Decision Making for People with Disabilities

An Overview for Self-Advocates, Family Members and Supporters

SUPPORT FOR FAMILIES
EDUCATION • EMPOWERMENT • EQUITY

California State Council on Developmental Disabilities

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

Managing Public Benefits (i.e. SSI or Calfresh)

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 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.

SUBSTITUTE 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

SUBSTITUTE

SUPPORT

Conservatorship

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

Conservatorship is the most restrictive choice.

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**.

California Courts, Self Help Guide, Conservatorships

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 the person can enter into a contract.

7 powers that can be restricted in a limited conservatorship

Medical	Give or withhold medical consent on the person's behalf.
Relationships	Exercise or limit the person's right to control social and sexual contacts and relationships.
Education	Make decisions for the person about their 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 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)

SUBSTITUTE

SUPPORT

Supported Decision Making (SDM)

Team	A person with a disability (PWD) chooses a team of supporters to help them to 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.
- In some instances, PWD may not be acknowledged (or treated) as the decision maker, the focus may be on the supporter(s).

Companion Documents /Alternatives to Conservatorship

PWDs use other alternatives to conservatorship, which usually 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

SUBSTITUTE

SUPPORT

Common Companion Agreements (alternatives to conservatorship)

Durable Power of Attorney	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.
Authorized Representative	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.
Advanced Care Directives	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.

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

Considerations in Decision Making Options

Families may consider this a decision between autonomy/agency and safety for the PWD (person with a disability) – but that is an oversimplified picture.

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 ?

California State Council on Developmental Disabilities

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)