Supported Decision Making:
A Critical Analysis

Commentaries on Supported Decision Making, Adult Guardianships, and the Growing Tension Between the Two Systems

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Preface

Advocates for supported decision making or SDM want a “paradigm shift” in the law. Many of them want to abolish guardianship laws and other parts of the legal system that are premised on the idea that some people sometimes lack the capacity to make important decisions. They want the law to establish an irrefutable presumption that insists, with enough support, every person has the capacity to make every decision all the time.

The Disability and Abuse Project acknowledges that SDM is a novel concept, based on lofty ideals, but also believes that in its current stage of development, SDM is not ready to be adopted by policy makers. “Model legislation” being promoted by the Autistic Delf Advocacy Network (ASAN) on medical SDM has major flaws and poses significant risks. SDM should be analyzed, discussed, and debated – not promoted – until there is more evidence to show how it works in practice, especially with people who have a significant cognitive disability or a severe mental illness.

Applying the SDM “paradigm shift” to all areas of law would have consequences for large segments of society and to many fields of law, such as probate law, contract law, medical law, and criminal law, to name a few. It also would affect the administration of justice, as well as the practice of law, medicine, and psychiatry.

The Disability and Abuse Project has closely examined “model legislation” being promoted by SDM advocates and we are deeply concerned about aspects of this legislative proposal. It diminishes the rights of people with disabilities and other vulnerable adults under current law, such as its call to abolish regulations regarding informed consent to medical procedures and capacity of contract. It also erodes the duties of providers to inquire further when they have reasonable suspicions about undue influence.

This report contains essays about supported decision making that examine the ramifications of such a “paradigm shift” and which are critical of proposals that we believe increase the risk of abuse and exploitation of people who are vulnerable. The report also contains something positive – a Framework for Model Legislation on Medical Supported Decision-Making Agreements. With proper protections, some forms of supported decision making will work and will not increase the risk of abuse.

We invite you to read these essays and share your views with us. We hope that this report and the commentaries, are widely distributed to those who will be affected by the major changes in law that SDM proponents are advocating – judges, legislators, administrators, lawyers, doctors, psychologists, and service providers, and, most importantly of all, people with disabilities, seniors, crime victims, and others.
## Contents

1. Our Position on Supported Decision Making ........................................ 1

2. Should the Limited Conservatorship System be Improved or Eliminated Altogether: Some Concerns about “Supported Decision Making” ................................................................. 2


4. The Effect that Senate Ratification of the U.N. Convention on Disability Rights May Have on Current Guardianship Laws ........... 14

5. A Review of “Model Legislation” for Supported Medical Decision-Making Agreements: The Defects are in the Details ............. 15

6. “Model Legislation” for Supported Medical Decision-Making Violates Medical Ethics .......................................................... 17

7. “Model Legislation for Supported Medical Decision-Making Violates the Supremacy Clause .............................................. 18

8. Supported Decision Making: Adverse Effects on Rape Prosecutions 19

9. Supported Decision Making: Implications for Seniors ................. 21


11. Indiana Reforms Adult Guardianship System: A Statewide Task Force Prompted Several Changes ................................................. 31

12. Framework for Model Legislation on Medical Supported Decision Making Agreements .......................................................... 33

13. Letter to the Chief Justice of California ........................................ 35

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Our Position on Supported Decision Making:

*Adult Guardianship Systems Should be Reformed, not Repealed*

The Disability and Abuse Project is aware that many disability rights advocates are promoting the repeal of laws on adult guardianship or conservatorship. Instead, they are urging the exclusive use of "supported decision making" mechanisms.

Supported decision making is a philosophy that rejects the notion that some people lack the capacity to make some decisions due to serious intellectual disabilities or severe emotional volatility. Instead, they want a "paradigm shift" to a conclusive legal presumption that, with sufficient support, every adult has the capacity to make every decision all of the time.

Under this philosophy, guardians or conservators are no longer needed because substituted decision making is never appropriate. The adult in question should be making his or her own decisions on all issues.

Supported decision making mechanisms involve powers of attorney and other documents which are contractual in nature. The adult designates one or more persons (agents) to help them make decisions and to communicate those decisions to third parties.

Courts are not involved in the process of appointing agents or monitoring their activities, therefore the adult does not receive a court-appointed attorney to assist the adult. Since an agent is merely a facilitator of the decisions made by the adult, the agent is not a fiduciary and has no legal responsibility or liability for his or her role in the process. There is no state agency that screens or approves potential agents to prevent conflicts of interest or undue influence or to weed out people who have abused the adult in the past or might do so in the future.

Current law states that limited conservatorships should be a last resort, not a first choice. Less restrictive alternatives are supposed to be explored and only if they are not available or are unworkable should conservatorship be allowed.

Under current law, proposed conservatees are given a court-appointed attorney who is supposed to defend the rights of the adult from infringement. Proposed conservators are supposed to be screened by court investigators and by the court-appointed attorneys.

The petition for limited conservatorship is reviewed by a judge. There is due process and a hearing if the adult objects to the conservatorship or its proposed terms. Investigations into the operation of the conservatorship, with a home visit and personal interview of the conservatee, are supposed to occur every two years at a minimum.

None of these protections are included in supported decision making since it is based on a contractual model. In effect, the repeal of limited conservatorship laws and replacement with supported decision making laws would be tantamount to the "privatization" of the adult guardianship or conservatorship system. Since a variety of current protections would be eliminated, risk would be shifted to people with developmental disabilities.

Our Project is very aware of, and sensitive to, the fact that adults with developmental disabilities face a high risk of neglect, abuse (physical, emotional, sexual), and financial exploitation. We cannot support proposals to eliminate or diminish protections for this vulnerable population.

Rather than calling for the repeal of the Limited Conservatorship System, we propose that the system have a major and comprehensive reform. Policies and practices affecting the constitutional and civil rights of people with developmental disabilities need to be strengthened.

We support the position of The Arc of the United States on the need for adult guardianship laws to be reformed. We believe that is the most responsible course of action at this time.

We have developed a position paper on this issue. We have also analyzed the effect that Senate ratification of the United Nations Convention on the Rights of Persons with Disabilities would have on adult guardianship laws. Commentaries on these issues are contained within this report.

We will continue to study any developments on these issues and will publish additional commentaries and update our website as it seems appropriate. We welcome comments from those with similar or differing views.
Should the Limited Conservatorship System be Improved or be Eliminated Altogether?

Some Concerns About “Supported Decision Making”

by Thomas F. Coleman

The first conference of the Conservatorship Reform Project was designed to inform representatives of various agencies and organizations about the ongoing violations of the rights of people with developmental disabilities – people who become involved in the Limited Conservatorship System in California.

About 20 conference participants were seated at a roundtable, waiting to hear the first scheduled speaker talk about how her adult son’s rights were infringed during a limited conservatorship proceeding in Los Angeles. Just as the speaker had picked up the microphone and was ready to start her presentation, a hand went up at the other side of the table. A disability rights lawyer wanted to speak.

Thinking it must be an important point of order, she was recognized by the conference chair. She told the Project Directors that we were asking the wrong questions at this conference. The lawyer said that our approach should not be to reform and improve the Limited Conservatorship System but rather to abolish it altogether.

She told the group that the conference should be focusing on “supported decision making” as a substitute for conservatorships. She said there is a growing political movement for a paradigm shift in the legal system – from the current premise that some individuals lack capacity to make certain decisions, to a conclusive presumption that every individual has the capacity to make decisions on every issue.

The conference chair thanked her for her comments, but reminded everyone that the purpose of this conference was to focus on specific problems with the current system and to develop ideas for specific reforms to correct those problems. The parent then began telling the story of the various ways in which her son’s rights had been violated.

A few weeks later, I had a conversation with a disability rights attorney from another organization. She recommended that I should review some specific materials about supported decision making.

In response to that suggestion, I have reviewed many documents that I have found online about supported decision making as a concept, limited experimentation with it in a few jurisdictions, critiques of it by various commentators, and reports about it by a few government agencies.

What I have found is that supported decision making is still in an experimental phase. It has been tested in only a few places, and in those places guardianship laws remain in effect. Studies of its operational performance and its effect on people with disabilities and on society are minimal.

The more reports, research papers, and other materials I reviewed, the more questions I had about supported decision making as a substitute for adult guardianship and the more concerns I had about the ability of a system based on a revocable contract (rather than a binding court order) to adequately protect vulnerable adults from potential abuse.

Before proceeding further, let me attempt to define the concept of supported decision making and how I believe that proponents of this mechanism intend for it to work. The specifics may vary from jurisdiction to jurisdiction – nation to nation or state to state – but this is a general summary of the key elements of the system as it is designed to operate.

Proponents want adult guardianship laws to be repealed because they are arguably inconsistent with the new paradigm that every individual has capacity to make every decision. The adult with the disability is said to need support from a network of people, not protection from a paternalistic government.
Proponents want the government to enact laws that allow any adult with any disability to enter into contractual arrangements for the support they need to make decisions regarding medical procedures, finances, and other important aspects of life. One or more persons would be designated by the agreement to assist the adult to communicate his or her decisions to third parties, such as doctors, hospitals, banks, or merchants.

The support person is considered a representative of the adult – an agent but not a fiduciary. The representative helps the adult facilitate the decision, but does not make decisions for the adult. As a facilitator only, the representative does not assume responsibility for the adult and has no legal liability even if the representative helps the adult execute decisions with which the representative disagrees.

There is no court proceeding involved with supported decision-making agreements. Since there is no ongoing judicial proceeding, the adult may not immediately complain to a judge that the representative is violating his or her wishes or is acting inappropriately. However, in some jurisdictions the agreement includes a monitor who is supposed to check on the welfare of the adult and respond to any complaints about the system not working properly.

It is unclear to me whether the monitor is paid and, if so, by whom. It is also unclear whether the monitor has any legal liability for failing to adequately perform the oversight service.

The concept of supported decision making, and the legislation to create it, contemplate the use of medical powers of attorney and other documents.

The legislation to create this new system is supposed to allow all adults to create representation agreements and other supported decision making instruments. This includes people with severe intellectual disabilities, extremely low I.Q.’s, and volatile and vacillating emotional imbalances. Virtually anyone who is not in a coma is allowed to create these supported-decision-making documents.

Being contractual in nature, the adult may revoke the documents at any time. It is unclear how a doctor, hospital, or financial institution would know for sure whether a representation agreement or power of attorney has been revoked. Unlike a guardianship, they can’t check with a court clerk about this.

**Origins of Supported Decision Making**

The concept of supported decision making as a replacement for adult guardianship had its beginnings in Canada. In 1993, a nonprofit group known today as Nidus proposed that the government of British Columbia should enact the first Representation Agreement Law. The provincial parliament enacted the law in 1995.

Nidus promoted the concept, educated various communities about this option, and helped people enter into Representation Agreements. It also created a Registry where people could lodge their agreements.

The word about Nidus and the concept of supported decision making spread through disability rights networks, not only in Canada, but throughout the world. With online communications widely available, and with disability rights networks growing, the concept gained support as a political cause.

**International Recognition**

The political movement for supported decision making then focused its attention on the United Nations. When that body was debating a Convention on the Rights of Persons with Disabilities, proponents of this new paradigm were successful in having Section 12 – Equal Recognition Before the Law – included in the final document.

Section 12 declares that individuals with disabilities have the right to recognition as persons before the law, and enjoy legal capacity on an equal basis with others in all aspects of life. It also requires governments that ratify the Convention to provide people with disabilities the access to the support they need in exercising their legal capacity.

Section 12 also requires governments to enact safeguards to protect people with disabilities from abuse. Such safeguards must respect the rights, will and preferences of the person, be free from conflict of interest and undue influence, be proportional and tailored to the person’s circumstances, continue for the shortest time possible, and be subject to review by a judicial body.

When Canada and Australia ratified the Convention, both nations stipulated that the provisions of Section 12 allowed nations to continue operating adult guardianship systems.
Applicability to California

The United States Senate has not yet ratified the Convention on the Rights of Persons with Disabilities. But even if it does, there are reservations in the Senate resolution that would ratify the Convention.

Those reservations declare that existing state laws comply with the Convention so long as they do not violate the federal Constitution, the Americans with Disabilities Act, or other federal laws.

Therefore, the ratification of the Convention by the United States Senate, if these reservations are included in the ratifying document, will not change the current situation. It will be a matter of policy considerations, and federal law, not a mandate from the Convention, that will guide the Legislature.

If proponents of this new paradigm were to present the Legislature with a proposal to repeal the Limited Conservatorship System and replace it with laws for supported decision making, lawmakers would be faced with policy decisions that involve both politics and science.

There is no doubt that legislators and state agencies would want to consider the professional and scientific views of the California Medical Association and the California Psychological Association. Proponents who want to repeal and replace limited conservatorship seem to have a philosophical or political ideology at the foundation of the supported-decision-making movement. It does not appear to be grounded in science, or on medical or psychological understandings of the capacities of people to make decisions.

I suspect that if pressed for a position on this issue today, the overwhelming majority of medical doctors, psychiatrists, and psychologists would not endorse a position that every individual has the capacity to make every decision, or that the law should recognize such capacity for financial or medical decisions.

I would venture a guess that the California Medical Association and the California Psychological Association, and probably banking and other financial associations as well, would not support legislation to repeal conservatorship laws without a major change in scientific research on decision-making capacity. Perhaps such research is already occurring, but I am not aware of it.

Reforming the Conservatorship System

Although proponents of supported decision making had a quick victory with the Representation Agreement Act in British Columbia in 1995, they were not able to have the guardianship law repealed. So even the “British Columbia Model” includes a guardianship system as well. It appears the same is true in other jurisdictions throughout the world that have experimented with legal reforms involving supported decision making, with the exception of Sweden.

Much of the literature on this subject notes the lack of academic studies on the results of supported-decision-making mechanisms where they have been authorized by law, their effect on the adults who have executed them, and the impact on society as a whole. In other words, research is scarce.

I believe that the California Legislature would be more inclined to incorporate some of the principles from the concept of supported decision making, and from Section 12 of the Convention, into revisions of limited conservatorship law. I doubt whether there is sufficient scientific evidence anywhere or legal precedents from other jurisdictions, to make the Legislature comfortable with a repeal-and-replace approach. Perhaps that could change in coming years, after proponents have academic studies in hand, as well as political endorsements from medical, psychological, psychiatric, and financial associations. That could happen, but is probably a long way off.

In the meantime, there are tens of thousands of limited conservatees in California whose rights have been or are being violated – and there are 5,000 or more being added each year. They need someone to pay attention to the violation of their civil rights now. What they do not need is for organizations and agencies to focus all of their attention on a long-range goal of supported decision making to the exclusion of existing constitutional and civil rights violations occurring in the here and now. Disability rights advocates should be able to do both simultaneously.

The general principles of Section 12 of the Convention are laudable. The question of how to implement them are debatable. Some will fight for reform of the existing legal structure. Others may promote the creation of a new paradigm. Regardless of our approach, philosophy, or politics, we should all agree to do what we can to remedy the immediate violations of the rights of limited conservatees.
It is important to emphasize that the Disability and Abuse Project supports many of the principles articulated in Convention on the Rights of People with Disabilities. We also support the policy statements set forth in the Lanterman Act – that people with developmental disabilities are entitled to the same constitutional and civil rights that are guaranteed to every American.

At the same time, we are mindful that people with developmental disabilities are at a much greater risk than the general population for being victims of physical, emotional, psychological, and sexual abuse, as well as financial exploitation. We therefore want any legal framework protecting rights and providing protection to be developed and implemented in a context of trauma-informed justice.

We share the goals of disability rights advocates for the development and implementation of laws and legal mechanisms that respect the dignity of each individual and that provide as much independence as possible to people with developmental disabilities.

The Lanterman Act includes and embraces such principles. The creators of the Limited Conservatorship System also codified principles promoting independence and using the least restrictive means to provide protections that are proven to be necessary by clear and convincing evidence.

That is not to say that additional liberty-promoting policies should not be added to the Limited Conservatorship System or that monitoring mechanisms and quality assurance procedures should not be created or expanded. They should.

The Conservatorship Reform Project seeks to build on the vision of those who created a conservatorship system that was limited in scope and restricted in the extent of interference with individual liberty, while at the same time providing as much protection as may be needed to minimize the risk of abuse of people whose decision-making abilities were shown to be limited.

While a time may come in the future to abolish the Limited Conservatorship System in favor of a new paradigm that places more emphasis on individual rights and less on the responsibility of the state to protect residents who are highly vulnerable and who have been shown to need protection, that time has not yet come. It may be a long time in coming.

We are not opposed to an eventual change of legal frameworks for people with developmental disabilities. But we cannot support the radical paradigm shift that the proponents of supported decision making are urging – especially not for a state as large as California. If experimentation is going to be done, it should be on a much smaller scale, and it should then be studied for its effects on individuals and the ramifications for society as a whole.

Medical and psychological professionals and academics need to formulate a position on proposals to move away from the current evidence-based analysis of capacities for medical, financial, and other important decisions, to a new politically-based presumption that, with proper support, every individual has the capacity to make every decision.

We will continue to study this issue and to engage in dialogue with the proponents of supported decision making. We are eager to learn more and we have an open mind to broadening our knowledge base.

What we have learned so far has not caused us to shift our focus away from reforming the Limited Conservatorship System. We are not convinced that it would be in the best interests of people with developmental disabilities, or society, to repeal that system and replace it with a new system that seems rather vaguely defined and that has not been sufficiently vetted in other jurisdictions.

We are unaware of any jurisdiction in the world, except Sweden, that has repealed its guardianship system and replaced it with a system based solely on contract law and premised on the principles of supported decision making.

The pages that follow contain excerpts from various documents we have reviewed about supported decision making as it has been discussed or partially tested in various parts of the world.

These excerpts reinforce our decision to be cautious and not to endorse supported decision making as a political ideology or philosophical construct. However, we are open to learning more as additional information becomes available.
Excerpts from Resource Materials

Nidus

The following statements are taken from a presentation given by Christine Gordon, President of Nidus, at the International Conference on Good Policies for Persons with Disabilities in Vienna, Austria, in January 2012.

After identifying the successes of the Representation Agreement Act in British Columbia, the presentation listed the weaknesses of this program for supported decision making.

One weakness is that several planning documents must be prepared in order to cover health, financial, personal, and legal decisions. “There is no single planning tool. The result is complexity and public confusion.”

Although the 1993 reforms “set out to abolish public guardianship” this never happened. The reform legislation was supposed to be a package of bills, but only the Representation Agreement Act was passed, while the companion legislation failed to do so.

The government has failed to engage in public education about the availability and use of Representation Agreements, leaving this educational function to Nidus itself. Nidus has insufficient funding to perform this task properly.

Many people who serve as representatives under these agreements need financial help in order to carry out their function in a responsible manner. Despite the fact that the Representation Agreement Act was enacted nearly 20 years ago, the government has failed to provide that funding.

One “lesson learned” by Nidus from its experience with the political process is that “Strategic political compromise is necessary in order to move from an ideal policy to a real one.”

I have reached out to Nidus for more information about current realities in British Columbia. How many Representation Agreements have been executed? How many are Registered? How many people are under guardianship? I am waiting to hear back from them.

A Comment on Article 12

Earlier this year, the United Nation’s Committee on Human Rights published a Draft Commentary on Article 12 of the Convention on the Rights of Persons with Disabilities.

Here is what one blogger with a disability had to say about the impracticality of implementing supported decision making for a person with a disability such as he has:

“If we took the Draft Comment literally (we won’t) it could become under-regulated, because the proposals made for supporting decision-making simply cannot be applied to people with volatile and unstable desires over time (and whilst I dislike emphasising my disability politics I have personal experience of epilepsy and psychosis and am genuinely confused as to how the Committee thinks anyone could support my decisions at times when my own will was unknowable to me).”

Australian Law Review Article


“This article cautions against rushing to embrace the concept of assisted decision-making through legal recognition (at least in all its manifestations) without due consideration of the potential problems that could result. It highlights the need for empirical research into the legal operation of assisted decision-making and whether such schemes would add any practical benefit to current Australian guardianship regimes.”

The article concludes:

“There is little doubt that the goals of assisted decision-making are laudable and consistent with the current trend in guardianship legislation to maximise the autonomy of adults with diminishing capacity. However, this article has demonstrated that, depending on how assisted decision-making is implemented in legislation, recognising these models legally can lead to a number of conceptual, legal and, in all probability, practical problems. To date, discussion
of the different assisted decision-making models and the concepts underpinning them has been relatively scarce, with literature often taking a broad-brush approach in discussing potential problems. This article has situated the new impetus for assisted decision-making within the historical social and legal context of guardianship laws to inform a thorough discussion of its nature and potential. Informed by this exegesis and by analysing international developments, this article has identified and analysed key legal, conceptual and practical issues which jurisdictions wishing to implement assisted decision-making models should consider in the context of their own guardianship regimes. Given the unanswered questions about how existing systems operate in practice, empirical research in this area is required to assess how well assisted decision-making models work and whether the aims of legislation are being achieved.”

Public Advocate of Queensland, Australia

The Public Advocate of this Australian jurisdiction issued a report on supported decision making in February 2014. The report reviewed literature on this subject from a wide variety of sources. (“A Journey Towards Autonomy? Supported Decision Making in Theory and Practice.”)

Here are some excerpts from that report:

“Commentators have recognised that supported decision making remains an ill-defined concept.”

“Many commentators agree that further research is necessary to realise proper safeguards for people with disability in these arrangements. While the aim is empowerment, Kohn, Blumenthal and Campbell argue that without more evidence as to how it will work in practice ‘there is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights’.”

The report discusses the lack of empirical evidence:

“Much of the literature in relation to supported decision-making focuses on the normative aspects of the model, that is the alignment of supported decisionmaking as a concept with principles of autonomy and self-determination as well as the principles underpinning the Convention on the Rights of Persons with Disabilities. Despite the existence of supported decision-making in practice, particularly in various Canadian jurisdictions for some time, there is little known about actual supported decision-making practices, how they work in practice, and what works well.”

“Perhaps a notable exception is the report produced by Michelle Browning, a Churchill Fellow, who undertook an investigation into new models of guardianship and the emerging concept of supported decision-making in the United Kingdom and Canada. Browning’s investigation into the use of supported decision-making, in Canada in particular, found that there had not been a large uptake of new legislative agreements such as Representation Agreements in British Columbia and Yukon. Often this is because the people who would benefit from these agreements do not have close trusting relationships with a person who could perform this role. Given there was no register of supported decision-making authorisations in Alberta, it was difficult for Browning to determine the prevalence and success of this tool.”

“In 2013, Kohn, Blumenthal and Campbell concluded, following a review of the empirical literature in relation to supported decision-making in practice, that while supported decision-making presents an appealing alternative to guardianship and should therefore be given serious consideration by public policy makers, there is currently insufficient empirical evidence to know how and if it can remedy the problems posed by surrogate decision-making processes.”

The report goes on to state:

“Carney and Beaupert conceptualise supported decision-making as part of the suite of social or community services and civil society measures ‘aimed at advancing the rights of people with disability to participate in society as active citizens, with choice and control over the resources they need to maximise their participation in all aspects of social life, in accordance with the ‘equality’ of the CRPD’. While they recognise that legislative models have been introduced in some countries, most
predominately in Canada, they argue that there is minimal available research on the practical implementation of supported decision-making in its different guises. They suggest that policy makers should be cautious and seek further empirical evidence about how supported decision-making should operate. ‘Supported decision-making, in its various social, quasi-legal and legal forms, warrants careful empirical research and pilot programs to guide legislative and social policy reform.’”

“Carney and Beaupart suggest that a number of critical issues need to be explored including what exactly is, or should be, meant by the term supported decision-making; the extent to which legal decision-making power resides with the supported person; whether statutory arrangements are necessary to incorporate protective measures or whether they will inherently change the nature of informal support arrangements that can be so empowering for people with disability; and finally whether formalising supported decision-making will lead to ‘net widening’, and at worst the creation of a de facto guardianship system. They argue that the ‘realisation of the right to equality of participation on the part of people with cognitive and psychosocial disabilities is too fragile to be entrusted to experimental law-making or well-intentioned but ultimately mistaken application of normative principles.’”

The report notes the lack of empirical evidence as to how legislation on supported decision making has been implemented in practice:

“While there is significant discussion in the literature in relation to the philosophical (including rights-based) imperatives for supported decision-making, and the various legislative models of supported decision-making (in particular in the Canadian and Scandanavian jurisdictions), there is little empirical evidence in relation to the effectiveness of supported decision-making in practice nor whether and how it achieves its objectives of maximising autonomy and self-determination.”

“There is also little information on the extent of the ‘uptake’ of the various supported decision-making mechanisms in Canadian jurisdictions such as representation and co-decision-making agreements, or details of how they work in practice.”

“Along with the small scope of trials to date in Australia, it is currently difficult to accurately assess how supported decision-making can and should be incorporated into the current mix of legislation, policy and support services.”

Public Health Journal Article

Another journal article expressed serious concerns that too little research has been done on the real-life implementation of supported decision making mechanisms. (Soumitra Pathare and Laura S. Shields, “Supported Decision-Making for Persons with mental Illness: A Review,” 34 Public Health Reviews 1 (2010))

“Canada and Australia, although having signed and ratified the CRPD and having provisions for varying forms of support for exercising legal capacity, have both entered a reservation on Article 12 of the CPRD, interpreting compulsory treatment and fully-supported or substituted decision-making as permissible under the CRPD, but only as a last resort.”

“Norway and Germany have mixed systems, offering both support and substitution decision-making. Sweden has abolished plenary guardianship and offers a system of support services in favour of the support paradigm ranging from mentors to trustees allocated to support PWD. Mentors can be family members, members of the community or professionals who act only with consent of the person receiving support. Trustees, however, are similar to guardians but the individual retains the right to vote.”

“Few studies have assessed supported decision-making beyond treatment decisions, such as how supported decision-making impacts legal capacity and other life decisions.”

“Our findings indicate a disconnect between international conventions (CRPD) and domestic legislation. We found very limited evidence on supported decision-making, and even less evidence on interventions assessing autonomy and decision-making outside treatment decisions. We found that the models of decision-making tested in the research arena are often very narrow and controlled and do not reflect the dynamic relations between health care professionals, legal professionals, clients, and carers that occur in practice.”

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“There is no single best practice for supporting people with disabilities to reach decisions, as systemic factors impact the provisions of these accommodations (resources, legal system, implementation of legislative frameworks, availability of support networks) as well as individual factors (level of need of the individual, accessibility to support networks and services, capacity at the time of need).”

“There is a substantial gap between supported decision-making models and actual practice; actual decision-making process rarely fits any of these idealised models. Similarly, while there is no problem in understanding the ideals of Article 12 of the CRPD, truly shifting from substitute decision-making to a more supportive mode is an entirely different problem.”

“The paucity of research in supported decision-making models for PWMI highlights the need for tested models, not only in HICs, but also in LMICs.”

**Penn State Law Review Article**

The writers of a law review article published last year noted that supported decision making was a promising concept that might be utilized as an alternative to guardianship or be incorporated into guardianship systems in the United States. (Kohn, Blumenthal, and Campbell, “Supported Decision-Making: A Viable Alternative to Guardianship?” 117 Penn State Law Review 1111 (2013).

Like others, they were concerned about the lack of data on how it has worked elsewhere.

“[W]e find that, despite much rhetoric touting its advantages, little is known about how supported decision-making processes operate or about the outcomes of those processes. Further research is necessary to design and develop effective supported decision- making systems.”

The authors suggested that lawmakers in the United States should explore “how supported decision-making could reduce the use of guardianship as well as how supported decision-making approaches could be integrated into guardianship systems.”

**Public Advocate in British Columbia**

The Public Advocate in British Columbia published a paper in 2009 reviewing and discussing policies and practices involving supported decision making.

The paper started with the premise that “guardianship (substituted decision-making) continues to be legitimate with appropriate safeguards.”

The report noted that reform does not have to be an all-or-nothing situation and that principles of supported decision making can be incorporated into existing guardianship systems. In the Public Advocate's opinion, Article 12 of the Convention authorizes such an approach.

“Many of the principles of supported decision-making can be incorporated into guardianship legislation. This is recognised in the United Nations Convention in Article 12 that states: ‘Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.”

The report had more to say about how principles of supported decision making could be incorporated into guardianship systems.

“It is now widely accepted in Australia that capacity is context and decision-specific, except in rare circumstances such as post-coma unresponsiveness or advanced dementia, and this is already the standard approach by which capacity is assessed for the purpose of guardianship applications. The issue of a person being able to make some decisions but not others can be dealt with by means of having more specific and targeted guardianship orders. The alternative, of going through a presumption of competency process at each decision point, would appear to make guardianship unworkable. Provisions such as full consultation and respect, wherever possible, for the person’s wishes would appear to better protect the person’s rights and improve outcomes for them.”

There was also a comment about the risk of abuse increasing when decision-making arrangements are more informal.
“Supported decision-making does open up the possibility of conflict, undue influence, abuse and exploitation. The more private and informal the arrangement the more likely it is that it will go undetected and unresolved if it does occur. Appropriate external monitoring or accountability requirements may alleviate the situation but thereby impinge on the freedom of action of the person with a disability. The balancing of freedom and protection is thus an issue in supported decision-making as in all other measures designed to promote the rights of people with disabilities in our community.”

**Government of South Australia**

In reaction to Article 12 of the U.N. Convention being ratified by Australia (with the understanding that guardianship laws can remain), the Government of South Australia adopted policies on supported decision making to help guide service providers.

The policy statement incorporates many principles from Article 12, but also notes that capacity may be lacking in some people for some decisions and that guardianship may be necessary.

“A person is presumed to have mental capacity unless proven otherwise. This policy also acknowledges that capacity is decision specific. That is, a person may have the capacity to make decisions in some circumstances or about some matters but not others.”

“It is the task of disability service providers and, if required, professionals such as psychologists and medical practitioners, to determine a person’s capacity. If a person’s mental incapacity has not already been predetermined, individuals should have all decisions referred directly to them. If there are doubts about a person’s ability to make a particular decision, efforts must first be made to facilitate supported decision-making. This support may be formal or informal. As a last resort, the Guardianship Board can make a determination on capacity.”

**Australian Law Review Commission**

The most recent review of supported decision making, and perhaps the most thorough, appears in a recent publication of the Australian Law Review Commission. (“Equality, Capacity, and Disability in Commonwealth Laws” (DP 81), Australian Law Revision Commission, May 22, 2014.)

Here are some observations and comments made by the Commission in this report.

“Arguments for the total abolition of substituted decision making in favor of supported decision making or co-decision making fail to address the question: what mechanisms will be in place for the persons who, even with the benefit of infinite resources, cannot or will not act to protect their own interests?”

“Some decision making impairments may be accommodated or rectified but at the end of the spectrum there will be a very small proportion of persons whose impairments mean that they lack decision-making ability, even with infinite resources available for support. For those persons, the appointment of a substitute decision maker becomes a reasonable accommodation to ensure that they are afforded basic human rights including the right to exercise legal capacity.”

“Legal and policy reform must also include consideration of when support amounts to full support—where a person is not able to exercise any decision-making ability and may not have access to supporters in their network of family. It is in such cases, where the appointment of someone to make decisions is needed, that the standard by which they act and the nature of their appointment become the critical focus.”

The Commission also referenced a submission from the New South Wales Council for Intellectual Disability, quoted below:

“Even with a comprehensive national strategy there will continue to be a need for a backstop of a substitute or fully supported decision-making system. In the absence of such a system, there will be no way to resolve many situations in which people with intellectual disability are being neglected, abused, exploited or overprotected on an ongoing basis and are unable to recognise these breaches of rights or and assert themselves in responding to the breaches.”

Referencing a submission to it from the Caxton Legal Centre, the Commission emphasized the need
for more research into the real-life application of supported decision making.

“[M]odels of supported decision making need to be thoroughly researched and evaluated particularly given the implications of profound change—the paradigm shift—across institutions, agencies, services and the community generally. The suggestion has been made that there is little evaluative research into the efficacy and acceptability of guardianship systems, and this too should be remedied. At the very least, guardianship should not continue on the basis of ‘business as usual.”’

**Final Comment**

Commentaries about supported decision making are plentiful enough, and valid enough, to cause concern about any “rush to judgment” on the merits of adopting this new paradigm into law in a jurisdiction as large and complex and California.

Further experimentation should be done on a much smaller scale. More research is needed on the effects of supported decision making mechanisms on people with disabilities, their families, and their communities. The studies need to be much larger than the small samples that have been used so far.

Questions need to be answered as to how Representation Agreements can be used for those with severe intellectual disabilities or extreme emotional vacillations. How can the law presume that some people with serious cognitive impairments, or elderly people with dementia, have the capacity to enter into such contracts in the first place? It is one thing for an agreement to be executed prior to the onset of a disability, but quite another after it exists.

The stakes are too high – the lives and well being of tens of thousands of vulnerable adults in California alone – for large scale experiments to be conducted based on philosophical reasons, no matter how good those reasons are. Lawmakers should use a careful approach as they explore the positive possibilities presented by the concept of supported decision making. New ideas, even radical ones, are often introduced in stages. Incremental approaches and forward-thinking reforms often happen gradually.

I am grateful that so much has been written about supported decision making and that such thoughtful critiques and suggestions have been offered by researchers and commentators throughout the world.

Our Project will continue to review literature on this subject as it is published. We will keep an open mind about how to implement the principles embodied in Article 12 and in the concept of supported decision making. These principles will inform our reform-minded actions, just as the concept of “trauma informed justice” will guide us too.

Rights and responsibilities go hand in hand. So as we promote the rights of people with developmental disabilities, we will also be keenly aware of our responsibility to ensure that society gives those who are vulnerable the protections they need to be free from abuse of any kind. Supported decision making, as a complete substitute for limited conservatorship, may not be sufficient to accomplish both – protection of rights and protection from abuse – for many segments of the population.

Maintaining the status quo is also not acceptable. The Limited Conservatorship System in California needs attention. It has major flaws, both in policy and practice. We are pointing out those flaws and recommending major changes. We are seeking input from those who participate in that system, as well as others who are concerned about the rights of people with developmental disabilities.

As some promote supported decision making as an exclusive goal, we will continue to work for major reforms in the Limited Conservatorship System.

Our efforts will be consistent with the Convention on the Rights of Persons with Disabilities as that treaty is ratified by the United States Senate. That will require adult guardianship laws to abide by the federal Constitution, the Americans with Disabilities Act, and other federal laws.

As we proceed, we will work to ensure that California’s Limited Conservatorship System protects the constitutional and civil rights of people with developmental disabilities, both in policy and in practice.

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Principles of Supported Decision Making
Already Exist in California Law

by Thomas F. Coleman

People who are calling for the repeal of a state-regulated system of limited conservatorship because they favor a private sector system of supported decision making, are not looking at the full picture. Supported decision making mechanisms, as an alternative to conservatorship, are already a preferred option under California law.

As explained below, the real complaints should not be focused so much on the law itself, but rather with the administration of the laws by those who are entrusted to enforce them. This would include Regional Centers, judges, court investigators, self-help clinics, and court-appointed attorneys.

The Lanterman Act declares that people with developmental disabilities are entitled to the same constitutional and civil rights protections as any other American. The California Constitution affords all people the right to freedom of speech, the right to privacy, equal protection, and due process. There are no exceptions for people with disabilities.

The Americans with Disabilities Act (ADA) requires people with disabilities to be afforded reasonable accommodations by government agencies and private businesses (such as attorneys and service providers). To the extent that any California law would conflict with the ADA, federal law prevails.

About 30 years ago, the Probate Code was amended to create a new form of protection for vulnerable adults – one that was more narrowly tailored to provide a blend of protection and independence than the general conservatorship system. A new system for limited conservatorships was codified into law.

That new system presumes that all adults have capacity to make decisions on all matters. This would be called presumed capacity. Anyone who wants to challenge this presumption, by filing a petition for a limited conservatorship must prove, by clear and convincing evidence, that the adult in question in fact lacks capacity. Such a showing must be made on each and every aspect of life that the petitioner is seeking authority to make decisions over for the adult: medical, financial, education, residence, social, sexual, and marriage.

The law stipulates that if a less restrictive alternative to conservatorship is available and workable, it must be used. This is where supported decision making arrangements would come into play.

The petitioner seeking conservatorship has the burden of proof that such alternatives have been explored and factually show why they won’t work.

The attorney appointed to represent the adult is supposed to protect his or her rights and should insist that the petitioner meet the burden of proof on the need for a conservatorship because of lack of capacity in one or more areas, and why supported decision making mechanisms won’t work.

The Regional Center is required to conduct an evaluation of the adult and file a report with the court. This report should state whether alternatives to conservatorship have been explored and why they are not a realistic option.

A court investigator is supposed to visit the home, interview the adult, review Regional Center evaluations and other medical or psychological records, and determine whether other options are available (such as medical and financial powers of attorney) and whether the adult in fact has capacity, with appropriate ADA accommodations and supports, to understand and execute such documents.

Based on all the evidence, a judge must find that conservatorship is the least restrictive alternative, and if so, must take the wishes of the adult into consideration in appointing a conservator.

The law requires the conservator to always consider the wishes of the adult when making decisions.
California law already allows for, and gives preference to, supported decision making mechanisms. Limited conservatorship is supposed to be a last resort, not a first choice.

The problem lies more with the administration of the law than the policies of the law themselves.

Regional Centers are not adequately helping their clients explore and execute supported decision making options.

Court-appointed attorneys are not being properly educated on their duty to demand that lesser restrictive alternatives be seriously considered and only be rejected because the client lacks capacity-in-fact to execute them or they are not a practical option.

Court investigators are not devoting sufficient time to cases to fully explore supported decision making alternatives. Due to budget constraints, these investigators either do not conduct investigations at all or they may not be doing a thorough job.

Judges are so pressed for time and have such heavy case loads, they are not insisting that all participants – Regional Centers, court-appointed attorneys, petitioners, and court investigators – fully explore the alternatives to conservatorship and demonstrate with evidence that they have done so.

The remedy for these deficiencies is not to push for the repeal of limited conservatorship laws but to insist on better monitoring and more funding.

Having said all of this, there is one area in which reform of the system, including more funding and some quality assurance oversight, will not satisfy proponents of repeal-and-replace. That has to do with the paradigm of the system itself.

The current statutory scheme is premised on legal concepts of presumptive-capacity and capacity-in-fact. These are grounded in a medical-psychological-legal framework.

Current law presumes that all adults have capacity to make all decisions. Someone petitioning a court to establish a conservatorship has the burden of proof to show that the adult lacks capacity-in-fact.

The factual basis for any incapacity is dependent on medical and psychological evaluations and scientific knowledge about the factual capabilities of individuals to understand concepts and to make informed decisions on matters such as medical procedures or financial transactions.

Under current law, judges look to the expert opinions of medical practitioners, psychiatrists, or psychologists about the abilities of the adult to make informed decisions in any or all of the seven areas under inquiry. Other evidence on this issue would be admissible as well, such as the observations and experiences of family members, neighbors, friends, teachers, and service providers.

Proponents of supported decision making oppose this evaluation process. They want a paradigm shift from presumptive-capacity to irrebuttable-capacity.

Under this new paradigm, every adult, with enough support, is conclusively presumed to have the legal capacity to make every decision all the time. As a result, there is never a need for a guardianship or conservatorship proceeding since the concept of incapacity-in-fact does not exist.

This is a relatively new concept – one that has not been tried and tested anywhere. Supported decision making is being used to a limited extent in some areas of Canada and Australia, but those jurisdictions continue to have guardianship laws as well. Canada and Australia specified, when they ratified a United Nations treaty promoting supported decision making, that their ratification was premised on their authority to operate adult guardianship systems.

Proponents of repeal-and-replace are not giving sufficient weight to the reality that people with developmental disabilities are at a high risk for abuse, often at the hands of the people closest to them or in their circle of support.

The Disability and Abuse Project is aware of this reality and, as a result, is not willing to support the repeal of limited conservatorship laws. Instead, we want the rights of vulnerable adults to be respected, more funding for the system, and quality assurance and monitoring mechanisms to be put into place.

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www.disabilityandabuse.org
The Effect that Senate Ratification of the U.N. Convention on Disability Rights May Have on Current Guardianship Laws

By Thomas F. Coleman


President Obama signed the Convention on behalf of the United States in July 2009. Soon thereafter, a process was initiated to have the President’s action ratified by the United States Senate.

The Convention has no legal effect in the United States until it is approved by the Senate. When it is ratified, the extent that it will have any effect on the 50 states will be determined by any “reservations, understandings, and declarations” which are attached by the Senate to the ratification.

The Convention was transmitted to the Senate by the Administration in May 2012. It was referred to the Committee on Foreign Relations for hearings. That Committee eventually forwarded it to the full Senate for a floor vote. The version of the Convention that the Senate was asked to approve had reservations, understandings, and declarations attached to it.

One reservation included in the measure states that the Convention is “not self executing” which means that without additional enabling legislation by Congress, private parties may not sue state governments for violating provisions of the Convention.

Another reservation in the resolution declared that state and local governments are not in violation of the Convention if their actions are consistent with the United States Constitution, the Americans with Disabilities Act, and other federal laws.

Finally, the version before the Senate declared that, in view of these reservations, current United States law fulfills or exceeds the obligations of the Convention for the United States of America.”

Despite the inclusion of these stipulations, the Senate was five votes short of ratifying the Convention when a vote was taken in November 2012. The treaty was automatically returned to the Foreign Relations Committee for further consideration.

Meanwhile, the United Nations appointed a Committee on the Rights of Persons with Disabilities to implement the Convention through consultations with individual nations. This Committee adopted a Comment on Article 12 on April 11, 2014.

The Comment interprets Article 12 as requiring states to abolish all guardianship laws because, in the view of the Committee, any system of substituted decision making, even if implemented for only one type of decision, violates Article 12. This Comment may have been prompted by the fact that Canada and Australia, when ratifying the Convention, reserved the right to operate guardianship systems in those jurisdictions despite Article 12.

A 2013 report issued by the Congressional Research Service clarifies that decisions by the Committee on the Rights of Persons with Disabilities “are non-binding under international and domestic law.”

In view of political realities, it is highly likely that when the Convention is eventually ratified by the Senate, it will contain the reservations described above. If so, the Convention itself, and the Committee’s interpretation of Article 12, will not require repeal of adult guardianship laws in the 50 states.

However, the policies contained in adult guardianship and conservatorship laws, and the practices implementing those laws, will have to comply with the United States Constitution, the Americans with Disabilities Act, and other federal laws.

That is what the Conservatorship Reform Project is seeking – comprehensive revisions of such statutory systems to protect the constitutional and civil rights of people with developmental disabilities.

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A Review of “Model Legislation” for Supported Medical Decision-Making Agreements: The Defects are in the Details

by Thomas F. Coleman

An email was distributed recently by the Autistic Self Advocacy Network (ASAN) announcing a “Webinar on Model Legislation for Supported Decision Making” in healthcare contexts.

According to the email, the model legislation, which ASAN developed in collaboration with the Quality Trust for Individuals with Disabilities, “would 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.”

The email contrasts this medical decision-making model with guardianship, stating that supported decision-making arrangements let people with disabilities keep the ability to make their own decisions. Advocates are encouraged to use the model legislation when talking to their state legislators about ways to help people make independent health care decisions.

Dr. Nora Baladerian, Executive Director of the Disability and Abuse Project, asked me to review the proposed law. Is it something that state legislatures should enact? Does it advance the rights of people with intellectual and developmental disabilities?

The legislation is titled: “An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities.” The term “disability” means “a physical or mental impairment that substantially limits one or more major life activities of such individual.”

The stated purpose of the Act is “to create an alternative to guardianship, maximize autonomy, and improve healthcare outcomes for persons with disabilities by permitting adults with disabilities to name supporters to help them understand health-related information and options so they can make their own health care decisions.”

The section defining the scope of the Act specifies that in a supported decision-making agreement an adult with a disability may authorize a named supporter to (1) access medical documents and information from medical providers; (2) assist the adult with a disability to understand that information; (3) assist the adult to understand the options, responsibilities and consequences of the health care decision(s) to be made so the adult can make his or her own decisions; and (4) to communicate or assist the adult in communicating his or her decisions to other persons, including medical personnel.”

The title, purpose, and section defining the scope of the Act are rather innocuous. HIPAA (Health Insurance Portability and Accountability Act) already allows a person with a disability to designate someone to access his or her medical records and information. People, with or without a disability, may have someone assist them in understanding medical options and help them communicate their decisions to medical personnel. These parts of the proposed bill are merely restatements of existing law.

The next section of the proposal contains a form clarifying that a supported medical decision-making agreement is not a medical power of attorney. The adult with a disability is not authorizing the support person to make medical decisions on his or her behalf. Again, this section is innocuous. It merely clarifies what the agreement is not.

Another section specifies that the designated support person is entitled to have access to medical records and information under HIPAA. Again, this is merely a restatement of existing law.
The offensive and troubling provisions of the proposed legislation are found in Section 8 which deals with “Immunity from Suit for Health Care Providers Who Act Consistently with a Supported Health Care Decision-Making Agreement.” These provisions take away existing rights of people with disabilities.

One clause declares that health care providers are immune from any action alleging that the agreement was invalid, unless the provider has actual knowledge of its invalidity. Actual knowledge of invalidity would be almost impossible to prove unless the provider was present at the time it was executed (which is highly unlikely).

The requirement of “actual knowledge” of invalidity gives an incentive to health care providers not to inquire into the circumstances involved in the execution of such an agreement. The law effectively tells providers that “what you don’t know won’t hurt you.” Under this clause, providers are better off if they don’t ask questions, especially when circumstances may arouse suspicion of undue influence.

Another extremely bothersome provision states that a supported health care decision-making agreement is effective even if the individual who executed it has been or would be found by a court to lack the capacity to independently execute a contract. Normal principles of contract law are to be disregarded, even though a supported health care decision-making agreement is a contract.

Make no mistake about it, this is a contract. The adult designates a support person and gives that person a degree of authority and complete access to medical records and information. The designated person agrees to assume responsibility for providing assistance to the adult with a disability. This is a contract. And yet, this legislation declares that the contract is valid even if a court determines that the adult in question lacked the capacity to contract.

The most dangerous provision in this legislation specifies that the provider, with very few exceptions, is immune from any action alleging that the person with a disability lacked capacity to provide informed consent. Although the provider must obtain the “consent” of the person with a disability prior to engaging in medical procedures, the consent need not be “informed” consent.

Informed consent is an existing legal right of every patient and the failure to obtain informed consent subjects medical personnel and health providers to liability. Beyond the issue of legal rights and responsibilities, informed consent is also a matter of medical ethics. The failure to obtain informed consent prior to engaging in medical procedures could result in professional discipline or the loss of a license to a credentialed person or agency.

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.

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.

Dr. Baladerian, especially considering the provisions on immunity from liability, I regret to advise you that this proposal does not advance the rights of people with intellectual and developmental disabilities. Unfortunately, I have concluded that state legislatures should not use this proposal as a model.

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“Model Legislation” for Supported Medical Decision-Making Violates Medical Ethics

by Thomas F. Coleman

The concept of supported decision making is gaining momentum among networks of disability rights advocates. The basic concept of “self determination” is good, but when it comes to legislation, the devil is in the details.

This essay builds upon previous essays that I have written about supported decision making. These essays raise legal and ethical concerns that need to be addressed by those interested in protecting the rights of people with developmental disabilities.

One of the essays was a critical review of “Model Legislation for Medical Supported Decision Making Agreements.” The legislation is titled: “An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities.” The term “disability” means “a physical or mental impairment that substantially limits one or more major life activities of such individual.”

That essay took exception to a provision in the model law that absolves medical personnel from liability if they perform medical procedures without the “informed consent” of a patient who has signed a Supported Health Care Decision-Making Agreement. It was also critical of a clause that prohibits doctors from questioning such an agreement on the ground that, at the time the patient signed the SDM agreement, the patient lacked capacity to enter into a contract – which is what a SDM agreement is.

Whether a doctor is given immunity from liability or not, medical ethics require doctors to obtain informed consent from a patient before performing a medical procedure. This model legislation cannot absolve physicians of their duty to adhere to the requirements of medical ethics.

“Informed consent is a basic policy in both ethics and law that physicians must honor, unless the patient is unconscious or otherwise incapable of consenting and harm from failure to treat is imminent.” (American Medical Association, Opinion 8.08 – Informed Consent)

“Informed consent must be preceded by disclosure of sufficient information. Consent can be challenged on the ground that adequate information has not been revealed to enable the patient to take a proper and knowledgeable decision.” J. H. Satyanarayana Rao, “Informed Consent: An Ethical Obligation or Legal Compulsion?, Journal of Cutaneous and Aesthetic Surgery, Jan. 2008) (Emphasis added)

The ethical duty to obtain informed consent requires more than having a patient sign a consent form. It must appear to the physician that the patient, having been given all of the facts, truly understands the nature of the procedure, as well as the potential benefits and risks, and can make an informed decision to proceed or not.

“Comprehension on the part of the patient is equally as important as the information provided. Consequently, the discussion should be carried on in layperson's terms and the patient's understanding should be assessed along the way.” (Jessica de Board, “Informed Consent,” Ethics in Medicine, University of Wash. School of Medicine, 2014)

Despite the grant of immunity from civil liability contained in the model legislation, it is doubtful that medical professionals or organizations will support the passage of a law that purports to authorize physicians to violate the requirements of medical ethics.

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“Model Legislation” for Supported Medical Decision-Making Violates the Supremacy Clause

by Thomas F. Coleman

This essay is part of a series of commentaries that are critical of “Model Legislation” for supported medical decision-making.

The legislation being reviewed is titled: “An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities.” The term “disability” means “a physical or mental impairment that substantially limits one or more major life activities of such individual.”

One provision of the model law absolves medical personnel from liability if they perform medical procedures without the “informed consent” of a patient who has signed a Supported Health Care Decision-Making Agreement. Another one prohibits doctors from questioning such an agreement on the ground that, at the time the patient signed the SDM agreement, the patient lacked capacity to contract.

The proponents of this model legislation contemplate that such a law would be enacted by state legislatures since it is the states that have primary jurisdiction over contract law and medical licensing. However, they have failed to take into account the requirements of federal laws pertaining to medical services funded through Medicare and Medicaid.

The Centers for Medicare & Medicaid Services (CMS) address the issue of informed consent through their Conditions of Participation (CoP). Health care organizations must meet these conditions in order to participate in the Medicare and Medicaid programs.

In the Patients’ Rights CoP (42 CFR §482.13(b)(2)), the interpretive guidelines state: “Hospitals must utilize an informed consent process that assures patients or their representatives are given the information and disclosures needed to make an informed decision about whether to consent to a procedure, intervention, or type of care that requires consent.”

“It is the physician's responsibility to determine if a patient lacks capacity to a reasonable degree of medical certainty.” (O’Leary and McGraw, “Informed Consent Requires Active Communication,” Anesthesia Patient Safety Foundation, Newsletter, Spring 2008)

“‘Capacity’ refers to a determination made by medical professionals that a patient has the ability to make a specific decision at a specific time. To have capacity, patients must have the ability to understand and reason about their medical conditions, and to appreciate the indications, risks, benefits, and alternatives to proposed treatments.” (Ibid.) “If a patient lacks capacity, consent must be obtained from an authorized decision maker, unless an emergency or other exception applies.”

Thus, federal law clearly precludes medical personnel participating in Medicare or Medicaid programs from dispensing with the necessity of informed consent prior to engaging in a medical procedure.

At least with respect to hospitals, clinics, or doctors who accept Medicare or Medicaid payments, any state law that purports to grant immunity to medical professionals who do not obtain informed consent would be preempted by federal law.

On this subject, and when federal payments are involved, federal law would be supreme and any state law that conflicts with the informed consent requirement would be unconstitutional under the Supremacy Clause (Article VI, Clause 2) of the United States Constitution.

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A new legal concept, called “supported decision making” is being promoted by disability rights advocates. SDM supporters want to repeal guardianship laws. They reject the idea that some people sometimes lack capacity to make some decisions.

SDM relies on a conclusive legal presumption that every person has the capacity to consent to every decision all the time. That’s why proponents call it a “paradigm shift.” Under SDM the legal concept of incapacity to make decisions ceases to exist.

Under current law – civil or criminal – capacity to consent involves a rebuttable presumption that can be overcome with evidence of incapacity.

In a criminal context, prosecutors can introduce evidence in a rape or sexual assault trial that, due to a cognitive or mental disability, a victim lacked the capacity to consent. They can also show that the lack of capacity was known to or reasonably should have been apparent to the alleged perpetrator. Even if the defendant testifies that the victim said “yes” to a sexual encounter, this would not be a defense if the defendant reasonably should have known that the victim lacked the capacity to consent to sex.

Right now, the “model legislation” for SDM is focused only on medical decisions. This model makes “informed consent” a relic of the past. It weakens protections against undue influence. If SDM wiggles its way into the field of criminal law, lack of capacity would become irrelevant and obtaining a conviction could be made more difficult. The next incarnation of such “model legislation” may involve financial arrangements. Then would come the inclusion of SDM into the legal regulation of other important decisions, such as consent to have sex. Proponents of SDM are building a “disability rights” mountain with a very slippery slope.

Because SDM involves people with disabilities, legal and medical professionals and others whose work primarily involves generic populations, are not paying attention to SDM. They should – especially since all of us will probably have a SDM-qualifying disability if we live long enough.

The enactment of SDM legislation will affect society as a whole. It chips away at core legal principles at the foundation of American jurisprudence – legal capacity for decisions, undue influence, and informed consent. These legal concepts are integrated into the fabric of our justice system, whether the context involves contracts, medical procedures, or even personal matters such as sex.

I have written other commentaries about the implications of SDM in terms of civil law, such as adult guardianships or conservatorships. This essay discusses how the rippling effects of the waves being created by SDM proponents may effect criminal law in a manner that undermines legal arguments currently available to prosecutors to protect sexual assault victims and punish perpetrators.

Victims rights advocates should scrutinize SDM very carefully. Such scrutiny should begin now, before SDM creeps from medical law and contract law into the field of criminal law. The broad sweep
of SDM is coming. One organization has already called for the repeal of incapacity laws “throughout
the legal system.”

Some 44 states have statutes on rape and sexual assault that define when a person is incapable of
consenting to a sexual act due to lack of capacity to consent, such as when he or she is incapable of
understanding the nature or consequences of the act.

In California, Penal Code Section 261 states that “Rape is an act of sexual intercourse accomplished
with a person not the spouse of the perpetrator . . .
(1) Where the person is incapable, because of a
mental disorder or developmental or physical dis-
ability, of giving legal consent, and this is known to
or reasonably should be known to the person com-
mitting the act.” The prosecutor has the burden of
proving that such disability rendered the alleged
victim incapable of giving consent.

Defense attorneys often raise the issue of consent as
a defense, putting the defendant on the witness stand
to testify that the alleged victim said or did some-
thing to affirmatively indicate that he or she was a
willing participant. The issue raised in this context
is that of actual consent.

In most sexual assault cases, there are only two
witnesses – the perpetrator and the victim – so the
issue of consent is a credibility contest.

To bolster their case, prosecutors may introduce
evidence, through expert witnesses, when the victim
has a serious intellectual or developmental disability
that significantly impairs cognitive functioning or
understanding. Such expert testimony gives the jury
a second option for a guilty verdict – that the victim
lacked the capacity to consent to sex.

A second option such as this is especially important
where the victim may have felt pressured by the
perpetrator and therefore assented to sex, without
really giving informed and voluntary consent.

Perhaps the victim was under an adult guardianship
or limited conservatorship. Perhaps the judge made
a factual finding that the adult in question lacked
capacity to consent to sex. Perhaps the perpetrator
was a guardian or household member or caregiver
who knew about the terms of the guardianship,
including the judge’s order regarding consent to sex.

The prosecutor of a rape case involving a victim
under such a guardianship would introduce evidence
of the court’s order and that the defendant knew or
should have known of the order, especially the
provision regarding sex. The chances of a convic-
tion in such a situation would be greatly enhanced.

Proponents of SDM want to abolish guardianship
and conservatorship laws. They point to Article 12
of the United Nations Convention on the Rights of
Persons with Disabilities as an international treaty
requiring the abolition of all laws that are premised
on the concept of incapacity to consent due to a
cognitive or other disability.

To be sure, there are upsides as well as downsides to
supported decision making. Unfortunately, the
proponents of SDM only focus on the upsides.
Negative implications or consequences are either
downplayed or avoided.

The Disability and Abuse Project brings a different
perspective to the conversation about supported
decision making. We are trying to find the right
balance between advocacy for rights and advocacy
for protection of a class of people who are at much
higher risk of abuse than the generic population.

Striking such a balance is a delicate task, one that
requires constant evaluation. One thing is crystal
clear to us as we participate in this ongoing analysis
– the repeal of guardianship laws or weakening laws
on informed consent, undue influence, and capacity
to consent, is not the right approach. In fact, it is
dangerous since it increases the risk of abuse.

Police, prosecutors and victims’ rights advocates
should scrutinize proposals made by proponents of
supported decision making. The implications for
sexual assault victims are serious and significant.

Contact: tomcoleman@disabilityandabuse.org
Supported Decision Making:
Implications for Seniors

_Repeal of Guardianship Laws Would Endanger Older Americans_

by Thomas F. Coleman
Disability and Abuse Project

As older adults enter their 70s and 80s, many of them begin to experience a decline in cognitive abilities. This could involve Alzheimer’s Disease, dementia, or other conditions that adversely affect mental functioning.

Such disabling conditions could trigger other impediments to making sound decisions, such as the illness of depression. Mental impairment can also occur due to brain injuries caused by falling.

Some seniors create financial and medical powers of attorney prior to the onset of any of these disabling conditions. However, many more do not.

A spouse or other family members may step forward once a senior shows significant signs of cognitive decline. A caregiver may be hired or the senior may move into an assisted living residence.

At a certain point, it may become apparent to a spouse or relative or doctor that the senior may lack the capacity to make some significant decisions, perhaps involving large financial transactions or major medical procedures. When this occurs, the spouse or family member may consider instituting an adult guardianship. Often this is done after the senior has already been taken advantage of by others and so a higher level of protection is explored.

Adult guardianships – called conservatorships in California and some other states – have been a part of the American legal system for decades. These proceedings are supposed to be initiated only as a last resort and after less restrictive alternatives have been considered but simply won’t work.

Supported Decision Making

There is a growing movement in disability rights circles for a legal construct called “supported decision making” or SDM. Proponents of SDM refer to it as a “paradigm shift” because at its foundation is the principle that, with enough support, every person has the ability to make every decision all the time.

Current law establishes a rebuttable presumption that adults have the capacity to make decisions of every kind – social, sexual, residential, educational, medical, etc. However, that presumption can be rebutted by evidence showing incapacity to make decisions in one or more of these areas.

The legal construct of SDM rejects the idea of a rebuttable presumption of capacity. It makes the presumption conclusive. Evidence of incapacity is irrelevant when the SDM model is adopted into law.

Proponents of SDM reject any legal framework that allows for a substitute decision maker. Powers of attorney are based on an agent making decisions for the principal when the principal is incapacitated. Guardianship allows for a court to appoint a substitute decision maker when a power of attorney does not exist and the adult in question lacks capacity to make decisions on significant matters.

Some organizations in the SDM movement are promoting “model legislation” to authorize SDM agreements in a medical context. As the SDM movement gains support, legislation will be drafted to cover other areas, such as financial matters.
Because this model legislation is intended to grant the right to anyone with a “disability” to create a SDM agreement, the SDM movement will have ramifications for seniors and their families. Dementia is a disability, as is Alzheimer’s disease.

The fervor of those promoting supported decision making needs to be tempered by close analysis and careful scrutiny of a legal construct that wants to eradicate protection systems such as guardianships.

Under the model legislation for medical SDM, grandma can sign an agreement designating the woman in the next room at the assisted living facility as her “support person.” The fact that grandma cannot consistently recognize her family members is irrelevant.

The model legislation prohibits anyone from challenging the SDM agreement on the ground that grandma lacked the capacity to enter into a contract. It also prohibits anyone from suing a medical provider who performs services to someone with an SDM agreement, unless the provider had actual knowledge that undue influence was used to pressure grandma into signing it. Of course, a provider will not have actual knowledge unless the provider was personally present when it was executed. And worst of all, the provider cannot be sued for providing medical services without “informed consent.”

Under current law, any agreement can be challenged on the ground that the person signing it lacked capacity to contract. So SDM is taking away this right. Under current law, a medical provider must have “informed consent” prior to performing medical services. The SDM model legislation takes away that right as well.

Current law also imposes a duty on a provider to investigate further if they reasonably believe that undue influence has occurred. The SDM law would change that standard of care to require action by the provider only if they have actual knowledge of undue influence.

The idea of SDM and the model legislation have been circulating primarily among those who are involved with disability rights. SDM has gotten little, if any, attention from agencies, organizations, and professionals who work with the elderly.

This essay is intended to alert advocates for seniors about the unintended consequences of endorsing supported decision making.

The Disability and Abuse Project has taken a close look at supported decision making. Several essays analyze SDM and caution people not to jump on the SDM bandwagon too quickly. Another essay discusses the adverse effect the repeal of laws on incapacity could have on the ability of prosecutors to obtain convictions when victims, sometimes seniors, lack the capacity to consent to sex.

We support alternatives to guardianship and conservatorship when they do not unduly increase the risk of abuse and exploitation of vulnerable adults, such as people with intellectual and developmental disabilities and seniors who have cognitive impairments. We support the use of powers of attorney when they were executed at a time when the principal had the capacity to contract.

We believe that guardianships and conservatorships should be used as a last resort, not a first option. But we do not support any movement to repeal guardianship systems in favor of a privatized SDM agreement system – a system without checks and balances and without judicial oversight.

We promote major reforms in the guardianship and conservatorship systems. We have a Conservatorship Reform Project that works toward that end.

Supported decision making, as it is currently constructed, poses great risks to people with disabilities, including seniors. The time has come for those who care about seniors to examine SDM and its potential impact on the elderly.

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Excerpt where otherwise noted as a comment, the language contained in this document are paragraphs taken from various parts of the Thinking Ahead Matters report published in August 2014 by the Coalition for Compassionate Care of California.

These excerpts serve as an executive summary of those parts of the 97-page report that focus on the Limited Conservatorship System. The findings reported here are consistent with those contained in essays and reports published by the Disability and Abuse Project.

Introduction

These are the questions considered in this report:

* What is the process of conservatorship for people with developmental disabilities in California?

* How large is the impact of conservatorship on healthcare decision-making for this population?

* What strategies would improve self-determination in healthcare decisions for people with developmental disabilities?

This paper considers these issues through the lens of people with developmental disabilities themselves as well as their advocates; including family members, attorneys, disability rights advocates, Regional Centers, bioethicists and providers who work closely with them. It relies on 21 qualitative interviews with a total of 22 key informants from these groups, as well as assembling background resources with strategies and policy recommendations on relevant topics that are intended to enhance the agency, dignity and choice of disabled individuals. The essential purpose is to strengthen the opportunity for the disabled person to make or actively contribute to making decisions important to themselves, up to and including the end of life.

Background

Today, with the reduction in institutionalization and over-crowded, understaffed and under-funded conditions, people with I/DD have a life expectancy near that of other adults, with an average life of 65 years compared to 70 in the general population.

Nationally, over 75% of people with I/DD live with their families, and more than 25% of family caregivers are over the age of 60.

A Pro-Disability Philosophy

Surrogate healthcare decisions, when needed, should be made by caregivers who know the patient well and attempt to view quality of life from the patient’s perspective.

Legal Issues

In the late 1970’s a series of reforms was instituted to the conservatorship process, intended to create due process and protect the rights of conserved persons. In 1977 the position of court investigator was created, and courts received authority to appoint an attorney to represent proposed conservatees. In 1980, California established the “Limited Conservatorship” specifically for adults with I/DD.

According to conservatorship attorney Stephen Dale, Limited Conservatorships are intended to give “just the right amount of powers – not too much, not too little.”

While the general conservatorship process begins with an assumption that all powers will be given and the judge may reserve some rights as the process unfolds, Limited Conservatorship does not presume the disabled person is incompetent. Limited
Conservatorships are designed to help persons with I/DD lead more independent, productive and normal lives, and the disabled person retains all legal and civil rights except for those the court specifically grants to the conservator. It requires consideration of the person’s abilities in seven fundamental areas, and awards the conservator rights to just those powers where the person needs assistance.

Limited Conservatorships involve a number of discrete steps. A recent report, Justice Denied: How California’s Limited Conservatorship System is Failing to Protect the Rights of People with Developmental Disabilities by the Disability & Abuse Project of Spectrum Institute, provides a general outline of the transactions associated with Limited Conservatorships.

Adults with I/DD Who Are Conserved

(Comment: Data obtained from the Department of Developmental Services show that out about 141,000 adults with intellectual and developmental disabilities in California, slightly more than 40,000 are conserved. Of those conserved, some 25,500 have a parent or relative servicing as conservator, nearly 900 have the Public Guardian, and nearly 800 have a private non-relative conservator.)

Critiques of the Limited Conservatorship Process

Attention has begun to focus on Limited Conservatorships and how they operate, raising concerns that they do not function as intended. There was strong feedback from informants involved in conservatorship about the negative impact of California’s diminished funding of both the courts and the Regional Centers. One described the court-funding crisis in particular as resulting in “chaos” in court processes. Several attorneys also believe that cuts to Regional Centers have diminished the assessment of the disabled person’s capacities. They believe that Regional Center assessments have become less individualized and more pro-forma, with boilerplate language submitted in many cases rather than accurate personalized reporting on client capacity in each of the seven powers. Other informants identify a lack of training and knowledge of the population amongst attorneys and court officials as a complicating factor. And while there are differences of opinion about the location of the dysfunction and how it is evidenced within the system, there is widespread agreement that lack of proper oversight and remediation are difficulties in cases where conservatorships are bad. Informants report that this is a significant problem that is hard to remedy, with serious consequences for vulnerable conservatees. All informants saw funding cuts as a core contributor to these problems and stated that they cannot be resolved without an appropriate level of funding for both systems.

Informants also provided feedback that there are many instances where the ideal process and legal requirements are not implemented. Copies of the petition are not always provided to the person with a disability and close relatives. One informant reports never having seen a court investigator review psychological and medical records as part of the process. One stated that disabled persons are frequently not in attendance at the court hearing even though they are medically able to attend, and proposed conservatees are rarely consulted about who should be appointed as conservator. Informants noted that annual or biennial in-person visits to the conservatee to check on their welfare only occur rarely, and reported that the initial in-person interview with the court investigator is often conducted without privacy, in the presence of the parent or potential conservator, thereby making it difficult for the disabled person to provide candid information.

The Justice Denied report outlines some additional ways that problems have manifested in the Limited Conservatorship process. Utilizing a review of Limited Conservatorship cases in the Los Angeles Superior Court, the report sees that the following problems have occurred.

First, there are too few court investigators to carry out the work. The law requires a court investigator to conduct investigations on all initial petitions, conduct an annual review one year later and a biennial investigation thereafter. One informant has called this investigation the most important information in the Limited Conservatorship process. If there
is a report of suspected abuse of a conservatee, that should also prompt an investigation. However, court investigators are paid by the court directly. Due to ongoing court funding constraints, an overwhelming caseload and consequent understaffing, the court investigator report appears to be frequently waived in Los Angeles, with substitution of the Regional Center report or the report of the attorney who serves as the conservatee’s court-appointed attorney, in place of the court investigator report.

This approach diminishes the impartial investigation of the circumstances and appropriateness of the conservatorship, and also creates a conflict-of-interest for the court-appointed attorney, who is ethically obligated to represent the rights of the client rather than the interests of the court.

Another issue called out is that in its minimal training, the Los Angeles Court gives court-appointed attorneys instruction that if they disagree with the “stated wishes” of the client, they should advocate for what they believe are the client’s best interests.58 While project informants point out that experienced conservatorship attorneys understand the duty to represent the proposed conservatee as specified in the Probate Code, this report concludes that such instructions can result in attorneys acting as de-facto guardians ad litem, advocating for what they believe are the best interests of the client rather than advocating for what the client expressly wants.59 That outcome does not appear to be consistent with the intention and purpose of the Limited Conservatorship process.

In addition, Limited Conservatorships are sometimes granted when the Regional Center report has not even been filed. Even when they are filed, these reports lack criteria and guidelines to make standardized and valid assessments of client capacities.60 Furthermore, ongoing biennial investigations by the court investigator, required by state law, do not appear to be occurring in Los Angeles.61 Informants to this project report this lapse is occurring in other counties as well.

The Justice Denied report finds, and informants to the current study concur, that education about the I/DD population as well as about the conservatorship process itself, are severely lacking. Courts and attorneys need better education about the population, including the requirement and importance of providing reasonable accommodations under the Americans with Disabilities Act, in order for disabled persons to be able to communicate their views and wishes in the process.62 Parents and other potential conservators who file petitions need training about the conservatorship process and the duties and responsibilities of conservators, including the responsibility to take the disabled person’s wishes into account even when they are conserved. All parties need better information about supported decision-making and appropriate alternatives to conservatorship. Finally, neither the Department of Developmental Services nor a client rights advocacy agency has a formalized role in monitoring the Limited Conservatorship process.

Although some of these findings may be unique to Los Angeles County, many appear to have validity in other counties. As far as we are aware there is no quantitative study of the outcomes of Limited Conservatorships across the state of California; however, differing county-to-county processes are a significant problem in the applicability of statewide legal standards and of equity across counties. Each county’s courts have differing policies and administration, which are often vastly different from one to the next.

The variability in policies of locally administered agencies, both the courts and those under the domain of county boards of supervisors, vastly complicate the real world outcomes of Limited Conservatorships and interventions in situations of abuse and neglect involved with bad conservatorships, and deserve further study and recommendations for improvement.

People with intellectual and developmental disabilities have rights under both state and federal law that protect them in a variety of ways. Among these are the Lanterman Developmental Disabilities Services Act (Appendix C) located in California Welfare and Institutions Code. Section 4502 ensures the same legal rights and responsibilities guaranteed all other
individuals by the United States Constitution and laws of the State of California, with protection against exclusion from participation, denial or discrimination under any program or activity that receives public funds. Section 4502.1 ensures the rights of individuals with I/DD to make choices about their own lives and requires public and private agencies to provide opportunities to exercise decision-making skills in any aspect of day-to-day living, provided in understandable form. Furthermore, Limited Conservatorship statutes require that under a conservatorship, the conservator is responsible to secure services which “will assist the limited conservatee in the development of maximum self-reliance and independence,” and reserves all rights not explicitly granted to a conservator for the disabled person. All of these laws are intentional in preserving the independence and choices of people with I/DD, and providing respect and protection for their decisions. How these laws are administered in practice, however, has a significant impact on the ability of a disabled person to exercise decisions in his or her day-to-day life.

**Medical Issues**

The role of conservatorship is seen differently depending on the vantage point of the observer. Conservatorship attorneys express that it is an appropriate tool depending on unique circumstances and individual and family needs; neither good nor bad but sometimes necessary. They emphasize the importance of conservatorship in protecting vulnerable people from harm, exploitation and abuse. Regional Center informants who see many complex situations report that in some cases family members have been the ones abusing disabled adults, and have used their status as conservator to obstruct investigation and intervention by Adult Protective Services. On the other hand, a father whose son is conserved uses the authority of conservatorship to help stand on his son’s side and empower his wishes when service providers and social workers try to “browbeat” or coerce his son to do things that are not in his interest.

Explaining the alternatives to conservatorship for healthcare decision-making is not, by itself, a full solution. A conservatorship attorney who works with low-income families reports that tension often exists between parents and Regional Centers; families see conservatorship as a means of empowerment when Regional Centers are not responsive and do not give them a “say” in the type of services they receive. For these families, conservatorship can be seen as a strategy to navigate complex systems and advocate for services their loved one needs. This can be especially important for undocumented families.

(Comment: The statements in the following paragraph are even more significant when one considers the requirement of the California Constitution that laws of a general nature must operate uniformly throughout the state.)

A key challenge to making improvements to processes of medical decision-making for the publicly conserved is the fact that Public Guardians (as well as courts) are locally administered, and each county and jurisdiction interprets and implements laws and policies differently. Drought comments, “The extreme variation in practices noted across counties seems to exceed what the ambiguities in the law might suggest.” Another informant stated, “The interlocking gears of these systems are not necessarily a good fit and at times create friction that is unbearable for the people who are caught in it.” The Legislature and DDS have an interest in making these gears work more smoothly and ensuring that local policy is implemented with enough consistency so that clients of Regional Centers are protected and afforded the benefits of the Lanterman Act, no matter in which county they reside.

A Regional Center Medical Director notes that without this depth, caregivers sometimes see it as an “assignment” to “sign people up” for an advance directive. This can lead to inappropriate prompting to make choices the caregiver sees as correct rather than a dynamic process of helping the disabled person to understand and express choices.

**Supported Decision Making**

Supported decision-making (SDM) is a process of seeking assistance from chosen family members,
friends or supporters to understand situations, consider options and use their help to make choices.

Advocates express concern about the appropriateness of systems that are dependent on overbroad conservatorship as a routine part of permanency planning for people with I/DD, asserting that laws are frequently misapplied. Although repeatedly proposed and sometimes implemented, “reforms have had remarkably little effect on judicial behavior,” and conservatorships are routinely granted. Research demonstrates that conservatorship can result in harm to the disabled person, hindering self-determination and community inclusion. Overly broad conservatorship can leave people feeling isolated and lonely, can cause depression, decrease motivation, create learned helplessness and undermine the disabled person’s physical and psychological well-being by reducing their sense of control over their lives.

It is important to note that the state of the art of SDM exists in the early stages. While several models of formalized SDM operate internationally, there is not much research. One comprehensive review by Kohn et al raises a number of important points: for example, while there is a growing body of literature about how SDM should work, there is far less information on how it does work. There is little information about the internal dynamics of SDM discussions, and almost no empirical evidence that SDM systems succeed in achieving their substantive goals.

Most importantly, the review notes that SDM arrangements can create new opportunities for abuse, potentially allowing unaccountable third parties to improperly influence persons with I/DD, disempower them and undermine their rights.

Some propose that SDM could take the place of conservatorship. Alternatively, it could be integrated into the legal system as a less-restrictive option that is implemented prior to the time that a Limited Conservatorship is even considered, resorting to the more restrictive option only when SDM arrangements have not functioned successfully.

The evolution of SDM should include empirical evidence about how to ensure that decisions truly express and effectuate the wishes or preferences of the disabled person and whether SDM decisions are more beneficial to the person compared to decisions made using other approaches such as conservatorship.

Findings and Recommendations

The following recommendations are based on our review of the literature, incorporation of best practices identified in cited works and the practical experience of key informants. They include recommendations in each of five critical areas, and they address both policy and funding that are important to improve the area of healthcare decision-making for people with I/DD.

California Probate Codes governing Limited Conservatorship (Probate Code §§ 1827.5, 1828.5, 1830, & 2351.5) should be amended to require that any client of a Regional Center may be subject only to a Limited Conservatorship rather than a general conservatorship. General conservatorships for Regional Center clients should be prohibited.

These Limited Conservatorship statutes should also be amended to include a meaningful requirement that alternatives to conservatorship were understood, explored and an explanation of the reasons why they were unsuccessful and conservatorship is needed, as part of the process of petitioning for a Limited Conservatorship.

Training about the I/DD population and the process, duties and responsibilities of Limited Conservatorship should be formally initiated for those seeking to petition for conservatorship as well as for attorneys who work on Limited Conservatorship. These trainings should include information about facilitating communication and providing reasonable accommodations under the Americans with Disabilities Act to allow disabled persons to have meaningful participation in the legal process.

The Legislature, in consultation with DDS,
Regional Centers and the state’s protection and advocacy agency, should undertake a series of special hearings to consider critical issues that are primarily locally-administered but have a substantial impact on persons with I/DD who may be subject to neglect or abuse. A statewide approach and legislation may be necessary regarding two critical issues: * The role of the Public Guardian and Adult Protective Services in interventions for people with I/DD who may be subject to neglect or abuse; and also in issues of end-of-life decision-making; * The role, processes and effectiveness of courts in investigating, intervening and changing troubled conservatorships.

A disability clients’ rights and protection organization with legal experience should be funded through contract with DDS and authorized to provide oversight, monitoring, reporting and policy recommendations on the Limited Conservatorship process statewide.

DDS should refine and improve its data collection on conservatorship, including specifically tracking three vulnerable populations: * Those who have a Limited or general conservatorship as well as an LPS conservatorship. * Those served by a Public Guardian as their conservator. * Those flagged by Regional Centers as having a conservator who has been reported to Adult Protective Services for suspected abuse or neglect.

California should launch and evaluate a pilot study to support implementation of a collaborative model that includes officials of the Court, the Public Guardian, the Regional Center and bioethics professionals, to improve medical decision-making for publicly conserved individuals as recommended in the Drought report.

Regional Center funding that has been cut should be restored in order to ensure that services are adequate, caseloads are manageable, individualized assessments are appropriately conducted and public educational efforts are restored.

Court funding should be restored to eliminate chaos in operations and ensure that the requirements of the 2006 Omnibus reform legislation are fully implemented. Within these restorations, funds should be earmarked to support the proper implementation and oversight of Limited Conservatorships, based on compliance with legal requirements for initial, annual and biennial investigations by court investigators.

**Concluding Comments**

Though project informants had diverse perspectives about conservatorship, they agreed on a number of points. First, they reported that mainstream society operates from a lack of understanding, experience and acceptance of people with I/DD, often influenced by perceptions of “normalcy” of appearance or behavior. They also report that as a result, people with mild to moderate disabilities are widely underestimated in their capacities for independence and decision-making. In addition, people with moderate to severe disabilities are also underestimated in their ability to make choices, but may require more supports to make their preferences meaningful and effective. These supports span the range of options from good care coordination to intensive supported decision-making to Limited Conservatorship depending on the situation. The optimal solution is the least restrictive intervention that also yields effective results.

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See Conservatorship Reform Project Materials at:
http://disabilityandabuse.org/conservatorship-reform.htm

Members of the Advisory Committee to the Thinking Ahead Matters Report and the 2014 Membership in the Coalition for Compassionate Care of California appear on the following pages.
2014 Membership

Organizations

- Alliance of Catholic Healthcare
- Bright Star Care
- Brown & Toland Physicians
- California Assisted Living Association
- California Association of Long Term Care Medicine (CALTCM)
- California Hospice & Palliative Care Association
- California State University (CSU) Institute for Palliative Care
- Camarillo Hospice Corporation
- Carehouse Healthcare Center, LLC
- Cedars-Sinai Medical Center
- Center For Healthcare Decisions
- Channing House
- Children's Hospice and Palliative Care Coalition
- Chinese American Coalition For Compassionate Care
- Citrus Valley Health Partners
- Community Hospice, Inc.
- Healthcare Partners Medical Group
- Health Plan of San Mateo
- Hill Physicians Medical Group
- Hope Hospice
- Hospice By The Bay
- Hospice of Humboldt
- Hospice of the Valley
- Integrated Healthcare Association
- LeadingAge California
- Masonic Homes Of California
- Napa Valley Hospice & Adult Day Services
- NorthBay Healthcare
- Outcome Resources, LLC
- Pallium India – USA
- Salus Hospice
- SCAN Health Plan
- Seniors*at*Home
- Seton Medical Center
- Sharp HealthCare
- Sharp HospiceCare
- Sutter Health
- Tahoe Forest Hospice
- TrueNorth Healthcare
Advisory Committee

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Indiana Reforms Adult Guardianship System

A Statewide Task Force Prompted Several Changes

by Thomas F. Coleman
Disability and Abuse Project

Steps are now being taken by all three branches of government in Indiana to implement changes in the operations of the state’s adult guardianship system. These reforms were stimulated by the work of the Indiana Adult Guardianship State Task Force.

The Task Force was convened in 2008 by The Arc of Indiana, with funding from the Indiana FSAA Division of Disability and Rehabilitative Services. The Arc of Indiana is a non-profit organization that helps people with intellectual and developmental disabilities realize their goals of learning, living, working, and fully participating in the community. It has 20,000 members and 42 chapters in Indiana and is part of a network of 140,000 members and 700 state and local Arc chapters nationwide.

The Arc of Indiana provided leadership by convening the Task Force – a collaboration of more than 35 organizations and many individual advocates who worked together for nearly three years to study the adult guardianship system in Indiana.

The Task Force examined the level of need, availability of resources, and quality of adult guardianship services across the state and did an extensive legal review of Indiana guardianships, practices, and statutes. It gathered information from service providers and from the responses to a statewide needs assessment. (“Who’s Overseeing the Overseers? A Report on the State of Adult Guardianships in Indiana,” Report of the Indiana Adult Guardianship State Task Force, February 2012).

Indiana has 7,000 adults who are under court-ordered guardianships. This population includes seniors with dementia (38%), adults with intellectual and developmental disabilities (12%), people with a mental illness (8%), those with physical disabilities (17%), and others (25%).

Despite the large number of adults who have court-appointed guardians, Indiana had no statewide tracking system or central repository for adult guardianship cases that could be shared by courts, state agencies, and service providers. No individual was clearly in charge of the adult guardianship system and the operations of the system were not being monitored by any governmental agency.

We have made some good progress and are frustrated in other areas.

We now have funded 9 pilot programs throughout the state to assist people in deciding the question of guardianship, have legislation that requires professional guardians to register with the newly created office of adult guardian in the Supreme Court’s office and have continued a statewide task force that includes judges, advocates and consumers.

We still are frustrated with too many people seeking guardianship for folks instead of looking at ways to support them in decision making – but have our state agency interested in developing some new approaches.

– John Dickerson
Executive Director
The Arc of Indiana

The Task Force recommended that Indiana establish and fund (1) an Office of Adult Guardianship as a department of the Indiana Supreme Court – Division of State Court Administration; (2) a system of community-based volunteer guardian services to serve incapacitated adults who are indigent or without the support of family members; (3) mandatory guardian education, certification, and registry for all attorney, professional, and non-family member guardians appointed by the courts; (4) an adult guardianship registry to collect data and issue reports on all adult guardianship cases, and; (5) a resource center to provide public education on advanced directives planning and options available to individuals and families for substitute decision-making.

December 27, 2014
It also recommended that the Indiana Probate Code Study Commission undertake a comprehensive review and revision of the sections of the probate code dealing with adult guardianships.

Rather than disbanding after its report was issued in 2012, the Task Force has continued its work by advocating for implementation of its recommendations. With cooperation and support from the Indiana Supreme Court, some of the proposals were approved, with funding, by the Indiana Legislature.

The Legislature approved and funded the Indiana Supreme Court Adult Guardianship Office, a Volunteer Advocates for Seniors and Incapacitated Adults Program, and the Indiana Adult Registry Program.

The Adult Guardianship Office serves as a resource for judges and the general public on adult guardianships. It also administers grant funding to increase the number of volunteer guardianship programs in Indiana. So far, grants of more than $300,000 have been awarded to eight volunteer-based guardianship programs serving 300 adults in 14 counties.

Indiana is in the process of creating a statewide Adult Registry Program. The registry will provide non-confidential information to the public, including: the name of the protected person, the name of the appointed guardian, and the guardianship case number. The registry will provide useful information that will help the courts track the status of open guardianship cases. It will also be helpful to agencies and service providers who need to know whether a person they are serving is under a guardianship and, if so, who the guardian is.

The work of the Task Force is gaining considerable attention. It was the focus of a workshop for service providers sponsored by the Indiana Professional Management Group on July 18, 2014. A presentation highlighted the work of the Task Force. It also provided information on the general operations of the adult guardianship system in Indiana.

The Task Force is also having a national impact. It was recently recognized as one of several special projects of the National Guardianship Network – WINGS Initiative (Working Interdisciplinary Networks of Guardianship Stakeholders).

The experience in Indiana is also being noted internationally. A presentation made on May 30, 2014 at the Third World Congress on Adult Guardianship was titled “Indiana Adult Guardianship Task Force: How a Highly Successful Collective Impact Initiative is Championing System-Wide Change in Guardianship Service Delivery.” The presentation was reported in Indiana Court Times.

Adult guardianship systems serve many more seniors than they do people with developmental disabilities. As a result, when reform efforts have occurred in some states, the needs and concerns of seniors have dominated the agenda.

For example, a Probate Task Force convened by the Chief Justice of California in 2006 made significant recommendations to reform the general conservatorship system which primarily serves seniors. Limited conservatorships, which serve adults with developmental disabilities, were not included in the work of the Probate Task Force. As a result, the many deficiencies of the Limited Conservatorship System in California continue to exist and the rights of limited conservatees continue to be violated.

Similarly, when the Pennsylvania Supreme Court decided to address various deficiencies in the adult guardianship system in 2013, it formed an Elder Law Task Force. By design, that Task Force did not address the needs and concerns of adults with developmental disabilities who are under the protection of the guardianship system in Pennsylvania.

The Disability and Abuse Project commends The Arc of Indiana and members of the Adult Guardianship Task Force for successfully promoting major reforms to the guardianship system in that state – reforms that will improve the lives of adults with developmental disabilities who are under guardianship.

We want similar efforts to occur in other states. For example, we envision a Task Force on Limited Conservatorships to be convened by the Chief Justice of California. Although California has often been a leader in protecting civil rights, in the case of guardianship reform for people with developmental disabilities, it lags behind.

The Chief Justice of California should look to Indiana as proof that a statewide Task Force is something to be done in all states. California should be next.
A statewide disability services organization may soon sponsor a bill in the California Legislature which, if adopted, would authorize medical service providers to recognize supported decision making or “SDM” agreements executed by patients who have disabilities. Such agreements would assist such patients to make their own medical decisions with the assistance of a support person designated by the patient in the SDM agreement. A medical SDM agreement is intended to be used, if possible, instead of a guardianship or a durable power of attorney for health care.

Prior to drafting legislation, proponents of such a bill should be clear about the purpose for the new law and have a basic framework in mind as to how it would operate in a medical context. Such a framework will inform the rest of the process of writing a bill and gaining support for it.

The Disability and Abuse Project offers the following suggestions as a “Framework for Model Legislation on Medical Supported Decision Making Agreements.”

1. The underlying purpose of such a bill is to provide a legal mechanism that would enable adults with disabilities to be at the center of medical decision making that affects their lives.

2. Another purpose is to establish legal requirements to inform participants in such medical decision making about their duties. This includes the person selected by the adult to provide support, as well as the professionals and staff who are involved in providing medical services to the adult.

3. Various legal principles should guide the drafting of legislation for medical SDM agreements:
   
   a. A medical SDM agreement is a contract between the adult and the person chosen by the adult to provide support for medical decision making.

   b. In such an agency agreement, the adult is the principal and the supporter is an agent who assists the adult to navigate through the medical decision making process.

   c. The agent assumes a fiduciary relationship with the adult and therefore has legal responsibilities as a fiduciary. Laws governing fiduciaries apply to this relationship.

   d. The agent is not a substitute decision maker but rather is assuming the role of a facilitator to help the adult make his or her own decisions. The agent helps the adult to communicate with the medical provider and helps the medical provider to communicate with the adult.

   e. Since this is a legal contract, the adult (principal) must have the capacity to enter into such an agreement at the time it is signed, and must have a basic understanding of the nature and consequences of such an agreement. The adult must in fact consent to the terms of the agreement at the time it is entered into.
When such an agreement is signed, there is a presumption of capacity to contract, but evidence may be produced at a later time showing that such capacity did not in fact exist at that time or that the adult did not in fact consent to the terms of the agreement when it was entered into.

Medical providers must allow the supporter to have access to medical information and records and must allow the supporter to assist the adult in making medical decisions.

Medical providers must not treat the supporter as a substitute decision maker, but instead as someone who is assisting the adult in making his or her own decisions.

When a medical decision is made, a medical provider has a legal and ethical duty to make sure that the adult has the ability to and is giving informed consent to the procedure. If there is a question about the ability of the adult to give informed consent, there must be further inquiry by the medical provider. If, after further inquiry, the provider is not satisfied that the adult is giving informed consent, then medical services may not be provided, absent an emergency situation, unless there is informed consent from another adult who has legal authority to make medical decisions on behalf of the adult, such as a guardian or an agent under a durable power of attorney for health care.

If, at any time, a medical provider has a reasonable doubt about whether the adult had the capacity to enter into the SDM medical agreement at the time it was signed, the provider shall inquire further. If further inquiry causes the provider to believe that such capacity was lacking, the provider may not provide services pursuant to that agreement.

Prior to performing medical services, a provider should ask the adult if he or she signed the SDM medical agreement and if it still represents the wishes of the adult or if it has been revoked. If the provider has a reasonable doubt about whether the adult has revoked or wants to revoke the agreement, there should be further inquiry. If further inquiry causes the provider to believe the adult has revoked or wants to revoke the agreement, the provider should not rely on that agreement for any purpose.

If, at any time, a medical provider has reasonable suspicion that the adult was under undue influence from another person at the time the agreement was executed or may be under undue influence at the time the decision is being made for a medical procedure, the provider shall inquire further. If further inquiry causes the provider to believe that undue influence has occurred or is occurring, the provider may not provide services pursuant to that agreement.

Thomas F. Coleman is the Legal Director of the Disability and Abuse Project. For more information: [http://disabilityandabuse.org/supported-decision-making.htm](http://disabilityandabuse.org/supported-decision-making.htm) Send your comments or questions to us at: [tomcoleman@disabilityandabuse.org](mailto:tomcoleman@disabilityandabuse.org)
June 23, 2014

Hon. Tani G. Cantil-Sakauye  
Chief Justice of California  
350 McAllister Street  
San Francisco, CA 94102

Re: Information on supported decision making and analysis of calls to repeal limited conservatorship laws

Dear Chief Justice:

I am writing to you in your capacity as Chair of the Judicial Council. This is a follow up to my previous letters to you dated May 15, 2014 and June 15, 2014, regarding limited conservatorships in California.

There are some organizations in California that are calling for the repeal of limited conservatorship laws. They want the Limited Conservatorship System to be “privatized” so to speak. They are promoting something called “supported decision making.”

Our Project believes there should be a proper balance between rights and responsibilities, protections and liberties, with only that amount of protection in any given case necessary to minimize the risk of abuse. We favor reform of the Limited Conservatorship System, not a wholesale repeal of it.

Since vague political calls for supported decision making as a substitute for conservatorships are starting to gain traction, we decided to look deeper into the matter. Our research reinforces our views that the Limited Conservatorship System should be reformed, not repealed. In fact, many of the principles involved in supported decision making are already a part of the limited conservatorship process.

I am enclosed three essays that I have recently written on these subjects. I am sending a copy of them to Justice Harry Hull, believing that he may want to share them with the Probate and Mental Health Advisory Committee since they are relevant to that committee’s evaluation of our request for the creation of a statewide Task Force on Limited Conservatorships.

Very truly yours,

cc: Justice Harry Hull
Encl: Three Essays

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