? **Health Care**

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

What kind of decisions?

Financial Matters

Personal Budget

Bank Accounts

Credits Cards



What kind of Decisions?

Education

Special Education or 504
plans in schools

Access to records (college
or K-12)

Disability Services in
college or university setting



What kind of Decisions?

Personal Decisions

Living arrangements

Personal relationships

Activities





What kind of Decisions?

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?

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.



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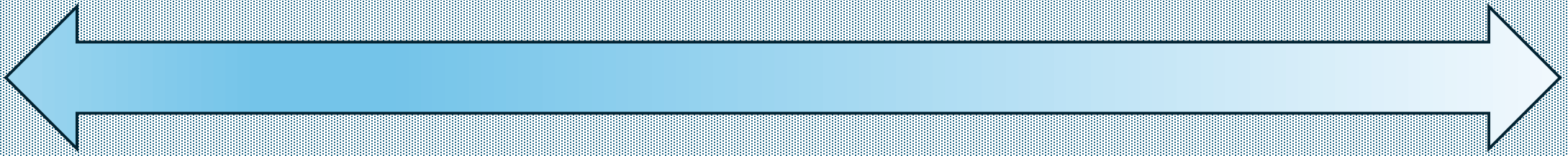
SUPPORT

Conservatorship

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



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Conservatorship

A judge can only appoint a conservator if it is necessary to promote and protect the person's well-being.



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

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

Medical

Give or withhold medical consent on their behalf.

Relationships

Exercise or limit their right to control social and sexual contacts 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

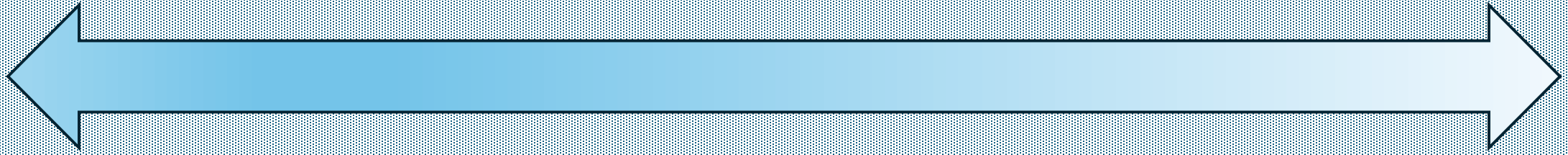
- **Most restrictive** means of helping a person with a developmental disability.
- Conservatorships are expensive and can require the help of an attorney. **(After AB 1663, if the conservator and the conservator agree, the court can terminate a conservatorship without a hearing.)**
- Courts make the 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 making your own decisions with the assistance of a trusted team that you choose.

They 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 individual makes.

SUPPORTED DECISION MAKING (SDM)



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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.

Supported Decision Making (SDM)

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.
- Some PWD may not be acknowledged as the decision maker, the focus may be on the supporter(s).

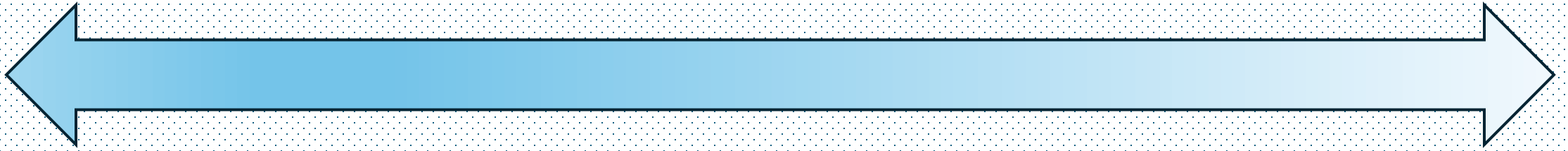
Companion Documents /Alternatives to Conservatorship

PWDs use other alternatives to conservatorship, which often consist of written agreement(s) between them and someone helping them. These can be broad, like a durable power of attorney, or they can be specific to an agency or service, such as an authorized representative for Kaiser Medical Care.

These documents can be stand-alone, or they can be used with a supported decision-making process.

Most of these documents allow the person named to substitute for the PWD, but the PWD has the right to terminate the agreements at any time.

COMPANION DOCUMENTS



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Common Companion Agreements (alternatives to conservatorship)

Durable Power of Attorney

This can give someone else the ability to make decisions for you. Some of these cover some types of decisions, like medical or financial, but some cover both.

Authorized Representative

A term used heavily in healthcare. An authorized representative may act for you on any issue, or you may limit what they can decide on. You may cancel or change this appointment at any time.

Advanced Care Directives

For medical care, allows a PWD to designate a health agent to make decisions when you are ill and allows you to make decisions in advance on health care.

Common Companion Agreements (alternatives to conservatorship)

Representative Payee

Appointed by Social Security to provide benefit payment management. PWD can contact Social Security to change or dismiss a representative payee.

Joint bank accounts, Special Needs Trusts and CalAble

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 Companion Documents

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 the PWD understands but communication is challenging.
- Helpers can substitute their choices for the PWD, as these allow for both support and substitution.

Considerations in Decision Making Options

Families often consider this a decision between autonomy/agency and safety for the PWD (person with a disability).

There are many choices for PWD and their families to consider, with positives and negatives.

But there is no guarantee of safety in any arrangement, including conservatorship.





QUESTIONS ?



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

Resources

<https://selfhelp.courts.ca.gov/conservatorship>

(California Courts)

<https://www.disabilityrightsca.org/publications/limited-conservatorships-alternatives>

(Disability Rights California)

<https://scdd.ca.gov/supported-decision-making-resources/>

(State Council for Developmental Disabilities)

<https://supporteddecisionmaking.org/>

(National Resource Center for Supported Decision Making)