

With Support AND WITHOUT THE COURT

DISABILITY
VOICES
UNITED

Supported Decision-Making
Handbook for Parents
of Adults with Developmental
Disabilities in California

Sydney

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Introduction

This Supported Decision-Making Handbook is a guide for parents of adults with developmental disabilities who are interested in making sure their sons and daughters are supported and have their preferences respected for the rest of their lives. The handbook is based on conversations with parents like you. We listened to how important it is that your adult children are protected, and how you want to make sure you stay involved in their lives while giving them the ability to grow.

This handbook will help you understand

- What supported decision-making is
- Who supported decision-making is for (big hint: everyone!)
- When you can use supported decision-making
- Why it's important to use supported decision-making and avoid conservatorship
- How you can use forms to help you support your adult child with their health care, finances, and education

Supported decision-making (SDM) is an important opportunity to empower your adult children so that they continue to grow and learn, instead of taking all control away when they turn 18. SDM allows you to stay involved

in your adult children's lives, without involving a court process that has risks. Finally, SDM provides your adult child with a circle of support and ongoing encouragement, guidance, and protection long after you are gone.

We know that you were your child's first advocate and champion. We know that when your child was first diagnosed with a developmental disability, you rolled up your sleeves and got to work to ensure that they lived up to their potential. And now, as your child becomes an adult, that hope for their positive future should lead you on the path to supported decision-making.

This handbook will assist you on that path. As one parent told us, "Everyone can make decisions. Even if they're spitting out food, that's a decision If only we can get the right supports [to help them]."

This handbook has been written and edited by Disability Voices United, a California statewide organization directed by and for people with developmental disabilities and their families. We thank our staff and board for their contributions to this handbook, including Ed Hirtzel, Judy Mark, Suzanne Bennett Francisco, and Isita Tripathi.

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The Problems with Conservatorship

What is conservatorship?

When your son or daughter is a child, you often make all of their decisions for them. But when they turn 18, whether they have a disability or not, they are recognized as adults who can make their own decisions. At that point, many parents are told the best way to protect their children is by filing papers for conservatorship (called guardianship outside of California).

A conservatorship is created as a result of a court hearing. Usually the parents, but sometimes others, petition the court to say that their family member with a disability who is over 18 should not be able to make decisions about their lives, such as on spending money, health care, where to live, whom to date, and even with whom to have sexual relationships.

What if I'm in the process of conserving my adult child and I want to stop?

Conservatorship is created at a court hearing. If you haven't had the conservatorship hearing yet, you can stop the process. Even if you have a hearing date, it's not too late. You have the option to just not show up to the hearing. They cannot conserve your child if they are not present. Very rarely, courts will insist that you must go through to the hearing once it's been scheduled. If this happens, go to your regional center and ask for a letter stating that conservatorship is not necessary and that you as the parent(s) are practicing supported decision-making to support your child.

What if the professional conservator moved your child to a city far away from you? Or if they denied your child an important health treatment? Sadly, this kind of story occurs all too often.

The brief hearing in front of the judge usually ends with the court establishing a conservatorship over the person with a disability and appointing someone else to make their decisions for them. That person is called the "court appointed conservator" who now has full authority to make decisions for the person with a disability or "conservatee."

The illusion of protection

Many parents mistakenly believe a conservatorship is the only way they can protect their adult child with a disability and stay involved in their lives. They are told by doctors, regional centers, and teachers that conservatorship is the only way to be sure they aren't taken advantage of in financial and health care matters. Parents believe that their children will be safer if they are conserved.

The truth is quite different. Conservatorship offers no guarantees that a person with a disability won't be taken advantage of by financial scams. It affords no extra protection against physical or sexual abuse.

Conservatorship provides no extra legal protection if an adult with a disability is arrested by the police. Sadly, in reality, people who are conserved are taken advantage of, abused, and arrested every day.

Anyone can be a conservator – even a total stranger

Anyone over the age of 18 can become a court-appointed conservator, including a spouse, parent, sibling, relative, friend, as well as some regional centers, the California Department of Developmental Services, and professionals who are paid out of the conservatee's estate. In fact, half of all conservators and guardians in the United States are total strangers to their conservatee.

What if my regional center tries to conserve my child without my knowledge?

Unfortunately, regional centers have been known to initiate the conservatorship process on their own for a consumer. Please be aware that this occurs very infrequently. But there are two important tools to protect you in the rare event that this occurs. First, you may remind the court that California law requires everyone to consider alternatives BEFORE initiating conservatorship. Second, the courts must provide a reason for failing to choose the person that the conservatee prefers as the court-appointed conservator.

These two rules are sometimes overlooked by courts and regional centers. Use them to advocate for your adult child. You know your child best. Be sure to document if your child has chosen you as a trusted supporter. Video and visuals such as a person-centered plan can be strong evidence that help assure the regional center. It's also helpful to involve regional center staff in your child's supported decision-making whenever possible, so you can prevent this situation from happening.

While parents can ask the court to be appointed as conservator, the court is the one who chooses. This means the court can remove the parents as conservators, for any reason and at any time, and appoint a different person. That person might be someone that the conservatee knows, but too often they are a public guardian or even a professional conservator for whom the parents or the estate are forced to pay. Some professional conservators, who have gotten quite wealthy from this occupation, never even meet their clients in person and live hours away.

There are too many stories of courts removing the parents as conservators and giving it to a public guardian, professional conservator, or even a regional center. Sometimes the conservator restricts visitations with the parents.

What happens when the parents die

The fact that the court controls the conservatorship means that if you conserve your adult child, you cannot be sure who the conservator will be when you die. Even though you may set up a chain of succession for the conservatorship, such as requesting that a sibling take over as conservator, the court doesn't have to appoint the next person in line. Your adult child can end up with a professional conservator who may not have the same vision for that individual that their parents had. That professional conservator is able to do such things as restrict time with their surviving relatives, change where the person lives, or even institutionalize that person.

The cost of conservatorship

Conservatorship can be extremely expensive. In order to conserve someone, parents often need to pay thousands of dollars to lawyers. These lawyers commonly work on multiple cases at the same time and often don't provide parents with less restrictive alternatives – that would eliminate any legal fees.

Janice's Story*

Janice is a young adult with autism who had been conserved by her parents when she was 18. A few years later, the parents had a significant disagreement with Janice's regional center who believed that Janice should move out of her parent's home and into a group home. Janice didn't want to move out and wanted to stay with her parents. So the regional center sent a letter to the court stating that the parents were not good conservators and that it should be handed to a public guardian. The court approved this and the public guardian worked with the regional center to force Janice to move away from her parents, leaving her devastated.

*Names have been changed for privacy reasons.

That's not all, though. Remember the "professional conservators" mentioned earlier? Professional conservators are very expensive too. Their fees are paid by the estate of the person who is conserved. What does that mean for you? If you conserve your adult child and then a professional conservator is appointed for any reason, you may have to pay for that professional conservator with costs as much as \$20,000 a month.

Possible risks in involving the court

Conservatorship can also introduce unnecessary risk into a family's life. If a parent or other family member is undocumented, entering a courthouse invites the attention of the legal system. Immigration and Customs Enforcement (ICE) has been known to pick up people targeted for deportation after their court appearances on other matters. The court doesn't have to appoint a parent as conservator just because they filed the petition, and courts may not appoint a parent who doesn't have legal documentation in the United States.

The vast majority of conservatorships are permanent

Once a person is conserved, it is generally considered by the court to be a permanent decision. Even conservatorships labeled "limited" can deceive parents into thinking they are not as restrictive or can be changed. To get a conservatorship reversed is very difficult, often expensive, and rarely successful. The few cases where a court has ended a conservatorship – after likely many years of fees and fighting an uphill battle – have been seen as a huge victory.

Conservatorship is a life sentence for a person with a disability that will usually last beyond the lifespan of the parents. Parents often make the lasting mistake of asking the court to conserve their adult child, thinking that they can just reverse it at some point in the future.

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Frank's Story

Frank was an older adult with multiple developmental disabilities. He lived with his parents, who were his legal guardians, and went to a program every day that he liked. Before his parents passed away, they made specific instructions for the court that Frank's sister should become his guardian. But after their passing, the court decided that, because Frank's sister lived in another state, they would appoint a professional guardian to be paid for out of the money left to Frank. These funds were limited, so the guardian decided to place Frank in a publicly funded institution to save the money for his fees.

Even if a parent simply just wants to change who the conservator is or add a co-conservator, it is difficult. For example, it can sometimes take years and additional legal fees to add an individual as co-conservator. And courts don't have to grant the parent's request for a change.

Court checkups – the reality

Courts are required to check up on the conservator, but it doesn't always happen nor work out like you think.

The court is required to send a representative to check up on the conservatee to ensure they are safe and that the conservator is doing their job. In many counties, the visit is required every year, while others mandate it every two to three years. The reality is that in many places, it doesn't happen at all.

While providing safety checks on a conserved person sounds like a good idea, sometimes it ends up a nightmare. Suppose you did conserve your adult child. Imagine that a court representative shows up at your doorstep and your adult child is having a bad day or your house is a mess. Although the court is charged with listening to and speaking directly with the conservatee, the investigator may not speak your language or understand your culture. It is also likely they are unfamiliar with a non-speaking person's unique communication style or system. The court

could make assumptions, based on that moment in time, that you are not equipped to be the conservator. They could appoint a professional conservator, whom they work with every day and are close to.

Does a conservatee need permission to move or travel out of state or country?

If a conservatee wants to go on a vacation or take a trip out of state or the country, court authorization may be necessary. The court will usually approve the trip, but, once again, the court is in charge.

If you are a court appointed conservator and wish to move with your conservatee, you must get permission from the court. A court-appointed conservator must always consult the court to determine if the move is in the best interest of the conservatee, among other things.

If a court appointed conservator is moving without the conservatee, they must file a change of address with the court and the court investigator's office. If the court-appointed conservator wants the conservatee to move,

they have an obligation to let the court know at least 15 days before the move. The conservator has to file a notice for the proposed change. In some circumstances, the court-appointed conservator may need a court order for the move.

If you move within the state of California, the conservatorship itself does not change. However, each county has different rules and requirements for court investigators to check on the court appointed conservator and conservatee.

The most important thing to understand is reality that judges have the complete power to approve or deny a move by a conservatee.

Moving outside of California can also result in different outcomes depending on the circumstances. You might be required to have a probational guardianship in the new state until it is approved. The new state court could recommend a different guardian/conservator. Or the conservatorship process might be started from scratch. To transfer the conservatorship, you will likely need to file paperwork with both the state you are transferring from and transferring to. So, for instance, a move from California to anywhere else could involve a lengthy court process from start to finish between the two states.

If the conservatee wants to move outside of the country, the court can potentially restrict the move. The conservatorship likely dissolves and ceases to exist if a conservatee is able to leave the United States, as American probate law is not followed outside of the country.

My child is already conserved. Is there anything we can do to exit the conservatorship?

While it is possible to exit a conservatorship, it is extremely challenging. First, you will need to hire an attorney, which is likely to be a challenge because most probate attorneys are rarely willing to take these cases. (Many lawyers get a lot of business from conserving people and believe in the system.) After that, you will need to prove that your adult child has the ability to live their life with support, without being conserved, in a court hearing. This is very difficult because the court has already ruled that your child lacks the ability to make decisions during the initial conservatorship hearing.

There are steps you can take, however, such as ordering an independent evaluation of your child's capabilities called a functional skills assessment. You can also video record your child throughout their day to highlight their abilities. But there are no guarantees except that it will be a long and expensive process. This is why we advocate for SDM as the first option, with conservatorship as a last resort.

The most important thing to understand is reality that judges have the complete power to approve or deny a move by a conservatee. Any number of unanticipated events can occur when the court steps in that can and have ended badly for caring family members. The same matter can be presented to two different courts within two counties, or even to two different judges within the same

county, and produce an entirely different outcome.

Conservatorships are supposed to be the exception, not the rule

In California, conservatorship is only supposed to be granted by the courts if it is the only way to meet the needs of the person with a disability. If there is any other way, the court is not supposed to grant the conservatorship petition.

The problem is that the probate courts, where conservatorships are decided, don't usually follow that rule. Even worse, there seems to be no incentive to tell individuals and families that there is a better way. Lawyers, whose purpose is to represent the interests of the individual with a disability in probate court, make a lot of money through the promotion and establishment of conservatorships. Attorneys have often shared that advocating for alternatives would be a conflict of interest.

Unfortunately, our system is upside down, where conservatorship is the clear default, and parents are questioned if they don't take this path. Parents come under tremendous pressure to conserve their child with a disability from respected people in their lives, including other parents. Parents are panicked as their child approaches the age of 18 if they haven't already consulted a lawyer and started the conservatorship paperwork.

There's a better way

We understand that parents still need to protect their adult child, but there should be no panic. Don't rush to the courthouse. There is a better way, one where your choice not to conserve is respected and your adult child is both empowered and protected from the court. In this system, there's no need to conserve.

You have the ability to protect your child even more – **with support and without the court**. It's called **supported decision-making**.

Parents come under tremendous pressure to conserve their child with a disability from respected people in their lives.

Lanh's Story

Lanh, who has non-speaking autism and cerebral palsy, lived with his mom and conservator, a refugee from Vietnam, for the majority of his life. Lanh and his mom traveled and lived a happy person-centered life. But Lanh experienced anxiety and sometimes the sensory feedback in his surroundings would overwhelm him. When triggered, his major sensory issues would make wearing clothes extremely uncomfortable and he would prefer to roam in his own home with little or sometimes no clothing. When the conservatorship court representative conducted a required visit to his home, Lanh would not put on clothes. His mom, whose English was limited, had difficulty explaining this to the representative.

The representative recommended to the court that conservatorship be removed from the mother. Yet instead of looking to one of Lanh's siblings, the representative recommended a professional to be the conservator. Lanh had money in a trust and the representative saw that one of her colleagues could be hired – at a cost of over \$20,000 per month. The professional conservator moved Lanh out of his home with his mother and placed him in a terrible unlicensed private home with strangers. His loving family, who are allowed to visit only four hours per week and with a chaperone, suspects that Lanh is being abused and neglected. Despite thousands of dollars spent trying to get conservatorship handed to one of Lanh's family members, the court has repeatedly denied this request because the representative continues to advocate for the highly paid professional conservator.

How Supported Decision-Making Works

What is supported decision-making?

Supported decision-making (SDM) enables people with disabilities to choose supporters to help them make choices to the maximum of their unique abilities.

Maybe you count on your spouse to help you with your computer. Or you call a friend who is a nurse to give you advice on a medical procedure. Just because a person needs support on some decisions doesn't mean all of their ability to make all choices about their life should be taken away.

But unlike conservatorship, there is no need to involve the court in the person's life. There may be no need to pay for a lawyer, appear before a judge, or get visits from a court representative. Your adult child has the opportunity to lead their life with support, and without the courts.

A person using SDM chooses trusted advisors to serve as supporters. Supporters may be family members, friends, staff, or professionals. The supporters agree to help the person with a disability understand, consider, and communicate decisions. Supporters also give the person with a disability the ability to make their own informed decisions. Individualized tools, services and accommodations are key to empowering the person to make these choices, especially for those who use augmentative and alternative communication (AAC).

SDM can be very informal, though it can also be written into formal documents when necessary. It's also designed to change, just like people's lives and circles of support change. We'll talk more about that later on in the handbook.

*People without disabilities are seen as wise to seek advice on important decisions. **The same benefit should be given to people with disabilities as well.***

With a little help from your friends

Think about the last time you had to make a medical decision for yourself. Did you ask the doctor to explain something in plain speech without any medical jargon? Did you ask a friend or family member who works in medicine for their opinion? Did you Google a website that was written in a way you could understand?

Everyone seeks help with difficult decisions. People without disabilities don't have their choices taken away when they seek help. On the contrary, they are seen as wise to seek advice. The same benefit should be given to people with disabilities as well.



What does supported decision-making look like?

SDM looks different for everyone. A person might have one or two supporters. Another person may have many more. Each supporter may take a different role. If you are the parent of an adult who uses supported decision-making, you will recognize that it is often the same things you are already doing.

Making sure your adult child gets to express their preferences in whatever way works best for them. That may mean something as big as creating a person-centered plan or something as small as a facial expression displaying a dislike of something.

Example: Every time one of Eileen's nurses came into her house, she would turn her head away and frown. But when a different nurse came in, Eileen would have a big smile. Eileen is expressing her preference for which nurse she likes better. A supporter should identify Eileen's nonverbal communication of her preferences, acknowledge these preferences, and help Eileen take action.

Explaining choices in a way that you know your child will understand, whether it's through pictures, words, or voice. It's important that you help your child think through the pros and cons of choices and whether there are consequences of certain decisions.

Example: Josh loves McDonald's. He wants to eat there every day for dinner. He is an adult who can make his own choices. His supporters can help him think about these choices by explaining the consequences, in a way that Josh will understand, of eating unhealthy food all the time, such as obesity and diabetes. They will help Josh work out a plan that he likes.

Not letting others make decisions for your child, or rush or force them to make a choice when they haven't considered all of the options.

Example: Emma went to the doctor and needed to have her blood taken. When she resisted, the doctor suggested they hold her down and force her to do the blood draw. Emma's supporter, her mother, communicated her daughter's concerns about needles and advocated for her to have more time to get used to the idea. Emma went home and used her supporters to understand why she needed to have her blood taken and then went back a few days later and agreed to the blood draw.

Providing examples of what a choice might look like, using an experience of something that has happened in the past to them or someone they know.

Example: Hamid loves to buy and play video games. He just got a part-time job and wants to spend all of his paycheck on video games. Instead of taking away that choice, a supporter might give an example of one of Hamid's friends who spent all of his money and had nothing left to go to Disneyland. A supporter might help Hamid open up a bank account and show him how to save money for something special.

Actually, we all practice supported decision-making every day, regardless of whether we have a disability.

The Advantages of SDM

Expanding the circle of support

We know you have great concerns about who will care for your child after you die. Supported decision-making helps adults with disabilities expand their trusted group of supporters – including those outside of the family. Not only does this provide a sense of pride, competence, and community for your adult child, it also means they have a circle of trusted people who care about them and will be involved in their lives long after you pass.

Support without the courts

SDM doesn't involve the courts, which feels safer to many people with disabilities and their families. In SDM, the person with a disability, with the assistance and advice of their circle of support, is in control of their life choices. And the circle of support can change at any time – with no need to report to the court.

Plan to move? That's your choice!

If your child uses SDM and is not conserved, they do not need anybody's permission to move. Nor do they need to ask anyone if it's okay to visit another state or country. In SDM, your adult child has the same freedom of movement as anyone else.

Change your mind? No problem with SDM

You've read earlier that conservatorships are almost impossible to remove, and that it's even difficult to simply change who the conservator is. Supported decision-making, however, acknowledges that

people move in and out of your adult child's life, and so their circle of support should change to reflect that. In most cases, your child's circle is an informal group that is used whenever it makes sense. There is no one to report to and tell that the circle or supports have changed.

But in those areas where a written agreement would be helpful, so that your adult child can more formally involve you in their decision-making, you can create a Supported Decision-Making Agreement. (More information about this is included later in this handbook.)

Unlike conservatorships, SDM agreements can be ended or changed at any time without any court or official involvement.

An SDM agreement can be attached to legal documents, like powers of attorney and HIPAA Authorizations, can be modified at any time and has the benefit of being tailored to the person the Agreement is supporting.

*If a person
with a disability
needs less support,
wants to change their
circle, or needs support
in a new area, then an
SDM agreement can be
changed right away
at no cost.*



Tools to Practice SDM

Ways to Help People Understand their Options

Some examples of tools that supporters might use to help individuals with developmental disabilities understand their choices are:

- Chosen, trained partners who listen and facilitate communication – using AAC if needed
- Plain language visual or audio material
- Visual supports
- Lists of the pros and cons in choice-making
- Role-play activities to help the person understand their choices
- Frequent and consistent opportunities to practice safe choice-making
- Supporters attending appointments to take notes and help discuss options
- Consideration of a joint bank account and other ways to manage financial decisions together

Examples of Documents that Might Include SDM

SDM can simply be handwritten onto or into legal binding documents or an SDM agreement can be attached. Examples of these are:

- Individualized Education Program (IEP)
- Individualized Program Plan (IPP)
- Individualized Plan for Employment (IPE)
An IPE is a written plan that outlines what a person's goals for employment are and what supports can assist them in achieving those goals.
- HIPAA Authorization
HIPAA (the (Health Insurance Portability and Accountability Act) is a law that protects people's private medical information. This form lets a person give a supporter the right to see their private medical information.

I want to...	Documents to bring/use
Support my child at school	<ul style="list-style-type: none"> • SDM Agreement* • Educational Disclosure
Support my child at the doctor's or hospital	<ul style="list-style-type: none"> • SDM Agreement* • Durable Health Care Power of Attorney • HIPAA Authorization • Health Care Passport • SUPPORT Tip Sheet
Help my child manage money	<ul style="list-style-type: none"> • SDM Agreement* • Durable Power of Attorney for Finances
Help manage my child's SSI payments	<ul style="list-style-type: none"> • Representative Payee Form
Help secure my child's financial future	<ul style="list-style-type: none"> • Durable Power of Attorney for Finances • Special Needs Trusts • ABLE account
Support my child in dealing with their regional center	<ul style="list-style-type: none"> • SDM Agreement* attached to your child's IPP plan • Regional Center Disclosure
* You may not need an SDM Agreement to support your adult child in these situations, but may find it helpful depending upon the individual situation.	

- SSI Representative Payee Form
This is a form you can use if someone who receives Social Security or SSI (Supplemental Security Income) wants you to help manage their money.
- Advance Medical Directive
This is a document where a person writes what they want for their medical treatment if they cannot communicate their wishes to a doctor.
- Durable Power of Attorney (DPOA)
A DPOA legally authorizes a person(s) to make some or all decisions on behalf of another. DPOAs are generally low-cost, easily created and modified.

Supported Decision-Making Agreement

Supported decision-making can be very informal. Your adult child can be surrounded by a circle of people they trust that changes over their lifetime.

SDM can simply be written onto or into legal binding documents – like memorializing it in the school's IEP Notes or hand-writing the name of a chosen supporter onto a HIPAA agreement or a SSI Representative Payee form.

There may be other certain circumstances where you might need something in writing to show that you are a supporter helping your adult child make decisions. This is when you may want to consider a Supported Decision-Making agreement.

In an SDM agreement, your adult child with a disability and their supporters can sign a document in which everyone agrees to support the person with their decisions. This document can also be attached to the legal binding documents listed above. This gives the person the flexibility to choose who will have decision-making authority and how that authority may be exercised.

Tools to Help Nonspeaking Adults in Supported Decision-Making

Individualized tools, services and accommodations are key to empowering the person to make choices – especially for those with intellectual or developmental disabilities who use augmentative or alternative communication (AAC).

Supported decision-making looks different for everyone who uses AAC. Here are some examples of customized tools to help people communicate and understand choices.

- Access to individualized communication and assistive technologies that are customized in real-time according to their environment
- Chosen, trained partners who listen and facilitate communication – using AAC if needed
- Plain language, visual or audio material
- Visual supports may include Person Centered Plans, Dream Boards, social stories and other tools

Additional resources on AAC and SDM from Assistiveware are provided on the Resources page,

Supported decision-making can be very informal. Your adult child can be surrounded by a circle of people they trust.



SDM in Health Care

What is supported health care decision-making? Like all of us, people with disabilities may need support to understand health information, communicate with their doctors and nurses, and manage their daily health needs.

Durable Healthcare Powers of Attorney, Advance Medical Directives, HIPAA Authorizations, and SDM Agreements are all tools that allow people with disabilities to practice supported decision-making. We have examples of these forms in Appendix A - Sample Forms.

In a Durable Healthcare Power of Attorney, the individual chooses a person, called an agent, to support them to understand the situations they face and help make health care decisions. The agent may help make all or only certain health care decisions, and gives primary consideration to the person's express wishes. Moreover, the agent and supporters assist the person to make health care choices to the maximum of their unique abilities - with access to individualized accommodations - in order to provide informed consent.

You may also want to consider an Advance Medical Directive. This is a document where a person writes specific instructions about what they want for their medical treatment if they cannot communicate their wishes to a doctor. An Advance Health Care Directive can also be used to give specific directions about life sustaining care and end of life care, psychiatric care, organ donation, burial requests, and other preferences. Disability Rights California has an extensive form and publication on writing an Advance Health Care Directive. This link is located in the Resources section on page 22. The advance healthcare directive is particularly useful if an individual is put under

an involuntary psychiatric hold. This will allow hospital staff to contact the listed supporters immediately.

If there is no advance directive, the patient can sign a Release of Information form so that the hospital staff can coordinate with the parents or supporters. You can find this form in the Resources section on page 22. Parents can also contact their Title 9 County Patients' Rights Advocates (PRAs) for assistance. Each county has its own PRA unit, which can help obtain the patient's approval for hospital staff to contact their supporters. A current directory of Patients' Rights Advocate Units is included in the Resources section on page 22

HIPAA, the Health Insurance Portability and Accountability Act, is a law that protects people's private medical information. With a HIPAA Authorization Form, a person can give a supporter the right to see their private medical information and discuss their medical care without the person in attendance.

An SDM Agreement identifies chosen supporters and the areas in which the person wants assistance - such as in health care decision-making. Uniquely tailored to the person, the SDM Agreement can be attached to legal documents, like powers of attorney, advance medical directives and HIPAA authorization forms.

Other valuable forms to practice supported healthcare decision-making are our Healthcare SUPPORT Tip Sheet and a healthcare passport.

The SUPPORT Tip Sheet, included as Appendix B in this handbook, is a one-page guide to help healthcare providers understand how they can understand, listen to, support and accommodate patients with intellectual and developmental disabilities. Often these patients use augmentative alternative communication (AAC) and assistive technology. Providers can create a smoother process for both the patient and health care staff by using the SUPPORT Tip Sheet as a guide.

A healthcare passport is a document that tells healthcare providers about someone's unique preferences, medical concerns, and ways of communication. You can find a link to a great sample healthcare passport in the "Resources" section of this handbook.

*Supported health
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decisions.*

SDM in Finances

Parents are usually very worried about their child being taken advantage of financially. You are concerned that someone will try to steal your adult child's money or make them sign a contract that makes them liable for paying out money they don't have.

A durable power of attorney for finances gives your adult child protection by giving a person they trust the legal authority to act on their behalf financially. It enables an individual to use support in their decisions and still have the opportunity to spend some of their money on things that they choose. The power of attorney does not require the involvement of the court but does require the signature and stamp of a notary. (Note: Some families have expressed concern about finding a notary who will notarize a document signed by a person with a significant disability. You should show them an SDM Agreement allowing their parent to support them in their finances.)

Using a durable power of attorney for finances can help with potentially dangerous circumstances. For instance, the durable power of attorney may help void contracts signed by your adult child by demonstrating that the person may not have understood what they are signing. In fact, regardless of a power of attorney, a person who does not have the capacity to understand a legal contract can sue to get out of that contract. States and local courts have the ability to void these contracts. But it may be much easier to advocate directly with the other party and show them the SDM agreement and other documents.

That being said, it takes work and advocacy to get out of contracts and exorbitant purchases. The best protection is to have a joint bank account and ensure that the person only has access to small amounts in their bank account at a time.

The sample "Help with Financial Choices" form (Durable Power of Attorney for Finances) is provided in Appendix A. You can attach this form along with a Supported Decision-Making Agreement to legal binding documents, such as the IEP. SDM language can also be written directly into the IEP Notes.

There are many options to support your adult child with their finances. Although we provide a brief overview here, we encourage you to visit the "Resources" section on page 22 for more detailed information on managing finances for the unique needs of you and your family members.

Avoiding Conflicts of Interest

A conflict of interest is when a supporter has an agenda or motivation other than supporting the adult child to make

their decisions according to their wishes and interests.

If your adult child designates a person other than you to be their power of attorney for finances, it is important to identify actual or potential conflicts of interest. You may want to ask: does the supporter have a financial interest that is connected to your adult child? For example, is the supporter paid staff? Would the supporter receive an inheritance from your child's will? It is critical to plan ahead to address conflicts before they happen.

The individual with a disability can also designate a monitor. The monitor's role is to ensure that the individual handling the money is being honest, using good judgment, and following the decisions made by the individual with support. In the SDM Agreement (in Appendix A - Sample Forms), there is a form to designate a monitor, and for the monitor to consent.

Joint Bank Account

A joint bank account can help an individual manage money and prevent overspending. Most banks can assist with setting up accounts to help manage money. With a joint account, spending money can be deposited regularly to the account and for a joint debit card to be provided. A parent or another trusted person can monitor the account to ensure that your adult child isn't overspending and maintains a balance that allows them to remain qualified for public benefits.

A joint checking account can be listed under only one social security number. The joint account can be filed under a parent's social security number, which will then protect your adult child's eligibility for public benefits. Remember that a person who receives Supplemental Security Income (SSI) cannot have more than \$2,000 in assets.

ABLE Accounts (Achieving a Better Life Experience) - A Path out of Poverty

ABLE accounts allow people with differences, their family and friends to contribute up to \$15,000 per year - without affecting their Social Security, Medicaid or Medicare. ABLE account money can be withdrawn, tax free, to pay for housing, transportation, health care and other basic living expenses.

If an ABLE account holds more than \$100,000, that person's SSI benefits will be suspended without the need to reapply, but not terminated. They will continue to receive Medicaid.

An ABLE account can be established for or by any individual with a disability - independently or with a preferred financial supporter. A person eligible or would be eligible for SSI (Supplemental Security Income) or SSDI (Social Security Disability Insurance) under the disability criteria for SSI/SSDI qualifies for an ABLE account. This is true even if the person has not been found eligible or would not be found eligible due to income.

ABLE Account fund can be used for:

- Education—including tuition for preschool through post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- Housing — including rent, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- Employment Support — including expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- Health — including premiums for health insurance, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, and nutritional management.
- Transportation — including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- Other Life Necessities — including clothing, religious, cultural, or recreational activities, supplies and equipment for personal care, community-based supports, communication services and devices, adaptive equipment, assistive technology, personal assistance supports, financial management and administrative services, expenses for oversight, monitoring, or advocacy, funeral and burial expenses.

You can learn more about ABLE accounts for Californians by visiting the CalABLE website, calable.ca.gov.

Special Needs Trust

Like an ABLE account, a special needs trust allows family and supporters to set aside funds for an individual with a disability without jeopardizing the person's

ability to receive public benefits, such as Medicaid and Supplemental Security Income (SSI). The assets held in the trust are controlled by a trustee, who pays for expenses from the funds in the trust.

Special needs trust funds cannot buy anything that Medicaid or SSI pays for, such as rent or food. But the trust can pay for computers, home furniture, vacations, recreation, vehicles and even out-of-pocket medical expenses and dental care.

Creating a special needs trust usually requires hiring an attorney and filing papers with the court. It is important that the trust language is correct so that the adult does not endanger access to public benefits. Using an attorney to set up a trust can cost up to \$10,000.

You can also consider a pooled special needs trust where a group, sometimes a nonprofit organization, manages the trust for a monthly fee. They often have an attorney who can draft the trust for you. Often, pooled trusts also offer case management.

Representative Payee Forms

If your adult child receives Social Security or Supplemental Security Income (SSI) and they would like your help managing their money, you can apply to become a representative payee.

A representative payee, or "rep payee," helps someone who receives Social Security or SSI manage their money. The person a representative payee helps is called a "beneficiary."

The Social Security Administration has several specific duties a representative payee performs. A rep payee must determine their beneficiary's needs and use their payments to meet those needs. The rep payee must keep very careful records of how all payments are spent and saved. After meeting the beneficiary's needs, the representative payee has to save any money left over in a savings account or bond for their beneficiary. The rep payee also reports to the Social Security Administration on behalf of the beneficiary.

You may notice that we have no representative payee form in the Appendix for you to fill out. That is because most of the time, the representative payee process has to be completed face-to-face with the Social Security Administration and requires several documents to prove your identity. Contact your local Social Security office to see what their current policy is. We have several websites in our "Resources" section that can help you with becoming a representative payee.

SDM and Education

Children, even those with disabilities, express preferences from the time they are born. As they grow, regardless of whether they are able to speak, walk, or stay at grade level, children show, in their own way, what they like and don't like.

But as they enter school, many children with disabilities unfortunately end up in special education classrooms where they are underestimated and not given the ability to make choices. They are given therapies where they are rewarded for complying and giving the "right answer," never learning that sometimes there is no right answer. They aren't given opportunities to fail and learn from their mistakes.

By the time these children enter their teenage years, it becomes more difficult for educators to see them as capable human beings who just need support. So, it is not surprising, as they get close to the age of 18, that school personnel pressure parents to conserve a

Despite special education best practices advocating for the least restrictive option, schools commonly promote conservatorship as the only option for students with intellectual and developmental disabilities.

student they feel has little capacity to make decisions.

The default advice from school districts to parents is to urgently obtain a conservatorship - especially for those with intellectual and developmental disabilities and who use augmentative alternative communication (AAC). Despite special education best practices advocating for the least restrictive option, schools commonly promote conservatorship as the only option for students with intellectual and developmental disabilities. With a fear-based message of one choice, parents often choose the sole option offered and file papers to conserve their child.

But it doesn't have to be this way. If schools become accustomed to seeing your child practicing decision-making from the earliest age, even for the smallest choices, they will see the potential competence that your child can have.

Students with intellectual and developmental disabilities who use communication devices are often presumed incompetent. School staff often do not believe the parents when they share their child's abilities. For this reason, it is crucial that school staff measure specific IEP goals through data collection. Parents can share video recordings of their student practicing their IEP goals at home to prove competencies and abilities.



Practicing supported decision-making from the earliest age

Studies have shown that children who practice self-determination and choice-making are happier, more likely to successfully transition to adulthood, less likely to experience abuse, and have better outcomes. But how do you assist your child in making decisions as they grow and encourage the schools to practice supported decision-making? Here are some ideas:

- Schools should focus on supporting your child to solve problems, make decisions, and advocate for themselves and, just as important, give students the opportunity to exercise these skills
- IEPs are an important time to showcase these skills. Your child should attend their IEP meetings from as early an age as possible, even if only for a few minutes.
- As your child gets older, they should assist in leading their own IEP meetings in their own unique way.

- IEP goals should be written as "I statements." For example, instead of: "The student will use proper grammar 75% of the time," try, "I will work with my teacher to pick subjects I am interested in and write stories, using proper grammar in at least 3 out of every 4 stories."
- IEP goals should be ambitious with objectives that are challenging and promote student involvement and accountability.
- IEP goals can promote decision-making and autonomy, such as self-determination, self-advocacy, problem solving, conflict resolution, self-care, organization skills, communication, and pre-employment.

The biggest challenge is that administrators, teachers, and parents need training on the use of supported decision-making. Be sure to show this handbook to your child's teacher!

After your child turns 18, if they are not conserved, some schools may create unnecessary issues for your continued involvement in their education planning. If needed, you should have your child sign an Educational Disclosure Form. An example of this is located in Appendix A - Sample Forms. You can attach this form along with a Supported Decision-Making Agreement to legal binding documents, such as the IEP. SDM language can also be written directly into the IEP Notes.

For additional information and ways to encourage supported decision-making in education, see Resources for Moving Forward, page 22. We specifically encourage you to review the presentation titled, "Supported Decision-Making: From Theory to Practice" by Jonathan Martinis. He discusses methods to write IEP goals as "I statements," and sample language to request that schools include self-determination and supported decision-making in the IEP goals.



Voting, Supported Decision-Making, and Conservatorship

The Right to Vote for People with Disabilities

The right to vote in a democratic election is fundamental to every citizen - including your adult child with a disability. All too often, despite a desire to vote, people with disabilities or their supporters may not know how to approach voting. Yet, voting is a valuable opportunity to build self-determination, self-confidence, and problem-solving skills that lead to greater autonomy. Importantly, our loved ones learn about new possibilities - and that their vote counts!

How to Support Your Adult Child with a Disability to Vote

As a parent, you may share your values with your adult child to help guide them in voting, as you would with your child if they didn't have a disability. But as an SDM team member, you have the obligation to be unbiased and support the person objectively according to their values and interests. There is no better opportunity to practice SDM than through the support you give in helping someone decide how to vote - and teach self-advocacy in the process.

There are various ways to help your adult child vote. You can start by asking what is important to them (consider using visuals). Is it being included and respected in the community? Access to employment, transportation, education, or affordable housing? Please use the resources below to relate their values to the ballot propositions and the candidates' policies. Here are some other ways to help your adult child vote:

1. Connect with other supporters - be open to all views and encourage questions.
2. Compare issues on the ballot to their own life.
3. Use examples of experiences the individual has had in their life.
4. Explain concepts in a simple and objective way. For example: "A 'party platform' is a group of plans that people in the same political party come up with and agree to together."

*There is no better opportunity to practice SDM than through the support you give in helping someone decide how to vote - **and teach self-advocacy in the process.***

5. Read voting resources slower, more than once, and emphasize key words.
6. Read through plain language or visual guides to the ballot many times, over many days, so that the person can take time to think about the issues.
7. Be present, be patient, listen, and check for understanding.

Accommodations for Voters

In recent years, voting protections put in place for people with disabilities include signing the voter registration (1) with a mark, (2) a cross, or (3) with a signature stamp. People with disabilities can also complete voter registration forms with a supporter's assistance. In fact, if "accessible materials" is marked during online voter registration, the person will be prompted to fill in the contact information of the person supporting them. California law also now enables a disabled person to complete the voter registration form with "reasonable accommodations" suited to their particular needs.

Presumption of Competency to Vote

In California, there is now a presumption that a person is competent to vote regardless of their conservatorship status. Being conserved does not automatically entail losing one's right to vote. Under current law, a conservatee can lose their right to vote only if there is clear and convincing evidence that they cannot communicate a desire to vote - even with reasonable accommodations. Many conservatees are unaware that their right to vote remains intact. People who are conserved who have lost their right to vote can get it back by contacting their regional centers.

Public Safety and Interactions with Law Enforcement

You may be concerned about your adult child interacting with first responders, since they could experience a behavioral crisis and 911 could be called, or they might have trouble following directions when approached by police. These are valid concerns that we have heard from many parents.

As stated earlier, neither a conservatorship nor an SDM agreement can protect anyone from being prosecuted for a crime. Some law enforcement officials mistakenly claim that a parent needs to conserve their child if they want to help their child in any emergency situation. This is not the case. The reality is that there are no forms that provide the protection that parents want for their adult children while interacting with law enforcement. In fact, many first responders are not trained to interact with people with intellectual or developmental disabilities, which creates the potential for misunderstandings that can quickly escalate.

This is why we recommend that you prepare in advance to find the resources that will be most helpful if your adult child experiences a behavioral or mental health crisis.

Prepare in advance

Identify and consider the community resources that are available to you. These may include:

- Specialized crisis lines
- Trusted professionals
- Neighbors and family members
- Service coordinator
- Behaviorist or doctor

If possible, establish an emergency protocol with community resources in advance. This might include educating people on your child's preferences, or discussing how your adult child may act differently than expected with first responders. In the event of a behavioral or mental health emergency, you may want to contact these community resources first, before calling 911. Calling emergency services through 911 for these types of crises does not always end in the way parents would want.

If your adult child does end up in an interaction with law enforcement, there are a few steps you can take in advance to improve the encounter. Certain paperwork, such as a Durable Power of Attorney, can help show law enforcement that your adult child has a disability. For mental health-related situations, ensure that you have an advance healthcare directive or release of information form available so that you can stay involved and support your adult child during the emergency. Remember, you do not have to be a conservator to remain involved.



Five Steps to Get Started with Supported Decision-Making

Now that you know you want to practice SDM with your child, how do you get started? There are simple steps you can take to practice SDM in the community - for example, in school, with the regional center, with healthcare providers, and with other service provider teams. Ultimately, you, your child, their supporters, and community members will become SDM advocates and educators in the process.

Step 1: Learn more about supported decision-making

The best way to learn about supported decision-making is to read and watch videos from self-advocates and experts in the field. We encourage you to visit the Resources section on page 22. Several of the websites include personal stories, examples, and experiences from self-advocates, doctors, attorneys, and their supporters.

Step 2: Identify supporters and create goals

It is often useful to create a Supported Decision-Making Team (or circle of support) with the people your child trusts. Ask your adult child to pick people they know and trust to help them make decisions. You can provide them with names and photos and have a discussion with them by explaining what their SDM team members can help them with. Your child should have the power to say "yes" or "no" to any supporter that you suggest. Once the team/circle is established, they can help your child brainstorm: What are the unique areas in which they require support? How and when will the team get involved? For help forming a team and thinking through these questions, check out the fillable guides in "Setting the Wheels in Motion" linked on page 22.

Step 3: Create a supported decision-making agreement

Parents can generally remain involved and act as supporters in healthcare and other settings as long as their child provides consent either verbally, by spelling to communicate, or through a gesture. No formal agreement is needed. To practice more formally, you can use the SDM agreement provided in the Appendix of this handbook. Remember, one size does not fit all with SDM, so feel free to change the language of the agreement. Like an education plan, the forms should be tailored to the person's preferences and needs.

Step 4: Attach SDM agreement to legal binding documents

The SDM Agreement can be attached to legal binding documents, such as an Individualized Education Plan (IEP), Individualized Program Plan (IPP), Individualized Plan for Employment (IPE), HIPAA Agreement, SSI Representative Payee Form, Advance Medical Directive, and Durable Power of Attorney (DPOA). SDM can also simply be handwritten onto or into these documents. You can find plain language examples of these forms in the Appendix of this handbook.

Step 5: Advocate for supported decision-making in your child's life

Encourage supported decision-making in school, regional centers, health care and other areas from the youngest age possible. It is helpful to start conversations about SDM with everyone your child interacts with so that you can answer their questions and concerns. You can also give people the guide on page 47 to educate professionals on SDM as well as show how to incorporate supported decision-making in their practices. Remember, supported decision-making is most successful if your child is empowered to make choices in every part of their life!

Resources for Moving Forward

NOTE: If you are using a printed version of this handbook, you can find links to all these resources on the Supported Decision-Making page of the Disability Voices United website, disabilityvoicesunited.org. This website also features many additional resources on supported decision-making and self-determination, including an Interchange forum and public access to this handbook.

ACLU Supported Decision-Making & the Problems of Guardianship. Learn about SDM, visit the ACLU's SDM Resource Library, and read news about SDM around the United States.

Autistic Self-Advocacy Network on Supported Decision-Making. ASAN has this excellent plain-language page on what SDM is, how it works, and where SDM laws exist. ASAN also has some model SDM legislation on this page.

Center for Public Representation - Supported Decision-Making Website This resource website from the Center for Public Representation has a library of SDM materials, an SDM News blog, and stories from people who successfully use SDM in their everyday lives.

National Research Center for Supported Decision-Making. Find tools for parents supporting children in SDM, California-specific resources on SDM, and lots of education on supporting someone in SDM.

Office of Developmental Primary Care Page on Supported Health Care Decision-Making. Find videos on supported decision-making in health care for self-advocates, parents and supporters, and professionals.

What's Next?: A Self-Advocate's Guided Tour Through Transition for Parents and Other Supporters by Melissa Crisp-Cooper & co-author Suzanne Francisco. This guide for transitioning out of school and into the adult world is from activist and self-advocate Melissa Cooper. It features a powerful section on teaching the young adult in your life self-advocacy, an extensive section on transition planning, and a packed resource section. This guide is vital for anyone supporting an adult through their age of transition.

Supported Decision-Making Teams: Setting the Wheels in Motion. With her daughter in mind, a mother and advocate helps people navigate the "what", "who" and "how" of setting a SDM team in motion. Its visual forms help to brainstorm directly with the person you're supporting.

UC Davis Mind Institute Supported Decision-Making Website A huge library of SDM information and videos in English, Spanish, and Vietnamese

SDM in Finances Resources

Disability Rights California - Consumer Information about the Social Security Administration Representative Payee Program. This plain-language resource about the representative payee program is addressed to people who may have representative payees appointed for them. It's a great resource if you're trying to explain what a representative payee is, or what the rights of a beneficiary are.

Social Security Administration - Frequently Asked Questions for Representative Payees. If you are interested in becoming a representative payee, this FAQ is a great place to start. It is written directly to the person applying to become a representative payee.

California Department of Health Care Services – Special Needs Trust information. This website has particular information for people who want to become representative payees in the state of California.

SDM in Health Care Resources

My Health Passport. A fillable pdf to provide important health care information, accessibility requirements, and preferences for people with disabilities to health care professionals. Fill out now to have ready

Advance Health Care Directive. A publication by Disability Rights California

Release of Information Forms for Mental Health. List of forms you can use to support your adult child in mental health settings.

Directory of Patients' Rights Advocacy Units in California, that you can contact in the event of an involuntary psychiatric hold.

SDM in Education Resources

DC Schools Practice SDM Beginning in Preschool. SDM tools that Washington, DC schools use and a Q&A on how they use those tools.

The School to Guardianship Pipeline, Journal of Disability and Policy Studies. An article that discusses how schools and educators often wrongly tell parents they'll need guardianship to continue being involved in their adult child's life

Assessing Support Needs: I'm Determined.org. A supported decision-making website for youth by the state of Virginia

Center for Resources and Parent Information Hub. Important information on the IDEA act, training materials, webinars for parents of students with disabilities, and more

Supported Decision-Making: From Theory to Practice by Jonathan Martinis. Presentation on using SDM in Special Education and Vocational Rehabilitation

SDM in Voting

Easy Read Edition, Your Vote Counts: A Self-Advocate's Guide to Voting in the U.S. by the Autistic Self Advocacy Network This guide provides a visual, plain language voter guide for people with intellectual and developmental disabilities.

Disability Vote California

The Disability Vote California Coalition resources brings non-partisan resources that empower voters with disabilities and their supporters. Here, you can access many of the tools you need—including helpful videos and visuals—to help you facilitate the right to vote for your adult child.

Your Voting Rights Under Conservatorship

Disability Rights California provides detailed information on voting for people with disabilities..

Resources for Nonspeaking Adults

AAC for everyone. A website on AAC from Assistiveware, a company that makes AAC devices.

SDM when you cannot speak. An article on SDM for nonspeaking people with examples of successful SDM.

Appendix A

Sample Forms for Supported Decision-Making

The following forms are examples of how a person with a disability can formalize supported decision-making. These forms are just samples. If there are parts your adult child or their supporters would like to change, you could change the wording to work for your family's unique situation. For example, if you are using an SDM Agreement to help your child with their finances, but your adult child doesn't want a monitor, you can completely skip the monitor portion of the form. If you or your child are not comfortable with how something is worded, then change it. The important thing is that your adult child has the ability to show documents that display the kind of supports that work best for them.

Several of the forms require the signature of a **notary** or **witnesses**.

A notary is a person whose job is to help make or certify legal documents like contracts and deeds.

A witness is someone who watches the signing of an agreement to make sure everyone agrees with what is being signed. The witness cannot be part of the agreement.

Supported Decision-Making Agreement

Adapted from the ACLU Disability Rights Program Supported Decision-Making Agreement

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

My name is: _____

I want to have people I trust help me make decisions. The people who will help me are called supporters. I know that I can rely on my supporters to offer information and discuss options and choices with me.

I make decisions about my life, with support.

This agreement can be changed at any time. I can change it by crossing out words and writing my initials next to the changes. Or I can change it by writing new information on another piece of paper, signing that paper, and attaching it to this agreement.

These are my supporters:

(If you have more than three, just list the first three)

Supporter's name: _____

Supporter's name: _____

Supporter's name: _____

This is my monitor:

Monitor's name: _____

My supporters can talk to each other about me: *(Check one box.)*

☐ Only when I say it is OK

☐ Whenever they want

Meeting with my support team

I can talk to my supporters anytime I want to. But my whole team might meet together sometimes to talk about how we are doing. (Check one box:)

☐ I want my entire support team to meet _____
(Write how often your whole team will meet, like "every week" or "every two months" or "before every IPP meeting".)

☐ I do not want my support team to meet on a regular basis.

Special directions and other information

I can write any other information or special directions here. I can also write more information on a separate piece of paper and attach it to this agreement. For instance, I may communicate here through the use of a visual system or format unique to me.

I am signing this supported decision-making agreement because I want people to help me make choices. No one is making me sign this agreement. I know that I can change this agreement at any time.

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

My printed name: _____

My address: _____

My phone number: _____

My email address: _____

Wait to sign your name until a notary or two witnesses are there to watch you sign.

My signature: _____

Today's date is: _____

My Supporter

(This page can be duplicated for as many supporters as you want to sign the agreement)

Supporter's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

I want this person to help me with these choices:

(check as many boxes as you want)

Personal Care:

- ☐ Making choices about food
- ☐ Making choices about clothing
- ☐ Taking care of personal hygiene (showering, bathing)
- ☐ Remembering to take medicine Staying Safe:
- ☐ Making safe choices around the house
(for example, fire alarms, turning stove off)
- ☐ Understanding and getting help if I am being treated badly (abused)
- ☐ Making choices about alcohol and drugs

Home, Work, and Friends:

- ☐ Making choices about where I live and who I live with
- ☐ Making choices about where to work or what activities to go to
- ☐ Choosing what to do in my free time
- ☐ Finding support services, hiring and firing staff

Health Choices:

- ☐ Choosing when to go to the doctor or dentist
- ☐ Making medical choices for everyday things
(for example, check-up, small injury, taking aspirin)
- ☐ Making choices about major medical care
(for example, big injuries, surgery)
- ☐ Making choices about medical care in emergencies

Partners:

- ☐ Making choices about dating, sex, birth control, and pregnancy
- ☐ Making choices about marriage

Money:

- ☐ Paying the bills on time and keeping a budget
- ☐ Keeping track of my money and making sure no one steals my money
- ☐ Making big decisions about money (for example,
opening a bank account, signing a lease)

Other:

(Write any other areas where you want support from this person):

- ☐ _____
- ☐ _____
- ☐ _____

My Monitor

If I want someone to help me make choices about money, I can also choose someone to make sure my supporters are being honest and using good judgment in helping me with my money. This person is called a monitor. The monitor should not be a supporter.

I do not have to write anything here if I am not asking anyone to help me with money. I do not have to write anything here if I do not want a monitor.

Monitor's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

Consent 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/their wishes. My support might include giving this person information in a way he/she/they can understand; discussing pros and cons of decisions; and helping this person communicate his/her/their choice. I know that I may not make decisions for this person, unless he/she/they ask(s) me to decide. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

Signature of supporter: _____

Date: _____

Consent of Monitor

I, _____, consent to act as a monitor for _____'s financial decisions under this agreement. I agree to review the financial records of the person with a disability when provided by the supporters at least every quarter. I agree to make reasonable efforts to ensure that the supporters under this agreement are acting honestly, in good faith, and in accordance with the choices of the person with a disability. If I suspect financial abuse, misuse of funds, bad faith, or failure to comply with the decisions of the person with a disability, I will require the supporters to explain their actions. If the supporter fails to provide this information or if I continue to have reason to believe that the supporter is abusing or failing to comply with the wishes of the person with a disability, I will promptly inform Adult Protective Services.

Signature of monitor: _____

Date: _____

Seal of notary:

My commission expires: _____

Signature of Notary or Witnesses

*This document must be read in front of either a notary or two witnesses.
Witnesses may not include supporters, monitor, or the person with a disability.*

Signature of Notary

State of California, County of _____

On _____ (date), before me _____ (name of person with a disability),

personally appeared, along with _____

(names of all signers), who proved to me on the basis of satisfactory evidence of identification to be the people whose names are signed on this Supported Decision-Making agreement.

The text of this agreement was communicated to the person with a disability in my presence by:

☐

Reading the full agreement aloud

☐

Otherwise communicating the agreement to the person with a disability

(describe communication used): _____

Seal of notary:

My commission expires: _____

or

Signature of Witnesses

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

Durable Health Care Power of Attorney

(Plain Language Durable Power of Attorney for Health Care, adapted from the
ACLU Disability Rights Program, adapted from CA Probate Code § 4701)

Help Making Medical Choices

My name is _____

My birthday is _____

My address is _____

My agents

If I cannot make health choices for myself, I want someone to make choices for me. The person who will make these choices for me is called my agent.

My agents cannot be my doctor or someone who works in the hospital or a group home where I live.

My agent will only make choices for me if I cannot say what I want.

My agent's name is _____

Their phone number is: _____

Their address is _____

If I need help and my agent is away or cannot help me, another person can help me. This person is a back-up agent.

Backup agent's name: _____

Their phone number is: _____

Their address is _____

When my agent can help me:

- My agent can make choices for me if my doctor says that I cannot make my own choices.
- If the doctor thinks I cannot make my own choices, he or she must explain why in writing.

What my agent can do:

(Select everything you want the agent to be able to do for you.)

- ☐ My agent can make choices for me if I cannot make my own choices:
- ☐ My agent can choose what medicine I will get.
- ☐ My agent can see the notes doctors and nurses write about me.
- ☐ My agent can choose when I should stay in the hospital.

When my agent is making choices for me, my agent must do what I want.
I will talk to my agent about what is important to me.

If my agent does not know what I want, he or she must make choices
that will help me the most or talk to other people who love me and care
about me.

I know that I have to sign this form with two people who are witnesses.
My witnesses will sign on the next page.

I know that I can stop or change this agreement at any time.

My signature: _____

Today's date is: _____

THIS DOCUMENT MUST SIGNED BY TWO WITNESSES.**Certain individuals cannot serve as witnesses, as set forth in the following witness statements:**

I declare under penalty of perjury under the laws of California

- (1) That the individual who signed or acknowledged this Power of Attorney for Health Care is personally known to me, or that the individual's identity was proven to me by convincing evidence.
- (2) That the individual signed or acknowledged this Power of Attorney for Health Care in my presence,
- (3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,
- (4) That I am not a person appointed as agent by this Power of Attorney for Health Care, and
- (5) That I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

Second Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operations of law.

Signature: _____

Date: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY IS UNABLE TO WRITE, BOTH WITNESSES MUST SIGN THE FOLLOWING DECLARATION:

_____, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

Signature of Witness #1: _____

Signature of Witness #1: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY LIVES IN A NURSING HOME, THIS SECTION MUST BE COMPLETED BY THE PATIENT ADVOCATE OR OMBUDSMAN:

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code:

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

Durable Power of Attorney for Finances

(Plain Language Durable Power of Attorney for Finances, adapted from ACLU Disability Rights Program)

Help Making Financial Choices

My name is _____

My birthday is _____

My address is _____

Why I have an agent:

- If I cannot make financial choices for myself, I want someone to help me make choices. The person who will help me make these choices is called my agent.
- My agent must make choices based on what is important to me. Even though I am giving the agent the power to make certain decisions for me, I want my agent to make choices that follow my wishes whenever possible.
- If my agent does not know what I want, he or she must make choices that will help me the most or talk to other people who love me and care about me.
- My agent must keep accurate records of my finances and show these records to me if I ask.

Who cannot be my agent:

- My agent cannot be someone who can benefit financially from the way my money is spent.
- My agent cannot be someone who will receive an inheritance from my will.
- My agent cannot be someone who is paid to support me or works in a group home where I live.

Who are my agents:

My agent's name is _____

Their phone number is: _____

Their address is _____

If I need help and my agent is away or cannot help me, another person can help me. This person is a back-up agent.

Backup agent's name: _____

Their phone number is: _____

Their address is _____

When I want my agent to help me:

(select one)

- ☐ My agent can make decisions on my behalf only when I am medically unable to make decisions, such as when I am unconscious.
- ☐ My agent can make decisions for me only after we discuss the options together, and I decide I want help. That means that I can make my own decisions with my agent's support.
- ☐ My agent can make choices for me whenever he or she thinks best. However, my agent agrees to consider what I would want while making those decisions.

What my agent can do

(Select everything you want the agent to be able to do for you.)

- ☐ My agent can make deposits to, and payments from, any account in my name in any financial institution
- ☐ My agent can sell, exchange or transfer title to stocks, bonds or other securities
- ☐ My agent can sell any real or personal property
- ☐ My agent can open and remove items from any safe deposit box in my name
- ☐ My agent can create, change or end a living trust
- ☐ My agent can make gifts of my money or property
- ☐ My agent can create or change who I identify as beneficiary of my trust (person who receives money from my trust)
- ☐ My agent can give some of the power granted in this document to someone else
- ☐ My agent can waive my right to be the beneficiary related to investment plans

I know that I have to sign this form with two people who are witnesses.
My witnesses will sign on the next page.

I know that I can stop or change this agreement at any time.

My signature: _____

Today's date is: _____

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I declare under penalty of perjury under the laws of California

- (1) That the individual who signed or acknowledged this Power of Attorney for Finances is personally known to me, or that the individual's identity was proven to me by convincing evidence.
- (2) That the individual signed or acknowledged this Power of Attorney for Finances in my presence,
- (3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,
- (4) That I am not a person appointed as agent by this Power of Attorney for Finances, and
- (5) That I am not the the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

Second Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this Power of Attorney for Finances and, to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operations of law.

Signature: _____

Date: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY IS UNABLE TO WRITE, BOTH WITNESSES MUST SIGN THE FOLLOWING DECLARATION:

_____, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

Signature of Witness #1: _____

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IF THE PERSON MAKING THIS POWER OF ATTORNEY LIVES IN A NURSING HOME, THIS SECTION MUST BE COMPLETED BY THE PATIENT ADVOCATE OR OMBUDSMAN:

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code:

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

HIPAA Authorization

(Plain Language HIPAA Authorization for Disclosure of Health Information, adapted from the ACLU)

Sharing My Medical Information

My name is _____

My doctor's office
or hospital is called: _____

It is in this city: _____

My doctors and nurses write notes about me. They also write about the tests they do. These notes are called records. I want to share my medical records.

The person who can see my records is:

Name: _____

Address: _____

Phone number: _____

Email address: _____

This person can see: *(Select one)*

☐ All of my medical records.

☐ Only some records. The records this person can see are:
(Write what records you want the person to see.)

This person can see my records until: *(Select one)*

☐ This date: _____.

☐ When I sign a form to say that this person can no longer see my records.

☐ I want this person to be able to speak about me with my health care providers even if I'm not present.

I know these records are usually kept private. I have chosen to share them with the supporter I named above.

My doctors and nurses have to be very careful with my medical records. They cannot usually show my records to other people. The person who I am sharing my records with cannot share them with other people unless I agree. I trust the person I am sharing my records with.

I know that I can stop this agreement at any time.

My signature: _____

Today's date is: _____

Educational Disclosure

(Plain Language Authorization to Disclose Educational Information; adapted from the ACLU)

Sharing My School Information

My name is _____

My address is _____

I go to school at _____

My school is in this city: _____

☐ I have an IEP.

☐ I want someone to help me make choices about school.

The person I want to help me is: _____

This person's phone number is: _____

☐ I want this person to come to my IEP meetings.

☐ I want this person to get all the information that I get from my school.

☐ It is okay for this person to see information that my school has about me.

I know that I can stop this agreement at any time.

My signature: _____

Today's date is: _____

Regional Center Disclosure

(Plain Language Authorization to Disclose Regional Center,
Department of Developmental Services, and Service Provider Information)

Sharing My Regional Center Information

My name is _____

I am a regional center client at: _____

My Unique Client Identifier (UCI)# is: _____

My service coordinator is: _____

My service coordinator's phone number is: _____

My Service Provider(s) funded by the Regional Center funded is/are:

1. Provider name _____

Phone number _____

2. Provider name _____

Phone number _____

☐ I want someone to help me make choices about
and support me with my regional center services.

The person I want to help me is: _____

The phone number for this person is: _____

Check everything you want this person to help you with:

- ☐ I want this person to support me at my IPP (Individual Program Plan) meetings.
- ☐ I want this person to get all the information that I get from my regional center.
- ☐ I want this person to be able request and see all information that my regional center has about me, including my IPPs, annual cost statements, reports from service providers, special incident reports, self-determination program, and other information.
- ☐ I want this person to get all the information that my service providers have about me, including monthly/quarterly reports to the regional center, special incident reports, person-centered plans, billing, and other information.
- ☐ I want this person to be able to speak about me with my service coordinator or others at my regional center, service providers, or DDS staff even if I'm not present.

I know that I can stop this agreement at any time.

My signature: _____

Today's date is: _____

IHSS Disclosure

(Plain Language Authorization to Disclose IHSS Information)

Sharing My In-Home Supportive Service (IHSS) Information

My name is _____

My address is _____

My IHSS Recipient Number is: _____

☐ I want someone to help me make choices about my IHSS services.

The person I want to help me is: _____

The phone number for this person is: _____

Check everything you want this person to help you with:

☐ I want this person to attend my yearly meetings with an IHSS social worker.

☐ I want this person to mail and email about my IHSS.

☐ I want this person to approve my IHSS workers' hours.

☐ It is okay for this person to see all information that IHSS has about me.

I know that I can stop this agreement at any time.

My signature: _____

Today's date is: _____

Appendix B

Supported Decision-Making Flyers

With Support AND WITHOUT THE COURT

A Supported Decision-Making Primer for Educators, Providers, Attorneys, and Other Professionals

What is supported decision-making?

Supported decision-making (SDM) enables people with disabilities to choose supporters—such as family members, trusted advisors, friends, and professionals—to help them make choices to the maximum of their unique abilities. The supporters agree to help the person with a disability understand, consider, and communicate decisions, thereby giving them the tools to make informed choices.

Supported decision-making is what everyone does every day. When we are not sure what to do or how to do it, we seek help from others. People with disabilities can and should have the same flexibility to ask for advice and get support on making decisions.

Why is supported decision-making better than conservatorship?

Conservatorship is often presented as the only option to protect people with disabilities. But the reality is that conservatorship strips them of their civil rights and too often makes them less safe. They may face problems with the court, high costs, and even the possibility that conservatorship will be taken away from their family member for no valid reason. Many individuals with disabilities suffer from abuse by public guardians who do not have their best interest in mind.

In contrast, SDM offers protection to people with disabilities by allowing the people they trust to remain involved in their lives—without involvement from a court system that can be abused. Moreover, SDM allows supporters to guide, teach, and empower people with disabilities in their choice making and self-determination, which has been linked to better outcomes. Since SDM is flexible, it can change over time alongside the changing abilities and needs of an individual—without any additional hassle or paperwork.

SDM is also beneficial for the people that serve those with disabilities. A conservatorship can stigmatize an individual with a disability and leads providers and educators to ignore their wishes. Conversely, SDM requires educators,

doctors, and providers to offer choices directly to the person with a disability, who can then use supporters to help them. SDM can change a provider's perspective about the person they serve, illuminating capabilities they didn't believe existed. And including supporters can help service providers understand valuable information about the person with a disability and their daily life that may otherwise be overlooked.

SDM can be practiced without the need for legal documents. If more formal accommodations are required, a person with a disability can sign an official document called a Supported Decision-Making Agreement, which lists their supporters and how they are helping. This agreement can then be attached to legal binding documents, such as IEPs, IPPs, and Durable Powers of Attorney.

How can I practice and promote supported decision-making?

- Don't push conservatorship on parents of teenagers with disabilities; provide information about SDM
- Presume competence and encourage the person with a disability to practice choice-making from the earliest age
- Offer extra time to discuss choices and use plain language, visual material, and role play
- Allow supporters to attend appointments and meetings

For more information on SDM, visit disabilityvoicesunited.org or contact info@dvunited.org.





SUPPORT

Patients with Intellectual and Developmental Disabilities in Emergency, Hospital, & Outpatient Care

SEEK INFORMATION

Ask about patient preferences for communication and care.* Many patients with Intellectual and Developmental Disabilities may converse using non-verbal gestures, or augmentative and alternative communication.

USE SUPPORTERS CHOSEN BY THE PATIENT**

Supporters can help obtain informed consent, discuss choices for care, and assist with the patient's decision-making. Chosen supporters may not always be present with the patient.

PRESUME COMPETENCE

Speak directly to the patient using a normal voice and plain language. Do not force eye contact—patients are still listening. Always ask patients or supporters if clarification is needed—do not make assumptions.

PROVIDE ACCOMMODATIONS

Be patient when time is needed to understand or use communication devices. Meet the patient where they are comfortable (e.g. some may sit on the floor or stay in the hallway). Provide a quiet, private environment with minimal distractions, when possible.

OBTAIN PERMISSION

Ask before making physical contact with patients—some do not like being touched. Explain what you are going to do before doing it, and check for understanding.

ROLE-PLAY WITH VISUALS

Use role-play with supporters to provide examples of treatment. Demonstrate on pictures, dolls, or the supporter.

TRAIN OTHERS

Share notes about accommodations, communication needs, and helpful strategies with the care team. Prepare new providers during shift changes. Ensure that patients and supporters understand discharge instructions.

*Patients may provide information in a health passport, one-page profile, or communication dictionary.

**Many states have issued guidance requiring health facilities to allow one support person for a patient with intellectual or developmental disabilities during the Covid-19 crisis.

This tip sheet was written by the self-advocates and family members of Disability Voices United, a California-based disability rights organization: disabilityvoicesunited.org.



Together We
Will Be Heard

We need your voice.

We are stronger together than we are alone. By supporting Disability Voices United, you send a clear message that you, too, want to improve regional centers and education — and you want major changes now for people with developmental disabilities.

To learn more about our work and opportunities to get involved, visit

DisabilityVoicesUnited.org

 Disability Voices United

 @DVoicesUnited

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