

Rethinking Conservatorship During Transition:

Less Restrictive Family Support Options

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

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 the Conservatorship Process

- 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 adequate oversights to ensure conservators work in the best interest of the conservatee
- Conservatorships can be ended when appropriate

National Council on Disabilities 2018 Report

1. States do not have needed data on conservatorships
2. People with disabilities are widely underestimated in their decision-making abilities
3. The rights of people with disabilities are often not protected during guardianship proceedings
4. People doing capacity assessments are often not properly trained
5. Courts often do not properly oversee conservators to make sure they are not taking advantage of their authority
6. Most state require trying less restrictive alternatives, but often do little to enforce this requirement
7. Every state has a process to end guardianships, but this process is rarely used and can be complex, confusing, and

Concerns About Our Current Conservatorship Process

- 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)

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))

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

American Bar Association Guide

- Clearly identify the reasons for concern driving the exploration of guardianship
- Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations
- 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
- If a conservatorship is needed, limit to areas absolutely required



Self Determination:

Having Information

Having Choices

Steering one's own life

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

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?

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

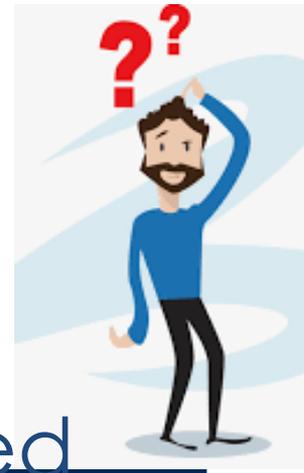
People with greater Self Determination have higher quality of life are more likely to:

- 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,

What is Supported Decision-Making?

- Supported decision-making is when one or more people help:
 - Explain information, issues and choices
 - Make sure people aren't rushed or pressured
 - Reflect on past experiences
 - Weigh options
 - Develop decision-making skills
 - Communicate choices when needed



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

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

Building a Circle of Support

- When families find people who help support their loved ones with disabilities:
 - Enriches their lives
 - Energizes the family
 - Increases perspectives and opportunities
 - Provides a safety net for when family supports need to end or need to be pulled back



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

Can Supported Decision-Making be an Alternative to Conservatorship?

- There is not currently a law defining supported decision-making in California
- Supported Decision-Making can be used along with other tools that do have legal standing:
 - Assignment of educational decision making authority
 - HIPAA release form
 - Agent under health care power of attorney or advance directive
 - Health care surrogate under state law
 - Agent under financial power of attorney



Can Supported Decision-Making be Used Within Conservatorship?

- “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.”



Conservatorship	Supported Decision-Making
<p>Clear legal authority</p> <ul style="list-style-type: none"> •Medical, Services, Access to information 	<p>Informal process</p> <ul style="list-style-type: none"> •Need involvement of person to access information and services
<p>Conservator is the decision-maker</p>	<p>Person is supported to make decisions</p>
<p>Legal removal of rights</p>	<p>Person retains rights</p>
<p>Court must make changes</p>	<p>All aspects can be changed as needed</p>
<p>Lifelong (with rare exceptions)</p>	<p>Can easily be ended or modified</p>

Upcoming Trainings

- 2019 Regional Trainings for families and professionals on implementing supported decision-making
 - Each training will have a family session and professional session to focused on helping families formalize their supported decision-making practices.
 - The trainings-- in San Diego, LA, Stockton/Sacramento, Bay area and Northern California-- will involve the SCDD regional offices and the local Regional Center.
 - **Sign up to be on our mailing list for training information**
 - **Check the Supported Decision-Making web page on the**

MIND Institute website for updates.
CENTER FOR EXCELLENCE IN **DEVELOPMENTAL DISABILITIES**
- **Watch for SCDD announcements**

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>
- **National Council on Disability, “Beyond Guardianship” Report**
 - https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf
- **American Bar Institute**
 - https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.pdf
- **National Guardianship Association**
 - http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf
 - http://www.guardianship.org/documents/Standards_of_Practice.pdf