

Supported Decision Making:

- *An Alternative to Conservatorship*
- *A Tool to Empowerment within Conservatorship*

UCDAVIS
MIND INSTITUTE

CENTER FOR EXCELLENCE IN **DEVELOPMENTAL DISABILITIES**

Conservatorships for People with Developmental Disabilities

- Conservatorship of the person
 - Responsible for the physical well-being of the person
- Conservator of the estate
 - Responsible for the person's property and assets

Conservatorship/Guardianship

Conservatorship is a legal process to determine if someone is “incapacitated”

A court decides if, due to a physical or mental condition, a person is substantially unable to:

- Manage their finances
- Care for their physical health
- Provide for their food, clothing or shelter

Limited Conservatorships

One or more of the following rights can be terminated through limited conservatorship:

1. To determine residence
2. To have access to confidential records
3. To get married
4. To enter into contracts
5. To give consent for medical treatment
6. To control social and sexual contacts
7. To make educational decision

<http://www.disabilityrightsca.org/pubs/PublicationsConservatorship.htm>

Full Conservatorship

Full, or plenary, conservatorship gives the conservator nearly full authority to make all decisions for the conservatee

- Limitations on some medical treatments , involuntary commitments and wages from employment

Family Beliefs about Conservatorship

- Conservatorship is a benign process that is required for them to continue as advocates after their loved one turns 18
- Conservatorship will remain within the family for as long as the family wishes
- Conservatorship is a safety net that allows them to intervene when necessary

What Message do Parents Receive?



Age 18

Parental Power Fail!



**On your way
to your High Five Day!**

What Message do Parents Receive?

Not Capable of
appreciating the
situation

**General
conservatorship**



“I need some
help, please”

**Limited
conservatorship**

“I got this!”

Powers of attorney

What Message do Parents Receive?

“Key Takeaways”

- “When your child becomes an adult, the rights you held as a parent typically transfer over to her.”
- “If a child isn’t seen as capable of handling these rights and responsibilities, the state may appoint the parent or another individual to represent her.”
- “Educating yourself and preparing your child for the age of majority can make the transition into adulthood smoother for everyone.”

[When Your Child With an IEP Turns 18: Your Parental Rights](#)

General Beliefs about Conservatorship

- Regional Centers review all petitions and make recommendations to the court
- Judges ensure that only people who require conservatorship receive them
- Most conservatorships are limited in scope to areas that the person has shown they require oversight in
- There are oversights to ensure conservators work in the best interest of the conservatee
- Conservatorships can be ended when appropriate

Concerns about Conservatorship

Conservatorship is a legal removal of civil rights and is almost always permanent

- Regional Center review
 - Often circumvented by attorneys not notifying Regional Centers that they are petitioning
 - Attorneys using the general conservatorship petition
- Legal proceeding
 - Investigators, PVP attorneys and judges favor family requests over evidence of need (Millar, 2003; Teaster et al., 2005; Moye et al, 2007; Kohn et al., 2013)
- Limited conservatorship process
 - Full conservatorship is granted in the vast majority of cases (Frolik, 2002; Teaster, Wood, Lawrence, & Schmidt, 2007)
 - “As long as the law permits plenary guardianship, courts will prefer to use it.” (Frolik, 1998)

"The typical ward has fewer rights than the typical convicted felon—they no longer receive money or pay their bills. They cannot marry or divorce. By appointing a guardian, the court entrusts to someone else the power to choose where they live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty." United States Representative ,Claude Pepper

Abuses in Guardianship of the Elderly and Infirm: A National Disgrace, H.R.641, Subcommittee on Health and Long-Term Care, House Special Committee on Aging, 100th Cong., 1st Sess. (Sept. 25, 1987)

National Guardianship Association

- “Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”
- “Modern day respect for individual rights dictates that we must allow each individual to make or participate to the extent possible in personal decisions. Therefore, incorporation of SDM into guardianship standards is essential to evolving practice.”

http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf

California Legal Requirement to consider less restrictive options

“....the petitioner or proposed conservator shall also file supplemental information as to why the appointment of a conservator is required. The supplemental information to be submitted shall include a brief statement of facts addressed to each of the following categories:

(3) Alternatives to conservatorship considered by the petitioner or proposed conservator and reasons why those alternatives are not available.”

(California probate code 1821 (a) (3))

American Bar Association Guide

- Clearly identify the reasons for concern.
- Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations
 - Ask “what would it take?” to enable the person to make the needed decision(s) or address the presenting concern.
- Ask the person whether he or she already has developed a team to help make decisions.
- Identify areas of strengths and limitations in decision-making.
- Screen for and address any potential challenges presented by the identified supports and supporters
- If necessary, appoint a reversible legal supporter or surrogate:
 - Agent under health care power of attorney or advance directive
 - Health care surrogate under state law
 - Agent under financial power of attorney
 - Trustee
 - Social Security representative payee
- If a conservatorship is needed, limit to areas absolutely required

American Bar Association Guide

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Self Determination:

Having Information

Having Choices

Steering one's own life

Capacity/Ability to Make Choices

- Can people make some decisions but not others?
- Can people make decisions at some times but not others?
- Can people make decisions when information, options and consequences are presented in some ways but not others?

Making Decisions is a Learned Skill

- The Lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity (Salzman, 2010)
- Most people slowly learn to develop responsibility and good decisions through transformational experiences in late adolescence
 - Driving
 - Dating
 - Work
- These experiences transform them and the relationship with their parents
- People with disabilities often don't experience these opportunities until later in life

Why is Self Determination Important?

When people are denied opportunities for self determination:

- Feel helpless, hopeless and self-critical (Deci, 1975)
- Experience low self esteem, passivity, feelings of inadequacy and incompetency (Winick, 1995)

Benefits of Self Determination

People with greater Self Determination have higher quality of life are more likely to:

- More ownership in service plans and goal setting
- Live independently
- Have a Paid Job/Higher Earnings
- Better physical and mental health
- Better able to recognize and resist abuse

(Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998)

We ALL get help in our life

- When we make difficult decisions, we sometimes talk to:
 - family members
 - friends
 - people who know the system
- Sometimes we might:
 - Ask friends or family to come with us to important medical visits
 - Speak to an expert to guide us before signing a contract
 - Ask someone to help us plan and follow a budget
 - Talk to friends and professionals when we are concerned about a relationship

Supported Decision Making Helps People:

- Understand the situation they are facing
- Understand information, issues and choices
- Reflect on past experiences
- Weigh options
- Ensure choices reflect their own preferences
- Interpret and/or communicate their choices

Building a Circle of Support

- Many families are sole supporters of their loved ones with disabilities
 - limited perspectives and opportunities
 - Can leave people vulnerable when family support ends
- Explore who knows, cares about and is *trusted*
 - *Family*
 - *Friends*
 - *Professionals*

Why Formalize Supported Decision Making?

- Although most people with disabilities receive *informal* supports similar to SDM, formalizing the process with an SDM agreement empowers people who receive support:
 - Allows the person receiving support to choose areas of support and decide ***who is*** and ***is not*** on their support team
 - Encourages developing an extended support team
 - Crystallizes boundaries for supporters
 - Encourages communication and teamwork

ACLU/Quality Trust

Supported Decision Making Sample Agreement

This agreement must be read out loud or otherwise communicated to all parties to this agreement in the presence of a notary. The form of communication shall be appropriate to needs and preferences of the person with a disability

ACLU/Quality Trust

Supported Decision Making Sample Agreement

My name is: _____

Today's date is: _____

I want to have people I trust help me make decisions. The people who help me are called **supporters**. I can say what kind of help my supporters will give me. If I want supporters to help me make choices about money, I will sign a different agreement called "Supported Decision- Making Agreement for Finances"

ACLU/Quality Trust

Supported Decision Making Sample Agreement

My supporter(s) are:

Supporter 1

Name: _____

Address: _____

Phone number: _____

Email address: _____

I want this person to

(Check as many boxes as you want)

- Making choices about food, clothing, and where I live
- Making choices about my health
- Making choices about how I spend my time
- Making choices about where I work

ACLU/Quality Trust

Supported Decision Making Sample Agreement

My supporters are not allowed to make choices for me. To help me with my choices, my supporters may:

- Help me find out more about my choices
- Help me understand my choices so I can make a good decision for me
- Help me tell other people about my decision

ACLU/Quality Trust Supported Decision Making Sample Agreement

I am including the following forms in this agreement:

(Circle yes or no for each choice below)

Yes/No A form that lets my supporters to see my medical records

Yes/No A form that lets my supporters to see my school information

(Authorization to Disclose Educational information)

ACLU/Quality Trust

Supported Decision Making Sample Agreement

This supported decision making agreement starts right now and will continue until the agreement is stopped by me or my supporters

Signature of adult with a disability

My Signature: _____

My printed name: _____

My address: _____

My phone number: _____

My email address: _____

ACLU/Quality Trust Supported Decision Making Sample Agreement

Signature of Supporter

I, _____ consent to act as _____'s supporter under this agreement. I understand that my job as a supporter is to honor and express his/her wishes. My supports might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate his/her choice. I know that I may *not* make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

ACLU/Quality Trust

Supported Decision Making Sample Agreement

My name is _____

I want to have people I trust help me make decisions about my money. The people who will help me are called **supporters**. I can say what kind of help my supporters will give me. If I want supporters to help me make other choices, I will also sign a different agreement called “Supported Decision Making Agreement”

I want my supporters to help me make choices about how I spend and save my money

Resources

- **CEDD at the UC Davis MIND Institute**
 - <http://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>
- **UCSF Office of Developmental Primary Care**
 - <http://odpc.ucsf.edu/supported-health-care-decision-making>
- **ACLU Supported Decision-Making Library**
 - <https://www.aclu.org/other/supported-decision-making-resource-library?redirect=supported-decision-making-resource-library>
- **American Bar Institute**
 - <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>
 - www.ambar.org/practicaltool
- **National Guardianship Association**
 - http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
 - http://www.guardianship.org/documents/Standards_of_Practice.pdf