



Supported Decision-Making

A companion booklet to the CEDD/ACLU video series

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Introduction

This booklet is a companion to the materials on the website of the Center for Excellence in Developmental Disabilities (CEDD), which is found at

<https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>

Supported decision-making is a natural process that we all engage in with people that we care about. Formalizing supported decision-making in our relationships with people with disabilities can be a way to ensure that we are providing supports rather than over-supporting or controlling people's lives. For many people, the supported decision-making process can eliminate the need for conservatorship.* For people who do need to have a conservator, supported decision-making can still be used to include people in the decisions that affect their lives.

CEDD's supported decision-making project was supported by a grant from the WITH Foundation.

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Concerns with the Conservatorship Process

When a young person with disabilities approaches the age of 18, the family is often mistakenly told that they must seek conservatorship or they will no longer be able to obtain information or provide guidance and support in the areas of healthcare, education and other services.

While some people with disabilities may need assistance to understand complex information, conservatorship is the most restrictive option available to provide support.



*Susan Mizner, J.D.,
ACLU Disability Rights
Program: “One of the*

problems with guardianship and conservatorship is that young people with developmental disabilities often have that guardianship or conservatorship imposed when they turn 18. And if we know anything about kids with developmental disabilities, we know that they develop differently. It’s not that they don’t develop.

So, someone who is 18 with a developmental disability is going to continue to learn skills. We would never want them frozen in time with the capacities that they have at that moment. When we impose a guardianship on them at 18, we are essentially having the court freeze that moment in time in terms of their skills, and having decision-making taken away from them means that the opportunity to develop those skills is also taken away.”

A Long-Term Commitment that is Difficult to Change

The conservatorship process begins with a petition to a court, where someone – often a parent – asks the court to appoint a conservator for the person.

Only a judge can grant, change, or end a conservatorship.

Because the restrictions of a conservatorship are rarely altered or reversed, conservatorship locks people into a long-term and often permanent arrangement whereby other people make binding decisions for them.



Susan Mizner, J.D., ACLU Disability Rights Program: Sometimes parents go to court in order to have conservatorship only for one or two areas of decision-making. But

once you've entered that realm of the court, the judge is the one who has then taken on the responsibility of deciding what the adult with disability needs help with.



Claudia Center, J.D., ACLU Disability Rights Program: One thing we see a lot is when both parents come to court and, let's say they're divorced, and each

parent tells the court, I want to be the guardian for my son or daughter with a disability. And the parents can't decide which of the two parents should be the guardian. Sometimes the court will say, ok, well, I'm going to appoint this third party to be the guardian, and so it's then not either parent; it's actually a stranger to the parents and a stranger to the person with a disability. Parents can sometimes be surprised by those kinds of decisions by the court.

Families are often unaware of potential complications of conservatorship or the alternatives available to support their loved ones. There are cases when conservators may not be available or willing to make the decisions that they are expected to make. This is especially difficult when the person who is conserved has the capacity to make the decision for her/himself.



Clarissa Kripke, M.D., UCSF: I have patients who have court-appointed conservators who've never met the person that they're supporting; who don't show up when the person is in the hospital. Sometimes conservators who know very little about the situation will sign off on informed consent, even without understanding the person's priorities and even without having very much of a relationship with them. Other times, when people can't be reached or are reluctant to make a decision, people go without care because you can't get informed consent and it isn't an emergency. It can delay care in ways that are very harmful.



One Family's Experience with Conservatorship



Linda Demer, M.D., parent: The reason I got the conservatorship was that the school administrators told me that it was necessary, that if I didn't, that my son would be alone at the IEP meetings and would have to negotiate services on his own. So I went to an attorney who was experienced in providing conservatorships, and she didn't provide any suggestions of alternatives, and nor did the school. So I was unaware of any alternatives to conservatorship.

I resigned as the conservator, that's all I could do. There was really no choice. And when I resigned, the court appointed a professional conservator. The new professional conservator company, they're located an hour and a half away from Los Angeles, and from his apartment, so that makes it very difficult for them to respond to an emergency. And it also means that they can't visit very often. I don't think that the new company has the time to come that far to get to know him and spend time talking with him.

My son's now 29, and in the last several years, he has continued to grow amazingly. He's learned how to make many of his own decisions, he's learned to communicate much better, to express what his decisions are, and to show consistency in his decisions. I'm very pleased – he's now got three part-time jobs, he's been living in his own apartment, he shops for himself, handles his own money, cooks, and cleans.

In my view, I think my son is now matured enough, and understands his decisions and understands explanations, that he would be a nice candidate for supported decision-making. His doctors feel that they can explain to him in a way that he understands, and that he can actually give consent. And so, with just the additional explanation from a person there who understands his language, to clarify the meaning of any jargon, or put it in language that he understands. With that kind of help, I think he'd be very capable of deciding what he wants and doesn't want.

Some people have suggested that we consider eliminating the conservatorship, given how much he's grown, and when I've asked about that, the attorneys pretty much tell me that it's an irreversible process, or just extremely difficult to undo.

The Difficulty of Terminating a Conservatorship

The process of trying to terminate conservatorship requires money, hiring a lawyer, obtaining numerous evaluations and reports, attending court hearings, and a judge who is willing to terminate the conservatorship.



Colleen Sonneborn, J.D., Marin County Public Defender: I've represented approximately 150 people over a ten year period in limited conservatorships and during that period of time I've

represented probably 5 individuals where there was an issue about whether or not the conservatorship was terminated. A lot more people get into conservatorships than get out of conservatorships. But its also more difficult to challenge the conservatorship later on because the burden shifts to the conservatee to produce all of the evidence to get off conservatorship.

Conservatorship can Stunt Opportunities to Learn



Susan Mizner, J.D., ACLU Disability Rights Program: Most families and lawyers and judges impose conservatorship or guardianship because of a desire to protect an individual. It is incredibly well-meaning. But the legal document doesn't provide that protection. And in fact, one guardian seldom can provide that protection. What studies have shown is that the best

protection is actually training in how to make judgments, how to recognize dangerous situations. The empowerment of self-agency so that someone knows how to say "no" or someone knows how to ask for help. That's what keeps people safe, not a piece of paper.

Clarissa Kripke, M.D., UCSF: Choice and control over your life is what promotes safety. Being able to say, "I trust this person and I want them to help me", or "I don't trust this person and I don't want them to help me" is what helps keep people safe.



Less Restrictive Options

Most state laws specify that conservatorship should only be imposed when there are no less restrictive alternatives available. Even the National Guardianship Association has a position statement that reads, “Guardianship should be utilized only when lesser restrictive supports are not available. Alternatives to guardianship, including supported-decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”

In practice, few people who have gone through conservatorship proceedings report that there was any discussion or exploration of less restrictive alternatives.



Robin Hansen, M.D., UC Davis MIND Institute: I think supported decision-making should be the first option that parents, families, and individuals with disabilities start thinking about as they're nearing 18. And I think that all of us who support teenagers and young adults in that process, should be knowledgeable about supported decision-making, we should know what the process is, who can help them develop and walk through how to make that decision. Rather than having the choice initially be presented as, "Most people choose conservatorship or guardianship, but there's this other thing called supported decision-making." I think we ought to flip that around, and start with, "Let's think and talk about supported decision-making, whether that might fit for you and your family."



Clarissa Kripke, M.D., UCSF Sometimes when I'm explaining what SDM is to a doctor, I use the example of a cultural broker or a language translator. The person is there to provide support, to support the communication, to make sure that things are understood. But they're not there to take over your relationship with your patient, or to make decisions for them.

What is Supported Decision-Making?



Clarissa Kripke, M.D., UCSF Making a choice means understanding your options, the risks and benefits of each option, weighing them against each other, and communicating a choice. People can have difficulties with any part of that process. Sometimes people need support to understand their options, or the risks and benefits, sometimes people need support to weigh them against each other, to help them

understand how that process works, some people need help with communication, so that they can communicate their choices.

Supported decision-making is a natural part of all relationships. When people we know are going through stressful or difficult experiences, we support them using these same strategies. People with disabilities may experience more situations in which they need support, but often have the ability to make many decisions with proper supports.

Supported decision-making begins with a person selecting trusted advisors that they can ask for assistance from. These advisors are called supporters. The supporter's role is to provide assistance but not make decisions for the person. The person receiving support is the decision-maker. Anyone can be a supporter, as long as the person with a disability *chooses* them and *trusts* them to serve in that role.

Clarissa Kripke, M.D., UCSF: That is a critical support of a supported decision-making relationship, is that the person using support chooses who supports them. The most important thing is that the person you choose to be your supporter is someone you trust to respect your decisions, not to make decisions for you.



The Role of the Supporter

The supporter can assist the decision-maker by:

- Explaining information
- Talking through issues
- Reflecting on past experiences
- Weighing options
- Making sure they aren't rushed or pressured
- Communicate their choices when needed



Susan Mizner, J.D., ACLU Disability Rights Program: The supporter is someone who provides advice. The supporter may look at different options, may help evaluate the pros and cons, may help translate information into plain language or help communicate decisions to the outside world. The decider is the individual with a disability.

Many people prefer to have a group of supporters. This provides a range of viewpoints and also allows the decision-maker to decide who they want to discuss specific issues with.

Susan Mizner, J.D., ACLU Disability Rights Program: One of the features of supported decision-making that we like the most is that there's seldom just one supporter. Usually there are two and often three, so there is more than one person who is checking in to see if someone is doing well, who might be able to recognize if there's a problem, if there's more support that is needed, or if someone is being neglectful or abusive.



Claudia Center, J.D., ACLU Disability Rights Program: A person with a disability might want different supporters to help with different types of decisions. So for example, the young adult with a disability might want their parent supporter to help them with financial decisions, or maybe help them with a lease if they're signing a lease for an apartment, that would be a very typical role for a parent supporter to provide assistance with. The person with a disability though, understandably, might not want to talk to their parent about romantic relationships, or intimate decisions, and so in that case, maybe it would be a

sibling or a friend who would provide that type of support. So the agreement can specify which areas go with which supporters.

Supported Decision-Making Agreements

Supported decision-making can be done informally, but many people find that using a supported decision-making agreement is helpful. A supported decision-making agreement helps to define who is on the support team and also clarify the role(s) of each supporter.

There are many templates for supported decision-making agreements available and they can be customized for each person. The agreement and members of the support team can be changed at any time, although it is a good practice to have the team come together when changes are made so that team members are aware of the changes and be confident that changes were made in good faith.

Supported decision-making agreements should be written in plain language and may be read out loud or explained as needed.

The agreement allows the person with a disability to select the areas that they feel they need assistance with and also to decide which supporter will assist in each area. S/he can have more than one person helping in some areas and no one helping in other areas.

The *How to Make a Supported Decision- Making Agreement* booklet can be found on our website at <https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>



Legal Tools Allowing Access for Supporters

Because supported decision-making is an informal process, there are times when people who are supporting people with disabilities need strategies to access information or participate in some appointments. It can be helpful to consider how we support typically developing young adults or aging loved ones who do not have conservatorship. It is also important to consider the family or service supports that the person either already receives or to which they may have access.

- If a person needs assistance identifying or responding to important mail, do family members or service providers regularly assist with that? If need be, mail from Social Security or other important sources can be sent to a supporter's address and then reviewed with the person.
- If a person needs support with finances, consider natural supports or, if needed, establishing a payee.
- If a supporter needs to have access to sensitive information, a supporter can accompany the person to appointments or can be present during phone calls, with the person's consent. If needed, the person can sign a release of information for the supporter. An example of a simplified HIPAA release for medical information and sample release of educational information are found at the end of the *How to Make a Supported Decision-Making Agreement* booklet on our website.
- Advance Directives have been simplified and used by people with disabilities to enable supporters to assist with making medical decisions. The PREPARE website has advance directives tailored to each state that are available in multiple languages. <https://prepareforyourcare.org/advance-directive-library>

For more information about using social and legal strategies when supporting someone with a disability, please refer to the Disability Rights California publication *Limited Conservatorships and Alternatives* and the American Bar Institute publication, *PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making* on our resource page and on our website at

<https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>

Resources

- **CEDD Supported Decision-Making Toolkit**
 - <http://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>
- **Disability Rights California**
 - **Principles: Conservatorship of Persons with Disabilities**
 - <https://www.disabilityrightsca.org/legislation/principles-conservatorship-of-persons-with-disabilities>
 - **Limited Conservatorships & Alternatives**
 - <https://www.disabilityrightsca.org/system/files/file-attachments/557801.pdf>
- **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” 2019 Report**
 - https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf
- **National Council on Disability, “Turning Rights into Reality” 2019 Report**
 - https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf
- **American Bar Institute**
 - <https://www.americanbar.org/groups/disabilityrights/resources/article12.html>
 - https://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALGuide.pdf
- **PREPARE Advanced Directives**
 - <https://prepareforyourcare.org/advance-directive-state/ca>
 - <https://betterhealthwhileaging.net/end-of-life-planning-easy-advance-directives-through-prepare/>