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 a 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

The abstract of this article, published in Australia, states: (Shih-Ning Then, "Evolution and Innovation in Guardianship Laws: Assisted Decision-Making," 35 *Sydney Law Review* 133 (2013))

"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."

"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 Advocates 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 persons mental incapacity has not already been predetermined, individuals should have all decisions referred directly to them. If there are doubts about a persons 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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