

# Supported Decision-Making: My Transformation from a Curious Skeptic to an Enthusiastic Advocate\*

By Thomas F. Coleman

When I was invited to make a presentation on supported decision-making at the Public Policy Conference of The Arc of California, I grappled with the approach I should take to the topic.

At first glance, the words “supported decision-making” seem simple to most of us. But the reality is that SDM only *seems* simple.

SDM is a process where someone helps a person with an intellectual or developmental disability make various decisions. That seems simple enough. We all need or seek help making decisions. What to wear to a dance. What food to select at a restaurant we have never been to before. What route to use when we take a new road trip.

Those types of supported decisions are rather routine. Giving or receiving advice to guide such decision-making is simple. But the process of SDM can be much more complicated from a legal perspective. No doubt about it, there are legal consequences when we make choices about sex, marriage, education, residence, medical care, or financial transactions.

If one of the parties in a sexual encounter lacks the capacity to consent, the other party can be prosecuted for rape. If a patient lacks capacity to give *informed* consent to a medical procedure, the doctor can be sued for battery or malpractice. If a party to a contract lacks the capacity to understand its essential terms, the contract can be voided.

These are all issues that I never associated with the words “supported decision-making” when the concept was first mentioned to me by a disability rights attorney a few years ago.


I first heard the words “supported decision-making” at a conference that I co-sponsored with my colleague Dr. Nora Baladerian. I had been studying the limited conservatorship system in California for two years and in the process was sharing my discoveries with Nora.

We were appalled by what I found as I examined individual cases and as I audited a large sample of such proceedings in the Los Angeles Superior Court. All evidence indicated that the system was dysfunctional.

The rights of adults with intellectual and developmental disabilities were being routinely and systematically violated by judges and court-appointed attorneys. Due process was ignored. Violations of the Americans with Disabilities Act were routine. Lawyers showed loyalty to the judges rather than their disabled clients. The system had no checks and balances.

So Nora and I, through our non-profit organization, Spectrum Institute, convened a conference to share our findings with individuals, organizations, and agencies who we hoped would help us search for solutions. The roundtable gathering occurred in May 2014.

As we went around the table having participants introduce themselves and explain why they came, a disability rights advocate brought up the issue of supported decision-making. She emphatically declared that the conservatorship reform conference was focusing on the wrong issue. We should be focusing instead, she said, on supported decision-making. I assured her that we would look into that issue in the near future.

 As long as there are adequate protections against abuse, exploitation, undue influence, and conflicts of interest, and if the individual has the factual capacity to make the decision in question. In other words, as long as the SDM process is *safe* and *legal*.

Two months later, when I was speaking with an attorney at the ACLU about a conservatorship case, she mentioned supported decision-making in the conversation. She suggested that I should acquaint myself with the concept.

## Research into SDM



Having heard about SDM from two different disability rights attorneys in a matter of a few weeks, I decided to educate myself on the topic. Little did I realize then that the process of self education would involve hundreds of hours of reading, research, and writing over the course of the next two years.

I got deep into the weeds of supported decision-making – reviewing government reports, political position papers, and legal memoranda on the subject. I read journal articles, learned about experiences with SDM in several other nations, explored international politics on the issue at the United Nations, and studied debates about SDM that had occurred in the United States Senate.

What I discovered is that supported-decision making is a topic that is being frequently discussed in academic and advocacy networks for and about people with intellectual and developmental disabilities. It is gaining popularity as an attractive alternative to guardianships and conservatorships. The SDM movement is gaining support and gaining admirers from coast to coast. Words of criticism or concern about SDM are rarely heard.

Supported decision-making is a legal construct as well as a political cause. Having spent more than four decades as a civil rights advocate and educator, I don't take legal issues or political causes at face value. I probe. I analyze. I discuss.

Especially with a relatively new phenomenon, I want to understand the strengths and weaknesses

before I jump on any bandwagon. I want ownership of the issues so that I am not embarrassed later because I overlooked some land mines that could have been avoided moving along the path forward.

The more I learned about supported decision-making, my initial curiosity morphed into modest skepticism. I began to bring inconvenient truths to the attention of SDM proponents as they unveiled “model legislation” or became advocates for specific legislative proposals.

## Model Medical SDM Legislation

The first encounter in my role as a critical analyst of SDM was when I came across “Model Legislation for Medical Supported Decision-Making.” It was developed by the Autistic Self Advocacy Network (ASAN) in collaboration with the Quality Trust for Individuals with Disabilities.



The model bill stated that it was intended to “enable people with intellectual or developmental disabilities to name a trusted person to help communicate with doctors, understand health care information, make informed decisions about health care, and/or carry out daily health-related activities.”

After a detailed analysis of the model bill, I wrote an essay titled “A Review of ‘Model Legislation’ for Supported Medical Decision-Making Agreements: The Defects are in the Details.” The essay noted that two aspects of the proposal were troublesome: a grant of immunity to health care providers and glossing over the requirement in existing law of informed consent by a patient prior to medical treatment.

I commented: “While the idea of supported health care decision-making has an attractive lure, it is imperative to go beneath the veneer to explore the details. What the proponents call ‘model legislation’ is more of a model for removing liability of

health care providers than it is for protecting the rights of people with disabilities – especially those with intellectual and developmental disabilities – in health care situations.”



With more than a little concern, I added: “This legislation creates a new type of contract, but it specifies that the person with a disability need not have the capacity to enter into

a contract. The agreement contemplated by the legislation could be used in situations involving life-and-death medical decisions, and yet the health care provider would be *immune* from liability for engaging in such procedures *without* the patient’s *informed consent*.”

I soon received a phone call from an attorney with Quality Trust who drafted the model legislation for ASAN. To his credit, he listened to these and other concerns I raised with the proposal and agreed to revise the model bill to address them.”

I was pleased when I saw the revisions. I endorsed the revised model bill as something that would empower people with developmental disabilities who had the factual capacity to make informed medical decisions after receiving assistance and guidance from a SDM supporter of their choosing.

I wondered what would have happened if I had been an unquestioning proponent of SDM rather than a curious skeptic. Would the original version of the bill have been distributed to information-hungry parents and disability rights advocates who were eager to find guardianship alternatives?

### Nevada Medical SDM Bill

My next encounter with SDM occurred when the issue arose in Nevada. A group of parents there were desperately looking for ways to avoid placing their adult children with developmental disabilities into guardianships. Some had encountered doctors

who were unwilling to allow the parents to make major medical decisions for their disabled sons and daughters who had cognitive impairments.

The doctors knew that the law required them to obtain informed consent from their *patients* prior to rendering medical services. The parents were not the patients and therefore lacked the authority to give such consent unless they were appointed as guardians for their adult children.

Someone came up with the idea of devising a simplified medical power of attorney to be used by patients with intellectual disabilities. Proponents drafted a bill which they marketed as a medical supported decision-making agreement. Parents were told that if they had their disabled child sign the agreement, they could make medical decisions for their son or daughter and could avoid the necessity of a guardianship proceeding.



Disability rights organizations signed off on the idea and AB 128 was introduced. Under the measure, an adult (principal) with an intellectual disability would sign a simplified medical power of attorney form and

*delegate* the authority to another adult (agent) to make medical decisions for the principal.

The mechanism created by the bill was not supported medical decision-making where the patient, with assistance from another trusted person, would make the ultimate medical decisions. Instead, the patient was delegating that authority to another person, presumably a parent. This was *substituted* and not *supported* decision-making.

Proponents showed insufficient concern as to whether the patient understood the terms of the document that he or she was signing. Nora and I analyzed the words used in the form authorized by AB 128 and found that the document was written at a tenth grade level of understanding. Many of

the terms are unlikely to be understood by many people with intellectual disabilities.



We reviewed the bill, section by section, and determined that it created serious and unnecessary risks – not only for adults with intellectual disabilities, but also for medical personnel who accepted such a document at face value.

Sharing our reports with legislators, medical professionals, and disability rights organizations, we were relentless in our determination to call attention to major flaws in the proposed legislation.

Eventually, the bill was amended to address our concerns. The final bill approved by the Nevada Legislature and signed by the Governor was a true supported decision-making law. Authority was not delegated from the patient to an agent. The ultimate medical decision rested with the patient. The role of the agent was to help the patient understand the benefits and risks of a procedure and make an informed choice on whether to proceed or not. Doctors still had to secure informed consent from the patient. If a doctor suspected any undue influence or abuse, authorities had to be notified.

The experiences with ASAN and Nevada amplified my concern that people who are eager to find guardianship alternatives might follow the lead of supported decision-making advocates without sufficient understanding of the risks and dangers.

Lest I appear to be too critical of SDM, don't get me wrong. I am not advocating for guardianship and conservatorship proceedings. I believe that people with disabilities should make their own decisions whenever feasible. Independence is good. Government overreach is bad.

But society has a duty to protect people who are vulnerable to abuse and susceptible to manipulation and exploitation, whether it is financial or sexual or otherwise. The law requires *capacity* to

make major life decisions – medical, marital, sexual, or financial – for a reason. Capacity laws exist to reduce the risk of abuse and exploitation.

Just as capacity laws serve this important societal purpose, so do laws regulating conflict of interest and undue influence. True freedom and independence do not exist – for people with or without intellectual disabilities – if these types of legal protections are ignored or overridden. That is why safe and legal supported decision-making agreements should incorporate and not bypass laws pertaining to capacity, conflict of interest, undue influence, and fiduciary duties.

### General Concern: Capacity



The issue of capacity is a legal issue that arises in connection with the decision-making process.

Children, for example, lack the legal capacity to make decisions on significant

issues involving medical care, education, residence, marriage, etc. Those decisions are either made for them by their parents or legal guardians, or they are made by the children but must be ratified by the adult who is in charge of their life before the decision can have legal effect.

When a child turns 18 and becomes an adult, the law presumes that the individual has the legal capacity to make all choices in his or her life – including decisions that carry high risks. However, this is not a conclusive presumption. The presumption of capacity for any adult, whether he or she is 18 or 88, will be replaced by a legal finding of incapacity if sufficient evidence is presented to a court in a judicial proceeding.

State statutes and judicial decisions on capacity and incapacity have been on the law books since the founding of our nation. The controlling legal principles have pretty much remained constant. An adult is presumed to have the capacity to make

decisions. Anyone claiming otherwise must present proof to a court before there can be a legal finding of incapacity.



Each of several areas of decision-making must be examined separately. For example, the capacity to make social decisions would have different criteria than capacity to make medical decisions.

The greater the risk associated with a particular area of concern, the more intense will be the judicial scrutiny as to whether the individual has capacity to make decisions in that area.

Each area of law has its own sphere of concern regarding capacity. Criminal law, for example, may focus on an alleged rape victim's capacity to consent to sex when a defendant is charged with rape. Civil law may inquire into a consumer's capacity to enter into a contract when someone is later trying to void a contract for an expensive item and the issue is whether the consumer truly understood the terms of the contract or may have been a victim of undue influence.

Family law may inquire into someone's capacity to consent to a marriage when things go sour and there is a request for the court to grant an annulment due to lack of mental capacity to marry. A probate court may be asked to invalidate a will or a trust because the decedent had dementia at the time the document was executed.

Legal issues regarding capacity to make decisions have long been a staple in American jurisprudence. In guardianship and conservatorship proceedings the issue of capacity is raised in each and every proceeding. In this field of law, capacity is always a major consideration.

California has a limited conservatorship system that is used exclusively for adults with intellectual and developmental disabilities. The issue of capacity is at the core of these proceedings.

Supported decision-making may or may not be an alternative to a guardianship or conservatorship. Since SDM often involves a written agreement between someone with a disability (principal) and someone who agrees to provide decision-making support (agent), the agreement will only be valid if the principal understood the terms of the agreement and entered into it knowingly and voluntarily. There again is the issue of capacity.

Some SDM proponents argue that everyone, regardless of the severity or type of disability that he or she may have, should be deemed by law to have legal capacity to make any and all decisions. They want the law to adopt this legal conclusion regardless of how divorced it may be from factual reality.



Arguing that everyone should be deemed to have legal capacity for all decisions may pass muster in a political debate in the United Nations, but it will not withstand scrutiny in an American court of law.

In our society, the issue of capacity is a function of forensic assessment – a hybrid of science and law. The science is based on psychiatry and psychology and what studies and experts have found in research as well as real-life clinical practice. The law is based on public policy, which includes constitutional requirements of due process and legislative balancing of competing interests.

I mention the United Nations because some supported decision-making advocates cite an international treaty as the basis for arguing that every person has the legal capacity to make every decision at all times.

The United Nations adopted the Convention on the Rights of Persons with Disabilities in 2006. Three years later it was signed by President Obama. The treaty has not been ratified by the Senate.

Article 12 declares “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Based



on a literal reading of this provision, the U.N. committee charged with enforcing Article 12 has called for nations that have ratified this treaty to abolish guardianship and conservatorship laws in their jurisdictions.

Article 12 leaves no room for substituted decision-making. Only supported decision-making is allowed because under SDM it is the person with a disability who is legally making all decisions.

This type of an all-or-nothing approach to capacity, declaring that people with severe cognitive disabilities have legal capacity to make complex and risky decisions, is divorced from factual reality. It is a political declaration, not a rational conclusion grounded in law and science.

Clinical assessments of capacity often find that individuals with cognitive disabilities factually lack the ability to make rational decisions. When a judicial proceeding inquires into the issue of decision-making capacity, it is not whether the person will make good or bad decisions. We all can and do make bad decisions from time to time. The inquiry is whether someone has the basic mental and emotional tools that, if used, could lead to a rational choice – good or bad.

A forensic assessment of capacity to make a particular decision will take into consideration the level of risk associated with such a decision. A decision to go to a movie with a boyfriend or girlfriend poses little risk and therefore the mental capacity for such a decision would be minimal. In contrast, the decision to engage in unprotected sexual intercourse with a stranger is high risk behavior which, therefore, would require a higher degree of evidence that the decision maker understood the risks and was capable of giving truly voluntary consent.

Medical confidentiality is one area where the issue of capacity may arise. The Health Insurance Portability and Accountability Act prohibits medical providers who receive federal funds for services from disclosing patient records to anyone other than the patient. The patient, however, can waive the confidentiality protection of federal law and consent to disclosure to another person.

A provider cannot have a patient with obvious or known mental or cognitive disabilities simply sign a waiver or consent form without inquiring into the patient’s level of understanding of what he or she would be signing. Can the patient understand the concept of privacy or confidentiality? Does the patient know that he or she does not have to consent to disclosure of records to another person? Would a waiver be knowing and voluntary?



These questions are not really avoided simply by providing the medical professional with a power of attorney or supported decision-making medical agreement. The provider would still be required to have an honest and good faith belief that the patient had the capacity to understand the terms of those documents at the time they were signed.

A medical provider might ask the patient if he or she signed the document in question. If the answer is yes, then a follow up question might be to ask what the document means. If the patient says that he or she does not know, there is a problem. Of course, the problem could have been avoided by obtaining a conservatorship order, even if it is only for the limited purpose of medical decisions and access to medical records.

Supported decision-making agreements might be executed for a broad range of decisions other than medical choices. The issue of mental capacity and its interplay with the process of supported decision-making in a wide variety of contexts will be discussed further in the sections below address-

ing SDM through an Individual Program Plan (IPP) and SDM through a conservatorship case.

### General Concern: Conflict of Interest



The issue of conflict of interest can arise in court proceedings or in executing legal agreements or financial transactions.

An attorney may not represent two clients who have conflicting or potentially conflicting legal or economic interests. One clear cut example is that an attorney could not be both the prosecutor and defense attorney in a criminal case. The attorney could represent the state or the defendant but not both.

Conflicts of interest can arise in civil cases too. If a husband and wife are in disagreement about the terms of a divorce, an attorney cannot represent both in family court. If it appears they are in agreement, the same attorney could represent both – so long as each party waives any potential conflict of interest.

The same would be true in a guardianship or conservatorship case. The attorney representing parents who are petitioning a court to place their adult child into a guardianship could not represent both petitioner and respondent.

The role of an attorney for the respondent would be to test the evidence presented by the petitioner and to challenge it for sufficiency. A petitioner's attorney is seeking to take rights away from a respondent. A respondent's attorney is defending those rights from any unjust encroachment.

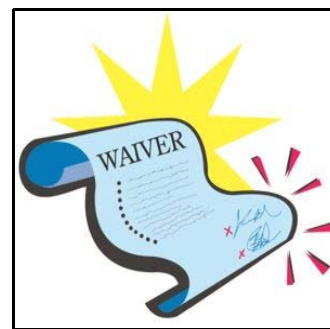
While a respondent could theoretically waive any conflict of interest and agree to be represented by the petitioner's attorney, a waiver must be knowing and voluntary to be valid. A purported waiver by a guardianship respondent would be suspect, considering that the petitioner has alleged that the

respondent lacks capacity to make important decisions. Waiver of conflict of interest is an important decision.

The issue of conflict of interest may arise in connection with the execution of supported decision-making agreements or powers of attorney. It is unlikely that an adult with a cognitive disability will think about such matters on his or her own. The person would probably not reach out to an attorney to prepare such documents.

It is most likely a parent or relative who would find an attorney. They would set up the consultation, bring the adult son or daughter to the appointment, and pay for the legal services. The parent would probably be listed as the agent in the power of attorney or supported decision-making agreement.

Under such circumstances, the attorney is primarily acting as lawyer for the parent, not the adult child. While it is theoretically possible for an attorney to act as legal advisor or advocate for an entire family, this is only permissible if each adult waives any potential conflict of interest.



Again, it is unlikely that an adult with serious cognitive disabilities would have a sufficient understanding to knowingly and voluntarily waive any actual or potential conflicts of interest.

Therefore, a second lawyer, who has not been selected or paid by the parents, would be needed to avoid this problem.

There are ways to overcome this obstacle. More will be said about this in the section below on SDM and the IPP process.

### General Concern: Undue Influence

Even if someone understands the purpose of a document, such as a power of attorney or a supported decision-making agreement, the document

is not valid unless the person makes a voluntary decision to sign it. To be voluntary, someone must understand that he or she has a choice to sign or not sign the document. It must be an exercise of free will.



An action is not done voluntarily if the action was taken as a result of *undue influence* from another person. We are all influenced from time to time by the actions or words of another person. That is normal influence. But *undue* influence is another matter.

Under California law, undue influence exists when four elements have affected a transaction: (1) the vulnerability of the victim; (2) the apparent authority of the influencer over the victim; (3) the influencer’s conduct, such as the use of affection, intimidation, or coercion; and (4) the fairness of the result.

Having a person with a cognitive disability sign a power of attorney is more likely to be subject to challenge for undue influence than having them sign a supported decision-making agreement. In the power of attorney, the person is transferring authority to another to make decisions. In an SDM agreement, the person retains authority to make his or her own decisions.

However, in both situations, the person is using the document to bypass a judicial procedure where there would be an investigation and vetting. Thus, the person is giving up important protections.

A document can be voided if there is a finding of undue influence. Such a finding is based more on the effect an action had on the free will of the person signing the document than the intention of the person who did the influencing. The issue of undue influence can be avoided by having an independent third person handle the transaction.

## General Concern: Fiduciary Duties

If someone with a cognitive disability signs a valid power of attorney or supported decision-making agreement, a fiduciary relationship is established between the parties. By accepting the responsibility designated by the agreement, the agent or supporter assumes fiduciary duties to the principal.

An agent owes the principal a duty of undivided loyalty. An agent may not engage in any activities that are adverse to the interest of the principal. The agent must use due care and act in the best interest of the principal at all times. The agent must keep the principal fully informed of what the agent is doing on behalf of the principal.

The agent or supporter can be sued for breach of fiduciary duty if he or she is negligent in any way and the principal suffers harm. Anyone who assumes the duty of an agent under a power of attorney, or supporter under an SDM agreement, should be made aware that legal liability may attach to this relationship.

## Special Concern: Sexual Conduct



Sexual conduct is an important aspect of decision-making that needs to be evaluated for adults with intellectual or developmental disabilities. Men and women have sexual feelings,

needs, and urges, regardless of whether they have a disability or not.

When I have read articles or listened to presentations about supported decision-making, the issue of sexuality has been conspicuously absent. Issues involving finances, medical care, and social interactions have been mentioned, but not sex. This is a huge omission.

Just as the issue of sexual conduct is addressed in a guardianship or conservatorship proceeding, it



should also be dealt with if supported decision-making is being considered as a less restrictive alternative. The fact that sexuality is considered a sensitive topic in our society, or may be an uncomfortable subject for parents who have a disabled child, the issue must be dealt with anyway. Failure to discuss and handle this aspect of adult decision-making can have serious consequences.



If conservatorship will be bypassed in favor of supported decision-making, what type of support will be given to the adult in question? What limitations, if any, will be imposed?

Who will enforce those limitations and under what legal authority will any restrictions be enforced?

With a conservatorship, a court can determine if the adult has the capacity to make sexual decisions. If capacity exists, the adult will retain the right to engage in solo sex or consenting sex with another adult under circumstances chosen by the adult. But without such a legal proceeding, who will decide whether the adult has the capacity to make sexual decisions?

Just as a conservatorship order must be tailored to the circumstances of a particular case and intrude on a person's rights to the least extent necessary, so too must a supported decision-making arrangement find the right balance between freedom and protection. But since SDM does not involve a court order, any restrictions on the sexual rights of an adult through an SDM arrangement must be voluntarily agreed to by the adult. Restrictions may not be enforced through coercion or undue influence.

If sexual decision-making rights are retained by an adult because there is no court order restricting them, the express or implied SDM supporter assumes a major responsibility for making sure the

adult does not become an unwitting perpetrator or victim. Sex education and risk-reduction planning are critical tools that must be used when sexuality is left to a supported decision-making arrangement.

Two helpful guidebooks on these topics are available from the Disability and Abuse Project of Spectrum Institute. (*The Rules of Sex: for Those Who Have Never Been Told* and *A Risk Reduction Workbook for Parents and Service Providers* – online at: <http://norabaladerian.com/books.htm>)

### SDM Planning Through an IPP

Now that a constellation of cautionary aspects of supported decision-making have been explained, it is time to review some practical suggestions for those who want to proceed with SDM as an alternative to guardianship or conservatorship. An IPP process at a regional center is one way to explore whether supported decision-making is a safe and legal option.

Regional center clients in California are entitled to develop a full Individual Program Plan every three years. A review or update to an IPP can be done annually.

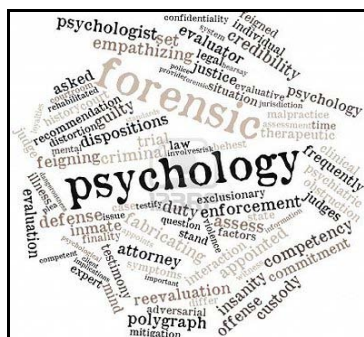


But the law allows a client to have an IPP review and update whenever it may be necessary, such as when a major life event occurs. This could be the divorce of the

parents, or moving to a new residence or school, or to evaluate whether a conservatorship may be necessary.

Parents can request an IPP review a few months before their child turns 18 – or anytime for that matter. They can inform the case worker that they want a special IPP to determine whether supported decision-making is a feasible alternative to a conservatorship. If the regional center refuses, the parents can file an administrative appeal.

A conservatorship proceeding examines the capacity of an adult to make decisions in each of several areas of concern – confidential medical records, medical care, residence, education, finances, marriage, social relationships, and sexual conduct. Therefore, these issues should also be explored in an IPP review conducted to explore SDM as an alternative to conservatorship.



Capacity to make decisions is a function of law and psychology. These are not matters to be evaluated by an untrained lay person. Forensic evaluations should be done by someone with professional credentials and training.

A regional center case worker, service providers, teachers, parents, and others who have experience with the adult can and should share their views on the adult’s capacity in each of these areas, but a professional opinion is also necessary. There are potential risks and consequences when an adult is allowed to retain decision-making rights in any of these areas in an SDM arrangement or to transfer decision-making authority to another person in a conservatorship. Such a significant decision should not be made without the professional opinion of a qualified expert.

The adult in question or the parents can insist that the regional center retain a qualified professional for this purpose. If the regional center refuses to do so, an administrative appeal may be filed to contest the decision.

Once a professional evaluation is done in each of these areas of decision-making, an IPP review meeting should be conducted for person-centered planning about SDM as an alternative to conservatorship. Prior to the meeting, someone trusted by the adult should meet with him or her to explain the IPP process and the specific purpose of this particular IPP review meeting.

If the IPP review concludes that the adult lacks the capacity to make decisions in any one of these critical areas, even with special supports and services, then the parents or other appropriate person should probably file a conservatorship petition. The petition should only seek to transfer authority to a conservator (of the adult’s choice) in those limited areas where there are significant decision-making deficiencies.

If it is determined that a conservatorship is not necessary, and that supported decision-making arrangements will be used instead, then the adult should be referred by the regional center to a lawyer who would draft the necessary supported decision-making documents. This should be considered a vendored service provided by the regional center just as other services are provided and paid for by vendors screened and approved by the regional center.

Parents should not be required to select an attorney for their adult son or daughter. This would be considered a conflict of interest and may also give rise to concerns about undue influence. The regional center is a neutral third party and, as such, can select an attorney to assist the adult by preparing the necessary documents and ensuring that the adult understands them.



If the attorney believes the adult lacks the capacity to understand the meaning of supported decision-making documents, the attorney would refer the matter back to the regional center and

would recommend that a limited conservatorship proceeding be initiated by the parents or other appropriate individual.

### SDM Through a Conservatorship Case

If a limited conservatorship petition is filed with the probate court, the issue of supported decision-

making should be explored as a less restrictive alternative. The law requires the court to only transfer decision-making authority in those specific areas where the adult lacks capacity. However, the court will not know whether capacity exists or is lacking in any given area unless evidence is presented on that issue.



Even when the petitioners (the parents or relatives) provide the court with the results of a professional evaluation of capacity in all of the areas in question, the court-appointed attorney for the adult

should ask the court to appoint an independent expert to conduct a confidential evaluation of the adult to assist the attorney to decide whether to contest the proceeding or not. Since most limited conservatorship respondents lack significant assets the cost of an evaluation under Evidence Code Section 730 would be paid for with county funds.

If the parents have not done a special IPP at the regional center prior to filing a conservatorship petition, the court-appointed attorney for the adult can ask the court to continue the case until such an IPP review is done. As the authorized representative of the adult, the attorney can make a request to the regional center for a special IPP review for this purpose.

If the professional evaluation done by a court-appointed expert or by a qualified professional in an IPP review shows that a conservatorship is unnecessary or that an SDM arrangement is sufficient to protect the interests of the adult, the court can ratify the legality of any SDM documents prior to dismissing the case. If the court finds that a conservatorship is needed in at least some of the areas of concern, the court can ratify an SDM agreement in those areas where conservatorship is not necessary. Either way, SDM will have been considered as a less restrictive alternative to conservatorship as the law requires.

## Protections from Abuse

When it comes to planning the future of adults with intellectual and developmental disabilities, the elephant in the room that nobody wants to discuss is the issue of abuse.

Research shows that people with disabilities are victims of abuse at higher rate than the general population. Some studies suggest that as many as 50% of people with disabilities experienced abuse during their childhood years.

Abusers of people with disabilities are generally not strangers. The most likely perpetrators are people in the circle of support, such as a parent, household member, relative, teacher, or service provider.

This is also the circle of people from which an agent is likely to be drawn for a supported decision-making agreement. There is at least some minimal screening of potential conservators in a judicial proceeding, but there is generally not a screening protocol in supported decision-making planning. Thus, the SDM process poses a risk to adults with developmental disabilities.



The risk of abuse would be decreased if a regional center were to include a vetting process in any special IPP review that is done for SDM planning. Also, any independent attorney to whom the regional center refers the client for the drafting of any SDM agreements should do some investigation before naming

anyone as a SDM support person.

Furthermore, a safe SDM agreement would include a provision for a periodic review of the SDM arrangement by the regional center, perhaps during the IPP annual review process.

## Educating Advocates and Professionals

People with disabilities, parents, advocates, and professionals who work with them should become



familiar with issues associated with supported decision-making as well as the various ways to make the SDM process and the end result safe and legal.

Proponents of supported decision-making should acknowledge the areas of concern and make sure to mention those issues when distributing literature or making presentations on the subject.

Medical professionals who are presented with a power of attorney signed by an adult with a cognitive disability should inquire to determine whether the individual had the capacity to understand the document when it was signed. They should be mindful that an SDM agreement does not dispense with the requirement that a patient must be able to give informed consent for a medical procedure.

Lawyers who are asked by a parent to draft an SDM agreement for his or her adult child should keep in mind considerations regarding conflict of interest and undue influence, as well as the need for the adult in question to truly understand the terms of any document he or she is signing.

Regional centers should pro-actively develop protocols and procedures for special IPP reviews for conservatorship planning and supported decision-making evaluations. They should find mental health professionals who are trained in conducting capacity evaluations in each of the several areas in question. If such professionals are not readily available in the geographic area they serve, the regional center should bring in an expert to train one or more professionals in their region.

Regional centers should invite lawyers in the area they serve to contract with the agency for SDM legal services. If no lawyers show an interest, the

regional center should work with the local bar association to conduct trainings to help members of the bar acquire the necessary expertise.

The Department of Developmental Services (DDS) should include language in regional center contracts for special IPP reviews for SDM and conservatorship planning. Funding should be allocated by DDS to regional centers for this purpose. The Association of Regional Center Agencies should offer model language for such contracts.

Attorneys who represent respondents in conservatorship cases should become familiar with the rights of clients to an IPP process to determine if SDM is a viable alternative to a conservatorship. These attorneys should initiate such a process in cases where one has not already been conducted.

## From Rhetoric to Reality

Supported decision-making is more frequently becoming a topic of conversation among disability rights advocates, parents, and service providers. Promoting independence and avoiding court proceedings are alluring options.



Not everyone with a developmental disability is a candidate for supported decision-making as an alternative to a conservatorship.

Some are, but some are not. Proper evaluation and vetting must be done in order to make sure that any SDM arrangement that may occur is both safe and legal.

Talking about supported decision-making is easy. Creating a legal SDM process with proper safeguards is not. The key to moving SDM from a topic of conversation to a practical reality requires more education and better collaboration. ◇◇◇

*Thomas F. Coleman is the legal director of Spectrum Institute. Email: [tomcolemanspectruminstitute.org](mailto:tomcolemanspectruminstitute.org) Website: [www.spectruminstitute.org/sdm](http://www.spectruminstitute.org/sdm)*