

With Support AND WITHOUT THE COURT

**DISABILITY
VOICES
UNITED**

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

Updated June 2025

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 ensuring that their children are supported to make their own decisions for the rest of their lives. This handbook is based on conversations with parents like you. We listened to the most common concerns and questions from parents who wanted their children to stay safe and protected, who wanted to stay involved in their adult children's lives, and who wanted to give their children every opportunity to learn and grow. This handbook aims to address those concerns, and answer those questions.

This handbook will help you understand

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

Supported decision-making (SDM) empowers your adult child to continue to grow and learn, instead of taking all

control and decision-making power away from them when they turn 18. SDM allows you to stay involved in your adult child's life without creating a conservatorship through a risky court process, and provides your adult child with a life-long circle of support, encouragement, guidance, and protection even after you are gone.

As your child's first advocate and champion, you are not new to rolling up your sleeves and getting to work to ensure that your child is able to reach their potential. As your child becomes an adult, that same hope for a self-determined future and passion for protecting your child's best interest has led you down the path to supported decision-making. This handbook will guide you down that path, centered around the belief that everyone can make decisions with the right supports.

This handbook has been written and edited by Disability Voices United, a California nonprofit organization directed by and for people with disabilities and their families. The first edition of this handbook was co-written by DVU President Judy Mark and Communications Coordinator Ed Hirtzel, with support from Suzanne Bennett Francisco, and Isita Tripathi. This updated edition was edited by our SDM Training and Information Center Manager Vivian Do and Program Assistant Mikaela Boudreau.

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The Problems with Conservatorship

What is conservatorship?

When your child is a minor, you often make all of their big decisions for them. When your child turns 18, whether they have a disability or not, they are legally recognized as adults who have the right to make their own choices. As your child approaches legal adulthood, also known as reaching transition age, many parents are advised that the only way to protect their child is to file papers to form a conservatorship (also known as guardianship outside of California).

This information may come from school officials, doctors, regional center staff, or other parents, but conservatorship should not be the default option.

The conservatorship process usually begins when parents, but sometimes others, petition the court to say that their

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.

family member with a disability who is over 18 should not be allowed to make their own decisions.

Following a petition, there is a brief hearing in front of a judge which usually ends with the court establishing a conservatorship over the person with a disability and appointing someone else to make their decisions for them. The person with decision-making power is called the "court-appointed conservator," and now has full authority to make decisions for the person with a disability, or "conservatee."

Once conserved, individuals can lose their right to decide how to spend their money, where to live, whom to date, with whom to have sexual relationships, and may no longer have control of their own health care decisions.

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 still stop the process. Even if you have a hearing date, you have the option to cancel the hearing, stopping the process. A court cannot conserve your child if you, as the petitioner, are not present in court. Very rarely, courts will insist that you must go 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 with your child.

The illusion of protection

Parents often believe that their children will be safer if they are conserved, but the reality can be quite different. Parents are told that a conservatorship is the only way to be sure that individuals with disabilities aren't taken advantage of in financial and health care matters, and that a conservatorship is required to enable parents to remain involved in their child's educational planning.

In reality, a conservatorship provides no additional access to healthcare and education decisions for parents that cannot be obtained without a conservatorship. Conservatorship offers no guarantees that a person with a disability won't be taken advantage of by financial scams, creates no extra protection against physical or sexual abuse, and provides no extra legal protection if an adult with a disability is arrested by the police. Sadly, people who are conserved are taken advantage of, abused, and arrested every day.

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. Recent changes in law now prohibit regional centers from directly conserving their clients – although they are able to continue the conservatorships that they already had in place. However, regional centers do ask the Department of Developmental Services to petition for conservatorship on their behalf. If DDS does successfully conserve an adult, they always appoint the regional center to be the acting conservator on a daily basis. The conflict of interest remains regardless of the change in law.

If you believe that a regional center or DDS is attempting to conserve your adult child, there are two important tools to protect you. First, you may remind the court that California law requires everyone to consider less restrictive alternatives such as supported decision-making 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 or supported decision-making agreements can be strong evidence to help assure the regional center that conservatorship is not necessary. Whenever possible, involve regional center staff in your child's supported decision-making, so you can prevent this situation from happening.

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, or friend. A county public guardian or the California Department of Developmental Services may be appointed as a conservator if nobody else is available, and sometimes private professional conservators are also chosen by the court.

While parents can request that the court appoint them as the conservator, the court makes the final decision. Once a conservatorship is formed, the court can remove the parents as conservators for any reason and at any time, and appoint a different person to replace them. Though the person appointed could be someone that the conservatee knows, data shows that half of the people currently under conservatorship or guardianship in the United States have a guardian who is a total stranger to them. Often these conservators are a public guardian from a government agency or a professional conservator that the parents or the estate are forced to pay. Some professional conservators have gotten quite wealthy from this occupation, serving as a conservator for clients they rarely ever see.

Janice's Story*

Janice is a young adult with autism who was conserved by her parents when she was 18. A few years later, her 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. The regional center sent a letter to the court stating that her parents were not good conservators and the conservatorship should be handed to a public guardian; the court agreed and appointed a public guardian to replace her parents. The newly appointed public guardian worked with the regional center to move Janice away from her parents' home against her wishes, leaving her devastated.

*Names have been changed for privacy reasons.

There are many stories of courts removing parents as conservators and appointing a public guardian, professional conservator, or even a regional center in their place. Once appointed the new conservator might even restrict visitation between the conservatee and their family.

The cost of conservatorship

Conservatorships can be extremely expensive. In order to create a conservatorship parents often need to pay thousands of dollars in legal fees to lawyers. These lawyers commonly work on multiple cases at the same time, and often don't advise parents on less restrictive alternatives to conservatorship that would eliminate any legal fees.

On top of legal fees, professional conservators can be very expensive too. Conservator's fees are paid by the estate of the person who is conserved, even if a professional conservator is appointed against the family's wishes, and can cost as much as \$20,000 per month. If you conserve your adult child and a professional conservator is later appointed, you may be responsible for paying the professional conservator's fees.

What happens when parents die—succession of conservatorship

Since the court ultimately controls a conservatorship, if you conserve your adult child you cannot guarantee who the court will appoint as the conservator when you die. Recent changes to the law direct the court to select a successor conservator according to the following preferences, only if the court considers the proposed successor conservatees to be equally qualified: 1) the conservatee's stated preference (whether verbal or non-verbal); 2) the prior conservator's preference, if known; 3) the spouse or partner of the conservatee; or 4) adult child, parent, or sibling. While you can outline a chain of succession for the conservatorship indicating who

*Conservatorship
is a life sentence for a
person with a disability
that will usually last
beyond the lifespan
of the parents.*

Frank's Story

Frank is an older adult with multiple developmental disabilities. He lived with his parents, who were his court appointed conservators, and went to a program every day that he enjoyed. Before his parents passed away, they made specific instructions to the court that Frank's sister should become his conservator upon their death. After their passing, the court decided that because Frank's sister lived in another state, they would instead appoint a professional guardian to be paid out of the money left to Frank by his parents. Frank's funds were limited, so the guardian decided to place Frank in a publicly funded institution to save the money to pay for his conservator fees.

you would like to take over in the case of your death, the court is not required to appoint the next person in your succession plan to replace you, especially if the judge doesn't find your choice to be equally qualified. It's possible that your adult child might have a court-appointed professional conservator who does not have the same vision as you had for your child's life. Professional conservators have the ability to restrict time with the conservatee's surviving relatives, change where they live, or even institutionalize the conservatee without the family's knowledge.

Court checkups – the reality

Courts are required to check up on the conservator, but it doesn't always happen how you would think. The court is required to regularly send a representative to check on the conservatee and ensure they are safe and that the conservator is doing their job. The courts are required to send a court investigator annually to visit the conservatee and discuss less restrictive alternatives to the conservatorship when possible. However, in reality, in many places, the visits don't always happen regularly because of high caseloads.

While providing safety checks on the conservatee sounds like a good idea, it can end up being a nightmare. Imagine that you have conserved your child, and a court

representative shows up at your doorstep when 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, investigators may not speak your language, understand your culture, or be familiar with a non-speaking person's unique communication style or system. The court could make assumptions, based on a singular visit, that you are not equipped to be your child's conservator. They could then appoint a professional conservator to take over the conservatorship.

However, recent changes in law now requires investigators to discuss less restrictive alternatives to conservatorship with conservatees. It is possible that the conservatee can ask to exit their conservatorship, but it is unclear whether judges are granting their wishes.

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

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

If a conservatee wants to travel out of state or country, court authorization may be necessary. Trips are usually approved by the court, but there is no guarantee.

If you are the court appointed conservator and wish to move with your conservatee, you must get permission from the court.

The court will evaluate if a move is in the best interest of the conservatee, among other factors. To move with the conservatee, a conservator must inform the court at least 15 days before the move. The conservator must file a notice for the proposed change of address, and in some circumstances the conservator may need a court order to authorize the move. For a court appointed conservator to move without the conservatee, they must file a change of address with the court investigator's office.

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

Recent changes in California law make it easier to exit a conservatorship, and there are a few ways to begin the process of ending it.

The conservator, the conservatee, or both can tell the court investigator or the court that they wish to end the conservatorship, and provide information about why the conservatorship is no longer necessary. If a judge thinks there is a good basis to reconsider the conservatorship, they will appoint a lawyer to represent the conserved person and will set a termination hearing.

The conservatee or any relative or friend of the conserved person can also file a petition to end the conservatorship. The petition should include facts about why the person no longer needs the conservatorship.

Relevant facts and evidence might include:

- That the person is using supported decision-making or has a supported decision-making agreement (attach the agreement);
- A video or description of how the person uses supported decision-making;
- Information about other tools that the person uses, such as a representative payee, a release of information, or a power of attorney

A petition can be filed without a lawyer, but having a lawyer throughout the process is a good idea. The conservatee or their supporter can reach out to the lawyer who was previously appointed to represent the conserved person when the conservatorship was formed and ask for their help.

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 conservator and conservatee.

Moving outside of California can result in different outcomes. You might be required to have a probational guardianship in the new state until your full guardianship is approved. The court in the new state could recommend a different guardian/conservator, or may require that the conservatorship process be started again from scratch. To transfer a conservatorship, you will likely need to file paperwork with both the state you are transferring from and transferring to. A move from California to anywhere else could involve a lengthy court process between the two states.

For the conservatee to move outside of the country, the process can be even more complicated and the court could potentially restrict the move. The conservatorship would likely be dissolved if a conservatee is able to leave the United States, as American probate law is not followed outside of the country.

The most important thing to understand is that judges have complete power to approve or deny the move of a conservatee. Any number of unanticipated events can occur when the court weighs in on a potential move, which can have negative consequences for caring family members. The same matter can be presented in two counties, or even to two different judges within the same county, and produce different outcomes.

Additional risks in involving the court

Conservatorship can introduce additional unnecessary risk into a family's life dependent on their immigration status. If a parent or other family member is undocumented, entering a courthouse to be involved in the conservatorship process can invite the attention of the legal system. Immigration and Customs Enforcement (ICE) has been known to pick up people targeted for deportation following their court appearances on unrelated matters. Courts are not required to appoint a parent as conservator just because they filed the petition, and courts may be unwilling to appoint a parent who doesn't have legal documentation in the United States.

The journey to end a conservatorship is an uphill battle

Once a person is conserved, it can be hard to end a conservatorship. Although AB 1663 has made changes so

that it's easier to end a conservatorship, it is important to think of conservatorships as a significant and long-term option that can be hard to change. Attempting to terminate your conservatorship will be an uphill battle that may take years and require significant additional legal fees. Remember that alternatives are easier, faster, and more flexible.

Manuel's Story

Manuel is a man with autism who recently exited his conservatorship to practice supported decision-making. In his early adulthood, Manuel's parents had decided to create a conservatorship for him after they were told it was necessary and their only option if they wanted to continue participating in his education and personal planning.

After the passage of the Conservatorship Reform and Supported Decision-Making Act in 2022, Manuel's parents learned about SDM and realized that they could support Manuel while preserving his rights with fewer restrictions by ending his conservatorship. Despite the reforms to the conservatorship system, Manuel and his parents met resistance at every step while trying to end his conservatorship. After reporting to their court investigator that both parties were ready to end the conservatorship, Manuel and his parents were forced to battle their way in front of a judge when the investigator ignored their request. Without access to specialized legal counsel, Manuel and his family represented themselves in court. In preparation for their hearing, Manuel and his parents made a presentation demonstrating on video how Manuel uses SDM to make decisions, and created a supported decision-making hearing. Following the hearing, the judge ended Manuel's conservatorship.

While Manuel and his family got the desired outcome, their legal process took almost two years and was only successful due to their persistence and determination.

Conservatorships are supposed to be the exception, not the rule

In California, a conservatorship is only supposed to be granted by the court if it is the only way to meet the needs of a person with a disability and less restrictive options have been tried and didn't work. If there is any other way to meet that person's needs, the court is not supposed to grant the conservatorship petition.

Unfortunately, in probate courts where conservatorships are decided, this rule is not usually followed. Even worse, there seems to be no incentive to tell families that there may be a better way than conservatorship to meet their child's needs. Many lawyers, whose purpose should be to represent the best 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 to conservatorship would be a conflict of interest for them.

Our system is upside down and conservatorships have become the default. Parents are questioned if they don't choose to conserve their child, and they come under tremendous pressure to conserve their disabled child from other parents, teachers, doctors, and regional centers. Parents are often rushed into the process with no information on alternatives if they haven't already consulted a lawyer and started the conservatorship paperwork by the time their child turns 18.

There's a better way

We understand that it's important for parents to try to protect their adult child, but this should not be achieved by rushing to the courthouse. There is a better way to support your child, one where the choice not to conserve is respected and your adult child is empowered to make their own decisions, protected from the court.

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

Lanh's Story

Lanh is a non-speaking person with autism and cerebral palsy. He lived with his mom, a refugee from Vietnam, who was his conservator for the majority of his life. Lanh and his mom traveled together and lived a happy, person-centered life.

Lanh often 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 preferred to roam in his own home with little or no clothing. Once when a 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 his sensory issues to the representative.

Based on this single experience, the representative recommended to the court that control of the conservatorship be removed from Lanh's mother. Instead of looking to one of Lanh's siblings to replace her, the representative recommended a professional conservator to take over Lanh's conservatorship. Lanh had money in a trust and the court representative knew that one of her colleagues could be hired as his conservator 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 only allowed to visit Lanh for four hours per week with a chaperone, suspects that Lanh is being abused and neglected. Despite thousands of dollars spent trying to get the conservatorship handed back 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

Supported decision-making empowers people with disabilities to select people they trust, usually family and friends, to help them understand, make, and communicate their choices.

Whether or not you have a disability, we all use supported decision-making in our lives every day. Counting on your spouse to help you if you have a problem with your computer, calling a friend who is a nurse to give you advice on a medical procedure, or seeking a second opinion before making a financial decision are all examples of using supported decision-making (SDM). Everyone seeks help with difficult decisions. People without disabilities don't have their ability to choose taken away for using SDM, on the contrary they are often seen as wise to seek advice or second opinions. The same benefit of using support while maintaining control of your life should be given to people with disabilities as well.

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

SDM can be very informal, though it can also be written into formal legal documents, known as supported decision-making agreements (SDMAs), when necessary.

*Your adult child
has the opportunity
to lead their life
with support and
without the courts.*

A sample plain language SDMA, along with other SDM resources, is provided in the Appendix of this handbook. Supported decision-making is designed to change over time, just like people's lives and circles of support often change, and even formal SDMAs can be terminated at any time simply by destroying the document.

Unlike in a conservatorship, supported decision-making has no requirement to involve the court in the life of your child with a disability. There is no need to pay for a lawyer, appear before a judge, or get visits from court representatives, and your choice to use supported decision-making will be legally respected in the state of California.



What does supported decision-making look like?

SDM looks different for everyone. While one person might have one or two supporters, another person may have a large team combining family, friends, and professional staff. Each supporter may take on a different role, and each person practicing SDM might need help with different types of decisions.

SDM should be flexible, ever changing, and a reflection of your adult child who is using it. While they may start off needing help with most decisions in their life, over time with practice they may become more confident handling certain types of decisions and no longer need the same support. Conversely, life events such as facing a medical challenge may create new support needs in areas where your child was previously independent. As often as your child is changing, the way they practice SDM can be changing too.

If you are the parent of an adult who is thinking about using supported decision-making, you may realize that SDM often includes many of the same things you are already doing, and that continuing to practice SDM meshes perfectly into helping your child lead a self-determined life.



Making sure your adult child gets to express their preferences in whatever way works best for them

The key to enabling your child to make their own choices is to ensure that they can express their preferences. Expressing preferences about their life may mean something as big as your child creating a person-centered plan, or as small as your child using facial expressions to display a dislike of something. However they communicate their likes, dislikes, and wants, it is the role of supporters to make sure that the individual with a disability has the tools needed to express themselves, and to confirm that their decisions are understood and respected.

Example: Every time one of Eileen's nurses comes into her house, she turns her head away and frowns. When a different nurse comes in, Eileen is visibly excited and flashes a big smile. Eileen is expressing her preference for which nurse she likes better and who she feels more comfortable with. A supporter should identify Eileen's nonverbal communication of her preferences, acknowledge these preferences, and help Eileen take action toward working with the caregivers she prefers.

SDM should be flexible, ever-changing, and a reflection of your adult child who is using it.



Not letting others make decisions for your child

While practicing supported decision-making, make sure that your child has the appropriate time and accommodations when faced with making a decision. Do not rush your child or force them to make a choice when they haven't had the opportunity to understand all of their options. Once your child is able to make an informed decision, do not let their decision be undermined or ignored; respect their right to decide.

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 of the blood draw. Emma went home and her supporters helped her to understand why she needed to have her blood taken and what the process would look like. Together they went back to the doctor a few days later and Emma agreed to the blood draw.

Explaining choices in a way that you know your child will understand

With the help of supports like pictures, spoken words, videos, or a pros and cons list, you can help your child to understand not only their options, but the potential consequences of their decisions as well. By understanding what works best for your child, you can support them in being able to provide informed consent.

Example: Josh loves eating McDonald's and wants to eat there every day for dinner. He is an adult who can make his own choices, but his supporters help him think about these choices by explaining the consequences of eating only McDonald's in a way that Josh will understand. After explaining to Josh the potential health concerns of an all McDonald's diet including diabetes and obesity with the help of visual aids, Josh agrees to work together on a meal plan that still occasionally includes the treats he likes while keeping him healthy with a well-balanced diet.

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

Providing examples of what a choice might look like

Help your child to understand a choice by relating it to an experience in their past or relating it to an example of something that happened to someone they know. Allow your child the opportunity to discuss and imagine what potential outcomes may look like, and to decide the path they would like to take to reach their desired outcome.

Example: Hamid loves to buy and play video games. He just got a part-time job and wants to spend all of his first paycheck on video games. Instead of taking away that choice, a supporter might give Hamid an example of one of his friends who wanted to go on a family trip to Disneyland, but had already spent all of his money. The supporter could describe how saving some money for future expenses can be balanced with buying the things Hamid wants now, and they might help Hamid open up a bank account and show him how to save some of his money for something special.



Assembly Bill 1663 – The Conservatorship Reform and Supported Decision-Making Act

In 2022, Assembly Bill 1663, the Conservatorship Reform and Supported Decision-Making Act, was passed in California putting supported decision-making into state law for the first time. The law was authored by Assemblymember Brian Maienschein of San Diego and was co-sponsored by civil, disability rights, and aging groups, including Disability Voices United, Disability Rights California, ACLU, California Advocates Nursing Home Reform, Disability Rights Education and Defense Fund, California Community Living Network, and the State Council on Developmental Disability. These organizations joined with the #FreeBritney movement to capitalize on the attention that the media was paying to the unfair conservatorship of pop star Britney Spears.

How did conservatorships change?

The intent of the law was to make it harder to conserve people with disabilities, realizing the ideal of making conservatorship the last resort. The law also makes it easier to exit a conservatorship and provides new rights to people already under a conservatorship.

Before a conservatorship is established

The petitioner must explain the less restrictive alternatives that they considered or tried and the reasons why those alternatives didn't meet the prospective conservatee's needs.

Once a conservatorship is established

The court must provide conservators with written information concerning their obligations to support the conservatee. The law also expands the annual duties and reporting requirements of court investigators conducting required visits to assess the progress of the conservatorship.

The conservatee's rights

Conservatees must now be provided critical information and told about their rights in plain language within 30 days of the establishment of a conservatorship and annually thereafter.

These include:

- The name and contact information of their conservator
- The name, contact information, and duties of their court investigator
- The person they should contact if they want to end or change their conservatorship

A personalized list of rights they still have, which might include controlling their own salary or spending, getting married, receiving mail, having visits from friends and family, having a lawyer, asking a judge to change conservators, voting, making health care decisions, among others.

Changing conservators

When a conservator resigns or dies, the court is now required to select a person that the conservatee prefers, if they are qualified. The court must also consider who the prior conservator prefers to be chosen as their successor.





as it placed supported decision-making into California law for the first time. It defined SDM in the Welfare and Institutions Code (section 21000) as:

"an individualized process of supporting and accommodating an adult with a disability to enable them to make life decisions without impeding the self-determination of the adult."

It says that SDM is a flexible way for adults with disabilities to maintain autonomy and decision-making authority over their own lives by developing and maintaining voluntary supports to assist them in understanding, making, communicating, and implementing their own informed choices.

SDM is only one alternative to conservatorship

The law states that SDM is just one way, and not the only way, to support adults with disabilities to make decisions. It lists other possibilities such as powers of attorney, health care directives, and release of information forms. It also points out that SDM is one way of strengthening the capacity of an adult with a disability.

Supported Decision-Making Agreement

An adult with a disability may choose to create a Supported Decision-Making Agreement, or SDMA. This agreement is not required except for the purpose of exiting a conservatorship. This handbook goes into more detail later about SDMA's, but the law details some specific requirements, which are laid out in this book's sample SDMA.

The law also says that having an SDMA doesn't mean that a person can't make decisions on their own. The

Exiting a conservatorship

The new law makes it easier to exit a limited conservatorship in the following ways:

- If a court receives communication from the conservatee that they want to exit their conservatorship and have their rights restored, the court must appoint a lawyer for the person and set a date for a hearing. This can only happen once every 12 months.
- A court must terminate a conservatorship without a full hearing if the conservatee and the conservator wish the conservatorship to end and no one else objects.

DDS and regional centers as conservator

The new law prohibits a regional center from petitioning directly to act as a conservator but would authorize the regional center to act as a designee of the DDS director.

The law also required the Director of the Department of Developmental Services to develop guidelines to mitigate conflicts that may arise when a regional center is acting as designee while at the same time providing service coordination activities to the same person. These guidelines have been laid out in a directive to regional centers which can be found in the Resources section.

Putting supported decision-making into California state law

This law was a huge step forward for the rights of people with disabilities



agreement can be changed any time the person wants to. The law also says that having an SDMA cannot be used by a court as evidence of lacking capacity.

Responsibilities of a supporter

1. Support and implement the direction, will, and preferences of the adult with a disability.
2. Respect the values, beliefs, and preferences of the adult with a disability.
3. Act honestly, diligently, and in good faith.
4. Act within the scope identified by the adult with a disability.
5. Maintain confidentiality of any information obtained by a supporter, unless the adult with a disability specifically authorizes its disclosure.

What a supporter cannot do

A supporter must not coerce an adult with a disability. A supporter cannot make decisions for the adult or sign documents on their behalf. The supporter must not obtain information about the adult that is unrelated to the manner in which they are supposed to be providing support.

Finally, a supporter must not participate in any life decision in which they have a conflict of interest. This includes having a financial or other tangible stake in the outcome of the decision.

Example: John has a supporter who is also one of his care staff who helps him with independent living skills. That staff might be able to support John in understanding and making decisions about his health care. But that staff cannot help Josh make decisions about how much he pays his staff.

Who cannot be a supporter

The law states that a supporter must be selected by the supported individual, but they cannot be a person who has been convicted of adult or elder abuse or fraud, or whom the person had a restraining order against in the past.



Other rights

The law makes clear that an adult with a disability is entitled to have one or more other adults present, including supporters, in any meeting or discussion, or to participate in any written communication. These might include individual planning (IEPs and IPPs) meetings, care planning meetings, meetings with health care providers and individuals who provide residential services or long-term services and supports, and communications with a bank, financial institution, or financial planner.

An adult with a disability may indicate that they wish to have others attend a meeting or discussion or participate in any written communication by a verbal statement, gesture, or any augmentative or alternative communication method.

A third party may only refuse the presence of these individuals if they reasonably believe that there is fraud, coercion, or abuse happening. That third party is then required to report this concern to the proper authorities.

Example: Kristina just turned 18 and wants to have her mom and dad attend her IEP meeting at her school. Kristina communicates through gestures, and she is able to point to her parents or grab their hands when walking into the meeting. The school must accept this as valid communication indicating that she has requested her parents' attendance at the meeting.

The Advantages of SDM

Expanding the circle of support

We know the safety and care of your child is your greatest concern. Supported decision-making helps adults with disabilities expand their trusted group of supporters to include those outside of the family to better protect them against abuse and manipulation. Not only does supported decision-making provide a sense of pride, competence, and community for your adult child, it also ensures that they will have a circle of trusted people who care about them and will be involved in their lives long after you pass away.

Support without the courts

SDM doesn't involve court processes or a reduction of rights, which feels safer to many people with disabilities and their families as it ensures control of their child's future will never fall into the wrong hands. In SDM, the person with a disability remains in control of their life choices with the assistance of their circle of support. The circle of support can change and adapt at any time as life changes with no legal fees or costs, and final decisions are not reported to or made by the court system.

Freedom to move

If your child uses SDM and is not conserved, they do not need anybody's permission to move to another state or to visit another country. While practicing SDM, your adult child has the same freedom of movement as anyone else without a disability. This is unlike a conservatorship where approval may be needed by the courts anytime they want to leave the state.

A flexible agreement

Despite recent changes to California law, conservatorships are difficult to end, even "limited" conservatorships. Supported decision-making, however, acknowledges that people move in and out of your adult child's life and allows their circle of support to easily change to reflect that.

In most cases, your child's circle is an informal group that is used whenever it makes sense. Even if you use a formalized SDMA, you can make changes to the supporters and their roles with your child at any time with no requirement to report changes to the court system or another authority.

In addition to being able to be changed at any time, SDMA can be created or ended at any time without a court process. An SDMA can be created at home with a single document. To end a supported decision-making agreement, you can simply destroy the document.

An SDM agreement can be attached to other legal documents like powers of attorney and HIPAA Authorizations, 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

Helping people understand their options

Tools that supporters might use to help individuals with developmental disabilities understand their choices include:

- Chosen, trained partners who listen and facilitate communication – using AAC if needed
- Plain language visual or audio material
- Visual supports or images
- Lists of the pros and cons of a decision
- 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
- A joint bank account and other ways to manage financial decisions together

Tools to support adults who use augmentative and alternative communication

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.



Examples of documents that might be used with SDM

Though SDM can be practiced without the need of formal agreements, a formal SDMA can be created, and attached to other legally binding documents. Examples of documents that can include SDM:

- Individualized Education Program (IEP)**
 An IEP is the planning document and agreement a student has with their school district to provide educational, therapeutic, and other services.
- Individualized Program Plan (IPP)**
 An IPP is the planning document and agreement a person has with their regional center to fund community services and supports.
- 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.
- 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 Healthcare 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 Durable Power of Attorney can be used for health care or finances to make some or all of the decisions on behalf of another. DPOAs are usually free, and easily created and modified.

Individualized tools, services and accommodations are key to empowering individuals to make choices

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.	



SDM in Health Care

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

A person practicing SDM can identify healthcare supporters and the areas in which they want assistance. For example, a person might not need help with basic healthcare decisions like whether or not to have a blood test or a general exam. But a person might want more assistance in making more complicated decisions, such as deciding on procedures or surgeries.

You should also consider creating an Advance Medical Directive with your child, a document where a person writes specific instructions about what they want for their medical treatment if at any point 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, end of life care, psychiatric care, organ donation, burial requests, and other related preferences. The Advance Healthcare Directive is particularly useful if an individual is put under an involuntary psychiatric hold, and will allow hospital staff to contact listed supporters immediately. The UCSF Prepare Program has an extensive form and publication on writing an Advance Health Care Directive, which can be found in the Appendix of this handbook.



If your child doesn't have an Advance Directive, they can sign a Release of Information form allowing hospital staff to coordinate with the parents or supporters. 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.

Supported healthcare decision-making allows adults with disabilities to name trusted supporters to help them access healthcare, understand medical information, and make medical decisions.

Substitute decision-making in health care

An individual may agree to substitute decision-making in certain circumstances. There are several possible ways to do this, including the Next of Kin Law, Durable Healthcare Powers of Attorney and HIPAA Authorizations. These are tools that allow people with disabilities to choose others, such as parents, to make their healthcare decisions for them in certain circumstances.

Next of Kin Law - Temporary Decision-Maker in Hospitals and Healthcare Facilities

In 2023, a new law took effect in California called the Next of Kin Law. It changes the Probate Code to say that a patient in a healthcare setting may designate an adult to act as their surrogate to make healthcare decisions without requiring conservatorship.

A patient can inform a healthcare provider that they want a particular person to be their surrogate and make their healthcare decisions for them while they are receiving treatment in a hospital or health facility. This designation cannot last longer than 60 days.

If a patient has already designated a person to be their power of attorney for health care, the surrogate they designate while in a hospital has priority. The power of attorney remains after the patient leaves the hospital.

The new law also adds important new provisions ensuring that if a patient is unconserved, lacks capacity to make a healthcare decision, and has no power of attorney, a healthcare provider can temporarily choose a surrogate on the patient's behalf. The healthcare provider must choose an adult who has demonstrated special care and concern for the patient, familiar with the patient's personal values and beliefs, and available and willing to serve. They can choose from among the following persons related to the patient: spouse or domestic partner, adult child, parent, adult sibling, adult grandchild, other adult relative, close personal friend.

Durable Healthcare Power of Attorney

A Durable Healthcare Power of Attorney, is an example of substitute decision-making. Many people without disabilities use this document to allow a spouse or parent to make healthcare decisions in case of emergencies. For some adults with disabilities, the individual chooses a person, called an agent, to help them understand the situations they face and make health care decisions on their behalf. The agent may help make all or only certain health care decisions, and gives primary consideration to the person's expressed wishes. Moreover, the agent and supporters assist the person to make health care choices to the maximum of their unique abilities, providing access to individualized accommodations so that the individual can provide informed consent.

HIPAA Authorization

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

A reminder that even without a signed HIPAA form, a disabled person can communicate with medical professionals verbally or through gestures or devices to indicate that they want their parents to speak with their doctor.

*A person practicing SDM
can identify health care
supporters and **the areas in
which they want assistance***

Other helpful information for support in health care

Other valuable forms to practice supported healthcare decision-making are the 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 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. A sample healthcare passport is available with other resources at disabilityvoicesunited.org/supported-decision-making.



SDM in Finances

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

An adult may wish to have support with all or just part of their finances. For example, they may want to control all of their paycheck but want support with managing their savings account. They may want to control their money, but have a family member review a contract they are signing to buy a car.

Both parents' concerns and the desires of their children can be balanced using supported decision-making to ensure that their child has the best financial future possible.

Joint Bank Account

A joint bank account can help an individual manage money and prevent overspending. With a joint account, spending money can be deposited regularly to the account and a joint debit card can 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 to help 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 at any time.

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

ABLE accounts allow people with disabilities to have a separate account to spend on things they want without jeopardizing their access to public benefits. A disabled person can put their own money into an ABLE account or have their family and friends contribute up to \$19,000 per year into the account without affecting their Social Security, Medicaid or Medicare eligibility. ABLE account money can be withdrawn tax-free to pay for a wide range of expenses.

If an ABLE account holds more than \$100,000, the account holder's SSI benefits will be suspended (without the need to reapply in the future) but not terminated. The account holder will still be eligible to continue receiving SSDI, HUD, SNAP, FAFSA, and Medicare/Medicaid services until they reach the California lifetime limit of \$475,000.

An ABLE account can be established for or by any individual with a disability - independently or with a preferred financial supporter. Any person 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 to fund:

- **Education**, including tuition for preschool through post-secondary education, books, supplies, 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.
- **Healthcare Expenses**, 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 ABLÉ 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. There is no maximum amount of money that can be placed in a trust.

Special needs trust funds cannot fund 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

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 must perform. A rep payee must determine their beneficiary's needs and use their payments to meet those needs. After meeting the beneficiary's needs, the representative payee must save any money left over in a savings account or bond for their beneficiary. The rep payee must keep very careful records of how all funds are spent and saved, and 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.

Substitute decision-making in finances

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, using substitute decision-making. The power of attorney does not require the involvement of the court but does require the signature and stamp of a notary. Some families have expressed concern about finding a notary who will notarize a document signed by a person with a significant disability. When seeing a notary, show them your child's SDM Agreement allowing you to support them in their finances. If you continue having trouble finding a notary who honors your SDMA, many documents can instead be signed in the presence of two witnesses.

Using a durable power of attorney (DPOA) for finances can help with potentially dangerous circumstances. For instance, a DPOA may help void contracts signed by your adult child by demonstrating that the person may not have understood what they were signing.

Regardless of whether you have a power of attorney for your child, a person who does not have the capacity to understand a legal contract can almost always 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 by showing them your child's SDM agreement and other supporting documents. While there is recourse when a contract is signed in error, it takes work, time, and advocacy to get out of contracts and exorbitant purchases.

Avoiding conflicts of interest

A conflict of interest occurs when an individual has an agenda or motivation other than supporting the adult to make their decisions according to their wishes.

If your adult child designates a person other than you to be their supporter in finances or their power of attorney for finances, it is important to identify any actual or potential conflicts of interest that person may have. Does the supporter have a financial interest that is connected to your adult child? Is the supporter paid staff? Would the supporter receive an inheritance from your child's will? When choosing financial supporters it is critical to plan ahead to address conflicts before they happen.

To avoid conflicts of interest and other issues, the individual with a disability can also designate a financial monitor. The monitor's role is to ensure that the person handling your child's money is being honest, using good judgment, and following the decisions made by the individual with a disability. The SDMA included at the end of this handbook includes a form used to designate a financial monitor, and for the monitor to consent to their responsibilities.

SDM and Education

As they enter school, many children with disabilities end up in special education classrooms where they are often underestimated and not given the full ability to make choices. In therapy they are often rewarded for complying and giving the “right answer,” never learning that sometimes there is no right answer. They aren't given equal opportunities to fail or to learn from their mistakes, essential experiences for building decision-making skills.

By the time these children reach their teenage years, it becomes more difficult for educators to see them as capable of making decisions with the proper support when they have not been allowed to practice these necessary skills. It is not surprising that as these children approach the age of 18 school personnel pressure their parents to conserve the student whom they feel has little capacity to make their own decisions.

The default advice from most school districts to parents is to obtain a conservatorship, this advice is especially pervasive for individuals with intellectual and developmental disabilities and who use augmentative

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.



alternative communication (AAC). Despite the fact that special education best practices advocate for using the least restrictive option, schools commonly promote conservatorship as the only option when the less restrictive option of SDM exists. . Led by this fear-based message, parents often choose the sole option presented by their school and file papers to conserve their child.

Students with intellectual and developmental disabilities who use communication devices are often presumed incompetent and staff frequently do not believe parents when they share their child's abilities. Supported decision-making, especially when implemented at the earliest ages, can help to change this stereotype. If schools become accustomed to seeing your child practicing supported decision-making even for the smallest choices they will be able to see your child's competence, and watch it grow over time.

Practicing supported decision-making from the earliest age

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

- Encourage schools to focus on allowing your child to solve problems, make decisions, and advocate for themselves with support
- IEPs are an important time to showcase decision-making skills. Allow your child to attend their IEP meetings from as early an age as possible, even if only for a few minute
- As your child gets older, allow them to assist in leading their own IEP meetings in their own unique way
- Write IEP goals as "I statements." For example, instead of writing: "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 using proper grammar in at least 3 out of every 4 stories"
- Write ambitious IEP goals with objectives that are challenging and promote student involvement and accountability
- Focus IEP goals on promoting decision-making, autonomy, self-determination, self-advocacy, problem solving, conflict resolution, self-care, organizational skills, communication, and pre-employment preparation
- Encourage staff to measure specific IEP goals through data collection. Parents can make and share video recordings of their child practicing their IEP goals at home to prove competencies and abilities



recordings of their child practicing their IEP goals at home to prove competencies and abilities

The biggest challenge when bringing SDM into your child's education is that administrators, teachers, and parents need training on the use of supported decision-making. If possible, share this handbook with your child's teacher and administrators.

After your child turns 18, if they are not conserved some schools may create unnecessary issues for your continued involvement in their education planning. California state law is clear that a student can ask anyone they choose to attend their IEP or other school meetings by using verbal communication, AAC, or gestures. A school must accept their form of communication and honor their choice of supporter.

If needed, have your child sign an Educational Disclosure Form, which is located 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.

Voting, Supported Decision-Making, and Conservatorship

The right to vote for people with disabilities

The right to vote in a local, state, or federal election is a fundamental right for every citizen, including your adult child with a disability. Voting is a valuable opportunity to build self-determination skills, self-confidence, and problem-solving skills that lead to greater autonomy. Civic participation allows our loved ones to learn about new possibilities, and that their vote counts. But all too often, despite having a desire to vote, people with disabilities or their supporters may not know how to approach voting.

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 to decide how to vote. You can start by asking what issues are important to them (consider using visuals to assist in brainstorming). Are their values being included and respected in their community? Do they have access to employment, transportation, education, or affordable housing? Using the methods below, you can help your child to relate their values to the current ballot propositions and candidate policies.

Here are some other ways to help your adult child vote:

1. Connect with other supporters in their circle, be open to all views, and encourage asking questions.
2. Help relate issues on the ballot to your child's own life.
3. Use examples of experiences your child has had in their life to understand policies.
4. Explain concepts in a simple and objective way. For example: "A 'party platform' is a group of ideas that people in the same political party come up with and agree to together."
5. Read voting resources slowly, 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. Plain language voter guides can be found online by searching for "Easy Voter Guide."
7. Be present, be patient, listen, and check for understanding.

Accommodations for voters

In recent years, voting protections have been put in place for people with disabilities, including allowing them to sign the voter registration with (1) a mark, (2) an "X", or (3) a signature stamp. People with disabilities can also complete voter registration forms with a supporter's assistance. In fact, if "accessible materials" is marked on their form during online voter registration, the voter will be prompted to fill in the contact information of the person supporting them.

Accessible voting guides are also available for voters. This includes large print voting guides, audio format, as well as electronic guides for use with a screen reader. California law enables a disabled person to complete the voter registration form with "reasonable accommodations" suited to their particular needs. Accessible options for voting include having up to 2 supporters assist while voting in-person, curbside voting, mail-in ballots, as well as remote accessible vote by mail which allows voters to cast their vote electronically and print their vote to mailed in.

Presumption of competency to vote

In California, there is 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 for help.

Public Safety and Interactions with Law Enforcement

Parents are often concerned about their adult children interacting with police. If your child experiences a behavioral crisis and 911 is called, they might have trouble following directions when approached by police. These are valid concerns that we have heard from many parents.

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. In reality there are no forms that provide the protection that parents want for their adult children while interacting with law enforcement. Many first responders are not trained to interact with people with intellectual or developmental disabilities at all, 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 in your community 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, consider contacting community resources before calling 911, keeping armed police away from your adult child whenever possible. Calling emergency services through 911 for these types of crises can often result in negative outcomes.



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 be used to show law enforcement that your adult child has a disability. For mental health-related situations, ensure that you have a Psychiatric Advance Healthcare Directive or Release of Information form available so that you can stay involved in decision-making and support your child throughout the emergency. Remember, you do not have to be a conservator to remain involved.

Getting 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 your community, 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 documents and watch videos from self-advocates and experts in the field. Many resources are available at disabilityvoicesunited.org/supported-decision-making, and several of the links there include personal stories, examples, and experiences from self-advocates, doctors, attorneys, and 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 adult child chooses and trusts. Ask your child to pick people they know and trust to help them make decisions, providing them with ideas of names and photos to help them brainstorm potential supporters. 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 the unique areas in which they require support, and help them to identify decisions they are comfortable making independently. A tool to help explore decision-making supports can be found in the Resources section on the following page.

Step 3: If needed, 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. Like an education plan, your child's SDMA should be tailored to their unique preferences and needs.

Step 4: Attach SDM agreement to other legally-binding documents

The SDM Agreement can be attached to other legally 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 hand-written onto or into these documents.

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

Encourage supported decision-making for your child in school, regional centers, health care facilities and other areas from the youngest age possible. Start conversations about SDM with everyone your child interacts with so that you can answer their questions and concerns. You can share the guide on page 53 to help educate professionals about SDM as well as show them 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 up-to-date 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

Tool for Exploring Decision Making Supports. A guide for exploring areas of life in which a person may need support and in deciding how much support they may need for types of decisions.

Department of Developmental Services Directive to Regional Centers on Conservatorships Guidelines regarding the mitigation of conflicts of interest when regional centers are acting as the conservator.

SDM in Financial 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 UCSF Prepare Program

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. Webinar Series on using SDM in Special Education and Vocational Rehabilitation

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.

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..

League of Women Voters Easy Voter Guide. A non-partisan guide that provides accessible information on elections and plain language explanations of ballot measures.

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
and edited by Disability Rights Education and Defense Fund

This paper is called a "supported decision-making agreement." A supporter is someone who helps the person with a disability. This paper says how the supporters will help the person with a disability. The person with a disability and their supporters need to understand and sign this paper for it to be used. There are different ways the person with a disability can understand this paper. The person with a disability can read this paper by themselves. Someone else can also read the paper out loud to them. The person with a disability can read the paper using a sign language interpreter. The person with a disability can use other ways to understand the paper. The way of communicating and understanding should be a way that the person with a disability needs and likes. Two witnesses or a notary must be there when everyone signs the paper.

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.

I will look over this document with my supporters **every two years** to make sure it is still what I want and to make any changes if I wish. I can also end this agreement if I want to. I can end this agreement by writing that I want the agreement to end. I can also end this agreement by saying that I want to stop using this agreement.

If my supporter acts against my wishes or hurts me, I have a right to report them under the Elder Abuse and Dependent Adult Civil Protection Act.

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, _____, (name of supporter)
consent to act as _____'s (name of decider)
supporter under this agreement.

I understand that my job as a supporter is to honor and express their wishes. I will not encourage the disabled person to make decisions that solely benefit myself. My support might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate their choice.

I know that I may not make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

I have read the areas that the decider checked and wrote above under My Supporter. I agree to support the decider in those areas.

I certify that I meet the requirements of serving as a supporter in the State of California. I would not be qualified to serve as a supporter if any of the following were true:

- (1) The adult with a disability previously made, or makes, an allegation against me under the Elder Abuse and Dependent Adult Civil Protection Act.
- (2) The adult with a disability has obtained, or obtains, an order of protection from abuse against me.
- (3) I am the subject of a civil or criminal order prohibiting contact with the adult with the disability or I have been subject to a restraining order with respect to the adult with a disability.
- (4) I have been removed as the conservator of the adult with a disability, based upon a finding that I did not act in the conservatee's best interest.
- (5) I have been found criminally, civilly, or administratively liable for abuse, neglect, mistreatment, coercion, or fraud.

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: _____

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 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 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: _____

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: _____

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 is based in California law and 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

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