

Thinking Ahead Matters: Excerpts from a New Report on the Limited Conservatorship System

Except 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.³⁶ 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,”⁶⁷ 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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<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.



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- Sharp HospiceCare
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