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California's Double-Edged Sword:

Exploring Regional Centers, Limited Conservatorship Policies, and Implications for Adults with Intellectual or Developmental Disabilities

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ABSTRACT

Despite a growing area of research focusing on social inequities, people with disabilities are frequently left out of the discussion. People with Intellectual and Developmental Disabilities (I/DDs) are especially marginalized and are at risk for having their civil rights limited or terminated as a result of such a diagnosis. In this study, I use Critical Disability Theory to analyze data collected from 16 surveys and 10 interviews of representatives of the 21 Regional Centers in California. I examine how these Regional Centers implement policies relating to restricting or terminating the civil rights of people with an intellectual or developmental disability, known in California as limited conservatorships. I find that different interpretations of the laws and budget constraints contribute to making limited conservatorship process non-individualized and highlight an extreme disconnect between the law in writing and the law in practice.

Keywords:

Adult guardianships, Critical Disability Theory, limited conservatorships, human services, intellectual and developmental disability, disability rights

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INTRODUCTION

In 2014, 39.7 million people, 12.6% of the population, reported living with one or more disability in the United States (Disability Status Report 2014). While the nature, degree, and form of a disability can vary, one commonality is that once disabled, a person is labeled as being impaired either physically or mentally. In some cases, whether or not a disability is impairing a person's decision making skills is questioned, and sometimes results in the assignment of a conservator or guardian[1]. Conservatorships, also known as guardianships outside of California, are judicial proceedings that result in civil liberties being legally restricted or terminated if a person is declared unfit (Hunsaker 2008).

There are three main types of conservatorships in California: General, Limited and Lanterman Petris-Short (LPS). LPS conservatorships are used when adults with serious mental health concerns, like chronic mental illness, are a risk to themselves or others (CANHR 2014). People under a LPS conservatorship can be involuntarily committed to a mental hospital, commonly known as a '5150'. Hunsaker (2008) explains that general conservatorships are utilized for adults who are considered completely incapacitated, and are generally used for elderly adults who are no longer able to manage any of their affairs. Limited conservatorships are only used for adults that are diagnosed with an intellectual and/or developmental disability.

The State of California (2014) defines intellectual and developmental disabilities as chronic impairments that begins before the age of 18. These include autism, cerebral palsy, intellectual disability (formally known as mental retardation), epilepsy (seizures), and other

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[1] California refers to conservatorships when an adult has had their liberties being legally restricted or once declared unfit. Conservatorships are also known as and referred to as guardianships in other states. This should not be confused with California's use of 'guardianship' that refers to minor children, not adults. Since much of the research discussed in this paper focus on locations outside of California, I will refer to both conservatorships and guardianships of adults.

related conditions, such as traumatic brain injuries. Not all of these diagnoses involve cognitive impairment and the inability to communicate verbally is not a reflection of having a cognitive delay.

Hunsaker (2008) explains limited conservatorships were specifically designed to limit the power of a conservator to only the control certain areas, not the whole person. This is because intellectual and developmental disabilities impact everyone differently. In other words, California recognized that not all people with intellectual and developmental disabilities need help making choices; and if they did need support it should not be assumed they need help in all areas. The intent of limited conservatorships was to ensure that civil rights were not removed without considering the individuals unique circumstances. Limited conservatorships designate seven powers [rights] that can be terminated and assigned to someone else. These include: 1) the right to choose living arrangements, 2) the right to make medical decisions, 3) the right to contract, 4) the right to make educational and occupational decisions 5) the right to marry 6) the right to confidential records, and 7) the right to manage social and sexual relationships.

My interest in limited conservatorships is the result of personal and professional experiences. I self-identify as being neurodivergent, which is another way of saying learning disabled. The concept of neurodiversity was developed by Steve Silberman's in *NeuroTribes* (2015) which argues that differences in neurology should be expected and should not signify weakness. Attention Deficit Hyperactivity Disorder (ADHD), autism, Asperger syndrome or dyslexia are all examples of neurodiversity. Years of navigating the special education system expanded my understanding of what it means to be labeled "special", seen as less, and therefore segregated.

Childhood experiences led me to spend over 15 years working with people with intellectual and developmental disabilities in a variety of settings. Nine of these years were spent working for two of the 21 Regional Centers in California-- private, nonprofit agencies that fund and coordinate services for people with intellectual and developmental disabilities in California. All Regional Centers are governed by The Lanterman Act which guarantees people with intellectual and developmental disabilities have the same rights as other Californians. Part of Regional Center's duties include assessing the need for limited conservatorships once requested by a family member, friend, or professional.

The different experiences I had with limited conservatorships while working at Regional Centers makes me view them as a double-edged sword. On one side, limited conservatorships provided a legal way to intervene when an adult was at risk for abuse. On the other side, many limited conservatorships were established without need or due process and did not guarantee protection as intended. I saw that the law was not always being implemented as it was designed. Limited conservatorships are meant to be seen as restrictive and as a last resort, yet in my experience, this law was not always prioritized or even followed. This led me to the question: How do Regional Centers implement limited conservatorship policies?

STATEMENT OF THE PROBLEM

Over the last twenty years there have been 272 bills on guardianships voted into law throughout the United States; however, there is not a single federal law in place guiding the way states handle guardianship proceedings (Millar 2013; Moye and Naik 2011). My experience in special education and case management experience at two Regional Centers has led me to focus on the I/DD population as this minority continues to be underrepresented.

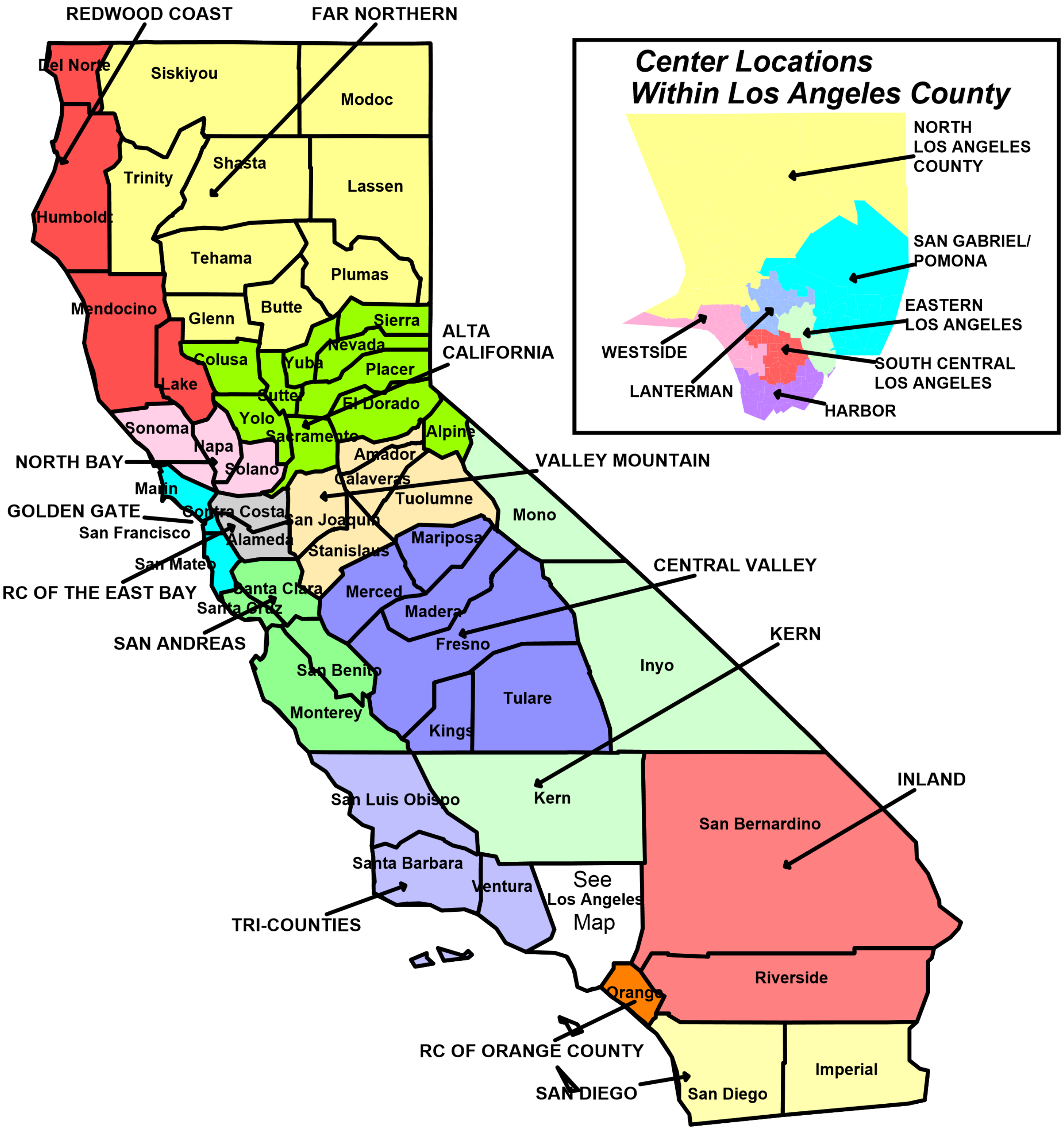
The Lanterman Act and Regional Center System in California

The Lanterman Act contains all of the laws and policies developed by California for persons with developmental disabilities and was developed as result of the state accepting responsibility to care for its developmentally disabled citizens. The Lanterman Act, which is comprised of California's Welfare and Institution Codes sections 4500-4906, is currently implemented/governed by the Department of Developmental Services (DDS), which is overseen by the California Department of Health and Human Services (CHHS). This law grants people with intellectual and developmental disabilities the same rights as everyone else. The Lanterman Act states that service recipients, or clients, are free to make their own choices (i.e., they are self-determined), and requires that they are informed of their rights and receive services in the least restrictive environment (California Welfare and Institution Code 4502). Least restrictive measures ensure that services are provided in order to maximize independence and productivity in the most inclusive setting.

The Lanterman Act is implemented by specialized medical agencies, Regional Centers, that provide diagnoses, counseling, case management, and referrals to services available in the community (State of California 2014). Regional Centers are private, non-profit corporations contracted by DDS to provide advocacy and referrals, as well as funding, for direct services provided to children and adults with developmental disabilities. Each Regional Center creates and implements its own purchase of service guidelines, hiring/training standards, and policies and procedures, all of which are guided by the Lanterman Act and related state/federal laws.

There are 21 Regional Centers located throughout California that have their own designated service areas. All the Regional Centers are all required to implement the Lanterman Act, but each is free to decide how they implement it. In other words, all Regional Centers have the same duties, but they each choose how they achieve those duties. This is important when considering that Los Angeles County has seven Regional Centers alone, meaning services could be different for people living within the same county. Exhibit 1 is a map displaying the geographic service area of each Regional Center.

Exhibit 1: Map of California Regional Centers
(Colors correspond to areas served by each Regional Center)



*Retrieved from http://www.dds.ca.gov/RC/docs/rcdcmap2.pdf (State of California 2014).

Limited Conservatorships in California

In California, guardianships refer to minors, while conservatorships refer to adults (Laham 2014). Hunsaker (2008) explains conservatorships are legal proceedings that result in civil liberties being restricted or terminated. There are two different types of probate conservatorships in California, general and limited. General conservatorships are generally used for the elderly who, due to some medical issue (e.g., dementia), are no longer able to manage their own affairs,in this case the courts grants general conservatorship over the whole person and estate. Limited conservatorships are specifically designed for those with intellectual and/or developmental disabilities (Hunsaker 2008). Limited conservatorships remove only certain rights from the individual (the conservatee) and grant those powers to someone else (the conservator).

To refresh, the 7 powers, or rights, that can be terminated include: 1) The right to choose living arrangements. This means the conservator can decide where the conservatee lives and with whom; 2) The right to consent to or refuse medical treatment. For example, deciding whether or not the conservatee uses birth control; 3) The right to enter into contracts. This means the conservator controls whether the conservatee can sign up for a cell phone, lease an apartment or sign for magazine subscription; 4) The right to make educational and occupational decisions. For example, the decision about whether the conservatee leaves school at age 18, or continues through age 22; 5) The right to marry. This means the conservator can decide if the conservatee gets married and to whom; 6) The right to confidential records, which means that the conservator can access the conservatee’s private records including medical and financial records and social worker notes; Finally, 7) The right to manage social and sexual relationships, which means that the conservator controls with whom the conservatee is allowed to socialize and have sexual contact.

Guardianships and conservatorships are intended to be used as a last resort and are considered very restrictive measures (Millar and Renzaglia 2002; Moye and Naik 2001). Disability Rights California (2015) discusses many less restrictive alternatives that could reduce the need for conservatorships. As discussed prior, supported decision making is a common alternative and is used by most adults, disabled or not. Power of Attorney allows an individual to assign someone else to make financial or medical decisions and Special Needs Trusts can protect financial assets while maintaining federal and state benefits. Additionally, Advanced Health Care Directives can be completed to assist with medical decisions and Regional Centers are allowed to authorize some medical and surgical care in certain situations.

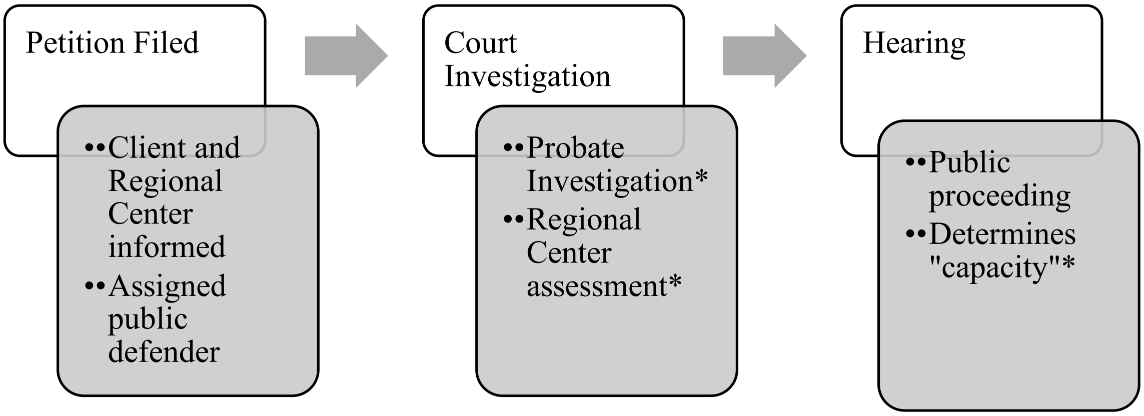
Process of Establishing a Limited Conservatorship

The process for requesting a limited conservatorship~~s~~ is primarily governed by the California Probate Code~~s~~ and is only mentioned once in the Lanterman Act (Coleman 2014). Exhibit 2 is a diagram explaining this process. The conservatorship process is initiated when someone, typically a parent or sibling (although anyone can request conservatorship), petitions to be appointed conservator over a proposed conservatee (Hunsaker 2008). Non-profits, government agencies, and professional conservators, also known as professional fiduciaries, can also request and act as a conservator (CANHR 2014). Limited conservatorship petitions must include evidence supporting why the conservatee is not able to care for him/herself and must list why alternatives are not suitable (CANHR 2014). The proposed conservatee and the Regional Center serving the proposed conservatee are provided with copies of the petition.

Once someone has petitioned the court for conservatorship over an individual, a formal hearing is scheduled and the proposed conservatee is assigned a public defender (California Probate Code 1471; Hunsaker 2008) and a court investigator (California Probate Code 1826; Hunsaker 2008). The court investigator is responsible for explaining the petition and court process to the proposed conservatee and makes assessments and recommendations to the court regarding the petition (Hunsaker 2008). California Probate Code 1827 requires the appropriate Regional Center to submit a report to the court prior to the hearing (Hunsaker 2008). This report is to consist of a summary of the client's functioning level and whether or not the Regional Center supports the need for conservatorship (CANHR 2014).

The final step in the limited conservatorship process is the hearing where a judge decides the final outcome of petition. Hunsaker (2008:5) explains that petitions are granted when a judge finds that "…the proposed conservatee lacks the capacity to perform some, but not all, of the tasks necessary to provide properly for his or her own financial resources." These hearings are public proceedings and become part of public record (CANHR 2014).

Exhibit 2:



*** Represents area where discretion is exercised**

Information compiled from CANHR 2014 and DRC 2015

Gaps in Policy Implementation and Regional Center Autonomy

As noted previously, there are twenty-one Regional Centers in California and they each are free to decide how they address and implement limited conservatorship policies, such as the fulfilling their reporting requirement with the court. The Disability and Abuse Project reports that there are 4,000 limited conservatorship requests made in California each year (Coleman 2014), which means that Regional Centers are responsible for assessing the needs of 4,000 adults with intellectual and developmental disabilities. One would think that reports of this nature would be orderly, clear, and objective, to ensure that removing civil rights is the last resort. In my experience, this was not the case.

I will now provide three scenarios that help explain and clarify how limited conservatorships double-edged- and can be a source of both protection and abuse. These examples are based off of my experiences, but names and some details have been changed to protect location of Regional Center and client's identity.

> Scenario1: At RC1, Karen was an 18-year-old white female with a diagnosis of moderate intellectual disability. Karen had been sexually abused as a child and once she turned 18, the alleged abuser reached out to her and asked her to move across the county so they could be together. Since Karen was over 18, she was legally allowed to fly across the country to live with a man who had previously abused her. Karen did not understand this and was ecstatic by the fact that a man would give her attention. In order to protect this young woman, the Regional Center in her area initiated the conservatorship process and paid for a private nonprofit agency to act as her conservator. The Regional Center made its case to the court and the judge agreed that a conservatorship was needed. Crisis avoided; Karen did not move across the country and we were able to legally intervene and assist her in obtaining a restraining order against the abuser.

> Scenario 2: At RC2, Eric was a 32-year-old black male with a diagnosis of moderate intellectual disability. Eric was able to verbally communicate his needs and held a paid job in the community. Eric lived in a group home in the community and his aunt would come visit him regularly. It was brought to my attention by group home staff that his aunt

always took Eric's cash and never provided receipts for where his money was spent. She also took his new iPad and replaced it with her old, broken iPad. After challenging the aunt's intention, she argued that Eric was an adult and was choosing to give her his hard earned money and TV, and was legally allowed to do so. When I mentioned my concerns of financial abuse to the client's rights advocate, who is an attorney who specializes with the I/DD population, she regretfully had to agree with the aunt and stated that legally he was an adult and Regional Center had no authority to intervene based off financial abuse. When I approached management on the idea of initiating a conservatorship through a professional agency, I was immediately led on with hopes of developing a new resource, but inevitably ran into systemic roadblocks that prevented development of a valuable resource.

Scenario 3: At RC2, Bob was a white male in his mid-60s diagnosed with mild intellectual disability. He had lived in the same home and had the same job for over twenty years. He was also able to verbally communicate his needs and wants. Bob's elderly mother had a disagreement with the group homeowner regarding medication. Instead of having a meeting to discuss concerns, the mother requested five areas of limited conservatorship and was granted all seven. Once she had been granted conservatorship she removed him from his home and job without notice and moved him back home with her. In this case Regional Center supported none of the five powers requested and indicated in their report that they did not agree that conservatorship was needed, however the public defender Bob was assigned did believe Bob needed a conservator because he was not able to read. The court granted family all seven powers, even though only five were requested.

The intent of sharing these stories is to highlight that such proceedings can be used to help protect adults with I/DD like Karen, but can also result in civil liberties being improperly removed or restricted like in Bob's case. Furthermore, individuals like Eric are left unprotected because no one will take legal steps required in order to protect him.   These complications are heightened when agencies such as the Regional Center are granted discretion to determine their level of involvement and level of priority given to conservatorship requests.

Some policies are proving to be problematic as some people with intellectual and developmental disabilities are left more vulnerable than others. For example, Rousseau (2010) reported that the average cost to establish a conservatorships in California is $1,500-$2000. This also makes conservatorships more available to those from a high socioeconomic status leaving those from a low socioeconomic status more vulnerable to abuse. Additionally, it places those from a highe socioeconomic status at higher risk of being conserved as their families have the financial means and knowledge to do so.

The assessments completed by Regional Centers serve as tools to provide the court with red flags regarding the actual need for conservatorship, as well as red flags regarding the appropriateness of the proposed conservator if someone other than family is the petitioner. This reporting requirement is a crucial component to the conservatorship process as it initiates communication between agencies. However, the amount of time and training that that goes into writing these reports can vary at each Regional Center, creating room for disparities.

Another responsibility of all Regional Center case managers is to advocate for their clients and ensure that clients are fully aware of their rights (California Welfare and Institution Codes 4502, 4640.6). Disparities exist in the way each Regional Center chooses to share valuable knowledge as each develops its own procedures for doing so. For example, some

Regional Centers require in-person meetings are held before making recommendations, and others do not, meaning some clients receive more knowledge than others. This discretion reflects a disproportionate amount of power as Regional Centers are in control of who receives critical knowledge and vital support.

Based on the autonomy granted to each, it is hard to ignore the potential for dramatic variation in implementation of limited conservatorships across Regional Centers. There is no universal understanding of how each Regional Center implements reporting obligations to the courts. This leaves room for Regional Center workers themselves to take their duties related to this process lightly and results in Regional Center employees having the discretion to decide how much time and energy they put towards considering conservatorship petitions. In other words, current policies do not ensure that each conservatorship request receives the same level of attention and due process.

There has been an increase of media attention surrounding the need for reform of conservatorships and guardianships. Corey, Lodise, and Stern (2007) review the history of guardianship reform and highlight the risk of using professional conservators, such as improper management of estates and lack of regulations. Sherer (2006) also exposes many risks associated with conservatorships and guardianships including financial abuse, fraud, and numerous civil rights violations. Additionally, the Associated Press (2014) reported that in a sample of sixty-one limited conservatorship cases in Los Angeles, ninety percent of conservatees had been disqualified from voting.

This little explored topic is an important one because it involves potential restrictions on a person’s civil liberties. Focusing on the Regional Centers’ role in conservatorship process is appropriate due to the level of discretion each has when implementing policies related to the process. Lack of streamlined policy among Regional Centers may compromise the rights granted to people with intellectual and developmental disabilities by the Lanterman Act.

LITERATURE REVIEW

Research on disability is its own field, but is also being acknowledged in other academic fields including sociology, education and even architecture (Meekosha and Shuttleworth 2009). While disability literature is growing in some areas, research on people with intellectual and developmental disabilities is limited and generally addresses approaches to treatment and ethical implications faced by researchers. Many studies on guardianships specifically focus on the elderly, while research related to individuals with intellectual and developmental disabilities as well as research on guardianships/limited conservatorship process is scarce (Millar 2013).

In this literature review, I will first consider the current studies on limited conservatorships and guardianships. These studies are very limited, but reflect a growing social interest in the topic. Second, I will review literature on the historical approaches to disability with a focus on civil rights. This literature focuses on the tension between the medical and social model of disability and resulting policies such as the Americans with Disabilities Act (ADA 1990). Finally, I will consider the role of governmental agencies in conservatorship processes. The proposed study will be a valuable contribution to the body of literature that examines the gap that exists between policy on paper and policy in practice.

Conservatorships and Guardianships

There are only five data-based articles addressing guardianships and I/DD (Jameson et al. 2015). The majority of literature on limited conservatorships and guardianships revolves around the elderly, transition out of public education and the potential for abuse (Millar 2013). Current literature also highlights problems associated with the guardianship process and the lack of federal guidelines.

Jameson et al. (2015) conducted a web-based survey on guardianships and found that 50% of guardianship cases had been recommended to parents by professionals such as teachers.

Of these professionals, 60% had not received any formal training related to guardianships. They also concluded that assumptions regarding people with intellectual and developmental disabilities lacking capacity to make decisions contributes to their civil rights being improperly terminated.

Dorothy Squatrito Millar (2013) conducted research on guardianships and use of alternatives. She explains how the last two decades of empirical research focus on the importance of self-determination while states attempt to limit use of guardianships, but highlights the disconnect reflected by minimal research conducted on guardianships of people with intellectual and developmental disabilities. Additionally, Millar (2007) conducted a focus group that found persons with intellectual and developmental disabilities and their parents had limited understanding of the guardianship process. This challenges the claim that all alternatives are to be explored prior to guardianships being granted and supports Jameson et al. (2015) findings that lack of federal guidance creates the opportunity to prioritize governmental needs above the needs of a human being.

Considering that the law requires that each case is considered on an individual basis and used as a last resort, it may be assumed that the conservatorship process would ensure due process and great care to preserve civil rights. However, Millar and Renzaglia (2002) found guardianships proceedings typically lasted seven minutes and resulted in guardians being appointed each time. Other studies including Millar and Renzaglia (2002), Millar (2007) and Millar (2013) cite concerns that assessments presented in guardianship hearing were confusing and standardized. Such studies may be modest, but the implications are clear; the process of terminating or restricting civil rights of people with intellectual and developmental disabilities is not individualized.

Conflicting Models of Disability

Current policies related to disability are framed through medical and social models of disability. The medical approach was initially utilized to cure people of their "condition" and was the primary model used through the 1960s. The social model became the preferred model during the Civil Rights Movement. This approach aimed to create equality for people with disabilities. Considering the socio-historical context of these models and civil rights helps explain why guardianship policies remain contradictory and ineffective.

The medical model of disability (1900s-1960s)

Prior to the 1900s people with intellectual and developmental disabilities generally lived within the community and were not seen as a threat in spite of being considered deviant (Carey 2009). The extent that they were able to exercise their personal rights was dependent on their perceived level of competence, family support, and class status (Carey 2009). Institutions existed, but they were utilized as a last resort and only after court proceedings declared individuals unfit to manage their own estates (Carey 2009). In other words, people with intellectual and developmental disabilities were seen as inferior, but were not all labeled incompetent nor were they all segregated.

The Industrial Revolution and rapid growth of capitalism created a shift in public opinion. Carey (2009) explains that "…capitalism required the differentiation of able-bodied and disabled, productive and non-productive." (48). This form of rationalization established the stereotype that persons with disabilities are inferior, incapable and a financial burden on society (Carey 2009; Devlin and Pothier 2006). Brosco and Feudtner (2011) summarized, "By the early 1900's the 'feebleminded'-- a catch-all term for idiots, imbeciles, and morons-- became associated in the public mind with drunkenness, poverty, criminality, and sexual promiscuity, and state institutions grew rapidly in size to protect society from people with cognitive impairment" (54). This train of thought led to the beginning of segregation and dehumanization of people with intellectual and developmental disabilities.

Institutions created during this time aimed to provide professional medical treatment to those in need while simultaneously protecting civilized society from them (Brosco and Feudtner 2011; Carey 2009). The goal of these institutions was to diagnose, prevent, cure and ease symptoms of disability (Barnes and Mercer 2013; Carey 2009). Laws were passed on state and federal levels that eliminated many of the rights people with intellectual and developmental disabilities had previously been entitled to, and eugenics was a common goal among medical professionals (Barnes and Mercer 2013; Brosco and Feudtner 2011; Carey 2009).

The medical approach to disability relies on binary categories and labels to establish and guide treatment and support (Barnes and Mercer 2013; Delvin and Pothier 2006). It established categories for "normal" and "not normal" and, "healthy" and "not healthy". Such categories leave no room for in between. For example how would a person who communicates with American Sign Language respond to the question, "Verbal or Non-Verbal"? Stewart and Ward (2008) argue, when it comes to intellectual and developmental disabilities, the medical model ignores "…intrinsic factors such as the nature and severity of the impairment and contextual factors such as attitudes of others" (303).

Categorical thinking severely impacted the extent that people with intellectual and developmental disabilities could exercise their civil rights. Being diagnosed with an intellectual or developmental disability brings an automatic assumption of incompetence; therefore making rights to decision making irrelevant (Stewart and Ward 2008). This is supported by studies that found people with intellectual and developmental disabilities are frequently denied opportunity to make basic choices, like where they live and spend their free time (Stancliffe et al. 2011;

Stewart and Ward 2008). These findings clearly show how generalized assumptions of incompetence actively contribute the marginalization of people with intellectual and developmental disabilities (Rood, Kanter and Causton 2015).

The social model of disability (1960s-1990s)

The medical model of disability was replaced by the social model in the 1970s, which argues that disabilities are not the problem, society is (Harpur 2011). For example, the social model would see the lack of a ramp the problem, as opposed to the person in the wheelchair. This model was advanced by medical sociology theorists like Mike Oliver and Irving Zola (Barnes and Mercer 2013). Policies established during this time aimed to end institutionalization, increase community integration and maximize independence of those with disabilities (Barnes and Mercer 2013; Carey 2009; Devlin and Pothier 2006) and were influenced by other social movements such as the Civil Rights Movement (Barnes and Mercer (2013).

The social model places high importance on maximizing independence and promotes self-determination and autonomy (Jameson et al. 2015). While well intentioned, it does not provide enough protection for individuals who are more vulnerable than others nor does it address other critical issues such as gender and class (Carlson 2013; Shakespeare 2010; Stewart and Ward 2008).

For example, Drew (2013) found that women with multiple disabilities were more likely to undergo a hysterectomy when compared to those with no or one disability and Watkins (1995) reports that parents labeled as developmentally disabled are more likely to have their parental rights terminated when compared to parents who are not labeled similarly. Such findings highlight the way some of the ways people with I/DD face differential treatment across a variety of identities, but continue to be left out of current research.

Policies established during the disability rights movement aimed to level the inequality created through the medical model. Laws such as Lanterman Act (1969), Rehabilitation Act (1973) and Individuals with Disabilities Education Improvement Act (2004) all claim to help people with disabilities access equal rights and opportunities. However, 28.1% of working age people with a disability were living in poverty in 2014 (Disability Status Report 2014). Such statistics challenge the claim that all people have equal opportunities and reflects that people with disabilities continue to be disadvantaged when compared to those without.

What these laws did not take into account is society's reluctance to include people with disabilities. Being included in the general population or community does not ensure that individual needs are met and does not guarantee acceptance or success (Devlin and Pothier 2011:65). The Disability Status Report (2014) states 21.6% of individuals with a disability work full-time, compared to 57.6% of those without a disability. The same report also shows that the median income for households including a disabled person was $40,200, compared to $64,100 for households that do not include a disabled person. Ignoring a biased and resentful community places individuals with intellectual and developmental disabilities at risk for discrimination. Clearly, inclusion has not secured equality or prevented discrimination.

Implications of Service Delivery

Dean Spade's concept of distribution of life chances as discussed in *Normal Life* (2011) and Michael Lipsky's concept of street-level bureaucrats as discussed in *Street-Level Bureaucracy* (1985) are central to this research. These two concepts refer to employees of service agencies (e.g. Regional Centers) who are free to use discretion when approving services. Examples of such agencies include schools, prisons, welfare services, social services, and individuals who administer them like police officers, public defenders, judges and teachers. Spade (2011) and Lipsky (1985) argue that the discretion granted to individuals in these positions of power are free to pick and choose who gets the majority of their time and services. Additionally, these people in power are free to act out in racist and sexist ways because bureaucracies protect individuals from being held accountable for individual actions. Research supports that individual actions within these agencies have a critical impact on the service recipients as outcomes depends on the person in power, not the service recipient (Carey 2009; Lipsky 1985; Spade 2011).

Policies driven by the social approach to disability mandate that people with intellectual and developmental disabilities live and participate in society in the least restrictive environment possible (Spade 2011; Turnball 2012). However, budget constraints limit how this can be realistically implemented. In theory, any person with an intellectual or developmental disability could live in an independent living environment, such as an apartment. The problem arises when the cost to keep an individual in their own apartment exceeds the cost of an alternative placement option, such as a community group home. Service agencies simultaneously aim to place clients in the least restrictive environment in the most cost effective manner. Such contradictory aims contribute to the agencies' power by preventing genuine autonomy (Carey 2009; Turnball 2012).

As discussed previously, Regional Centers are responsible for assessing the appropriateness of the conservatorship request and reporting these findings to the court. The Regional Center's report is to consist of a summary of the client’s functioning level and whether or not it supports the need for conservatorship (CANHR 2014). This is a very high level of individual discretion held by the case managers (Lipsky 1985). The views of Regional Center employees will be biased based on each employee’s own experiences as well as by the lack of streamlined training.

Hafemaster and Sales (1984) highlight concerns associated with state agencies' measuring capacity. They point out that relying on professionals to measure capacity to make decisions results in “absolute discretion” being granted to the professional completing the competency assessment. By defining capacity, a baseline to measure competence is established. This baseline is seen as the norm, and having been established, places people with intellectual and developmental disabilities at risk of having their civil liberties terminated (Spade 2011).

Roulstone (2012), Dowse (2009), Downes (1992), Ward and Meyer (1999) all reflect concerns regarding professionals controlling the lives of people with intellectual and developmental disabilities. They argue that service agencies were put in place to help ensure people with disabilities have choices, but in practice become the ones who make the most decisions. Such studies support the argument that current policies fail to deliver the equality granted to people through laws such as the ADA (1990) because social agencies are the ones holding the power due to the structure of service delivery.

Institutional paternalism has resulted in learned dependence and presumed incompetence. Limited conservatorship policies do not account for the paternalistic view society holds regarding those with disabilities. Jameson et al. (2015), Payne-Christiansen and Sitlington (2008), and Rood et al. (2015) all found that naturalized presumption of incompetence contributes to people with I/DD having their rights unjustly restricted or terminated. Millar (2013) and Rood et al. (2015) suggest historical paternalism must be addressed through training parents and professionals on alternatives to guardianships.

Review of current research reflects large gaps that exist between policy written in the books and policy practiced on the street and confirms ample space for further research. Jameson et al. (2015) reported a need to study guardianships beyond state levels. Additional research on differences in legislating and regulating conservatorships among states could explore and highlight new or subtle trends. Researching the impact state agencies, like the Regional Centers, have on individuals with intellectual or developmental disabilities will benefit this population by providing much needed data. Further research can be used to contribute to public education and training of service professionals on guardianship alternatives (Millar 2013).

CRITICAL DISABILITY THEORY

Frameworks currently guiding disability policy contribute to ineffective protection measures due to contradictory goals and failure to capture the various dimensions of disability. The Lanterman Act reflects the impact of contradictions as it aims to increase the independence and freedom of people with I/DD but fails to ensure Regional Centers have the resources they need to perform limited conservatorship policies. Critical disability theory provides a sturdy foundation for exploring how Regional Centers implement limited conservatorship policies.

Critical disability theory (CDT) was inspired by a variety of social movements like Women's Rights Movements and theories, such as critical race theory, feminist theory, and queer theory. These smaller, identity subsets of general critical theory address concerns relating to specific minority groups (Hosking 2008). CDT is critical in nature as it argues that political and economic oppression as contributing to the social control of people with I/DD and that outside factors, such as racial biases, influence legal decisions. Identity politics, like critical race theory, also contribute to CDT's foundation as critical legal studies frequently failed to address needs of oppressed minorities. In other words, CDT combines legal theories with identity theories creating a solid framework that connects theories from different disciplines that applies interdisciplinary and practical approach to disability.

CDT addresses seven factors that counter ineffective disability policies and continued oppression towards those who live with disability. These include: choice of model, multidimensionality, diversity, rights, voices, language, and transformative politics (Hosking

2008:5). Each element addresses its own concept that attempts to address problems faced by this population and society's role in creating and exacerbating such problems.

Choice of model

As discussed earlier, current policies are primarily based of the medical model of disability claiming that disability is biological in nature; or the social model of disability which claims that disabilities are not real and are socially constructed (Barnes and Mercer 2013). CDT suggests the social model of disability with the understanding that some disabilities can result in real impairments, like pain. In other words, CDT accepts that disability is both socially constructed and biological. This model, or approach, is called the "biopsychosocial model" by the World Health Organization (7) as it combines both the medical and the social models. Combining the models allows for a more inclusive approach to disability that acknowledges that disability is both medical in nature and socially created and both must be addressed for progress (Meekosha and Shuttleworth 2009).

Multidimensionality

Multidimensionality is the result of combining the concepts of intersectionality and hybrid intersectionality (Hosking 2008). Hosking (2008:9) explains Kimberlé Crenshaw's idea of intersectionality as "…the intersection of one axis of oppression with another." In other words, experiencing two separate forms of oppression. For example an individual who is disabled and woman faces is faced with sexism and ableism while a disabled white man is only faced with ableism. Another example would be persons with higher socio-economic status (SES) may have the ability to privately pay for services, while people with lower SES do not have that privilege (Carey 2009), which is an additional problem they must face.

Hosking (2008:9) goes on to explain Nancy Ehrenreich's idea of hybrid intersectionality as "…the intersection of an axis of privilege with an axis of subordination". Hosking goes on to provide the example of a "…privileged white, young adult, heterosexual man might experience the subordination of disability but he may well experience a relative privilege over a person disabled from birth who has another axis of subordination." (10). To summarize, CDT acknowledges that individuals all experience different levels of privilege and penalty (Hill Collins 1993).

Diversity

The element of diversity is also addressed with critical disability theory by challenging the urge to categorize people based on diagnosis and places value on personal experiences, not labels (Hosking 2008). It acknowledges invisible disabilities, such as dyslexia, and addresses the risks associated with openly identifying as disabled (Devlin and Pothier 2006). Carolyn Tyjewski explains hybrids as those who don't fit into pre-established categories such as a legally blind person who still has vision (Devlin and Pothier 2006). Another example would be people who are able to walk, but still use disabled parking signs. Not all disabilities are visible, and ignoring differences "…usually has the effect of rejecting and marginalizing the person" (Hosking 2008:11). CDT challenges the belief that a disabled person should conform to societal norms by understanding the importance that diversity should be seen as unavoidable but also accounts for the fact that "…difference should not just be dismissed as irrelevant, because ignoring the difference usually has the effect of rejecting and marginalizing the person" (Hosking 2008:11).

Rights

Critical disability theory also directly confronts the issue of rights and exposes the ways in which current policies are failing to balance rights with need for protection (Hosking 2008). CDT addresses that fact that in reality, not all people with I/DD are able to make decisions that will ensure their safety, success and independence. It calls for understanding that all people are independent and interdependent creatures and that this understanding will help protect those who are more vulnerable than others. For example, having the right to vote does not guarantee that people are able to get themselves to a polling location.

Voices

People with intellectual and developmental disabilities have a particularly hard time with having their voices heard (Hosking 2008). This could be due to the nature of the disability or due to limited access and knowledge of resources or the lack of and disorganization of self-advocate movements (Ward and Meyers 1999). CDT acknowledges the historical marginalization faced by people with intellectual and developmental disabilities and encourages researchers and service agencies to create space for their voices to be heard and prioritized. An example of this would be Regional Center clients being given the opportunity to voice their opinions on whether or not they agree they need a conservatorship and ensuring that this opinion is heard and respected.

Language

CDT also draws attention to how the language used to label and portray individuals with disability has a direct reflection on their status. It accounts for negative connotations associated with certain labels and addresses the impact of such portrayals (Hosking 2008). CDT acknowledges the power dynamics that exist between people with intellectual and developmental disabilities and the institutions created to manage them. An example of this would the common assumption that all developmental disabilities involve cognitive impairment.

Transformative Politics

The final element that completes CDT is that it highlights how the law is written differs from how it is carried out in practice. The use of contradictory language in disability related policies, such as “least restrictive” and “cost effective”, allows the policy on the books to be in contrast with the policy in action. Policies written with contradictory language allows agencies to avoid responsibility by allowing them to blame unpopular decisions on the wording of law. Limited conservatorship policy is also an example of this as the state law requires alternatives are exhausted, but does not provide a streamlined approach to accomplishing such, resulting in disparities. Critical disability theory draws attention to the contradictory policies in place today and provides the theoretical basis for making changes (Hosking 2008). In other words, CDT acknowledges that laws and policies that were created to ensure equality may actually be contributing to inequality through their implementation.

Application of Critical Disability Theory

Critical disability theory is the most appropriate framework for my research due to its interdisciplinary and structural nature. It addresses many of the issues I experienced throughout my career including the contradictory approaches to disability and level of power held by state agencies providing services to people with intellectual and developmental disabilities. Additionally, CDTs roots in legal theory and its political nature are appropriate when exploring how Regional Centers implement legal policies. CDT provides a lens that addresses the problematic areas I experienced related to service implementation by, 1) considering and resolving the overall approach to disability (combines medical and social models); 2) establishing that diversity and multidimensionality should be expected and celebrated; 3) prioritizing the voices and requests of people with disabilities as opposed to policy makers; and finally, by acknowledging the political nature of disability by pointing out the importance of language used in disability policies and by prioritizing the maintenance of civil liberties.

CDT and my experiences have guided my approach to this research. The focus on civil rights and impact service agencies have on those served intends to explore structure of service provision. Questions will be looking at how institutions deliver services and the level of priority given to services related to conservatorships. Additionally, the intent of this research is to create knowledge that could assist in creating policy changes.

METHODS

I used multiple methods to conduct this research, consisting of a web-based survey and semi-structured telephone interviews with Regional Center representatives. Utilizing an online survey was most appropriate due to its efficiency and affordability (Schutt 2012) as traveling throughout California is timely and expensive. Surveys were followed up with semi-structured interviews with willing respondents, which added depth to descriptive statistics by providing stories behind the numbers (Seidman 2013). The personal and political nature of this topic required a critical and fluid approach. This approach provides the most appropriate foundation to explore this topic by creating space for both quantitative and qualitative data.

Survey

The survey utilized was created online via Survey Monkey and consisted of 21 open and closed-ended questions. Contact with each Regional Center was initiated by calling the Executive Director's Office directly via telephone. Of the 21 Regional Centers contacted, two declined to participate due to budget, or staffing constraints and one did not reply. Eighteen executive directors agreed to participate in the survey and designated a point of contact. From this point an email was sent which included an information sheet and a link to the survey. Participants were given four weeks to complete the survey and were sent up to three reminders, as needed, prompting them to complete the survey.

Of the 18 surveys emailed, 16 were completed resulting in a 76% response rate. Survey participants had different roles at the Regional Centers they represented including administrative assistants, risk managers, directors of case management and executive directors. Participants were spread throughout California and included four in northern California serving 43,000 individuals, five in central California serving 65,000 individuals, and six in southern California, serving 114,000. Of the five Regional Centers that did not participate in survey included: one in northern California that serves 7,000 individuals; one in central California that serves 19,000 individuals; and three in southern California that combined, serve 35,000 individuals. Those who participated in the survey automatically received a chance to win an Edible Arrangement valued at $50.00 through a raffle. Participation was measured in terms of anyone who sent a survey back to me, even if the survey was only partially completed.

Interviews

The 13 individuals who agreed to participate in the interviews after completing the survey were contacted directly via email. Up to three emails were sent requesting to schedule interviews. Of the 13 contacted for interviews two declined due to lack of time and one did not respond, leaving a total of ten Regional Centers (62.5%) that participated in interviews and nine agreed to have the interview recorded. Interview length varied between 15 and 60 minutes. All interviews were conducted over speakerphone and recorded via a personal recording device while participants were at work. Interviews were then transcribed by rev.com, a professional transcription service. Questions were tailored to each individual Regional Center and the number of questions asked varied from eight to eleven.

Questions were developed based on the survey responses and were designed to obtain detailed descriptions of internal policies and trainings. Examples of interview prompts include:

- Does your Regional Center receive many general conservatorship requests?
- Does you agency ever attend the actual hearing?
- Walk me through the process of conservatorship requests.

The goal of these questions was to highlight themes regarding internal procedures, training received and general philosophy regarding benefits/issues with limited conservatorships. Those who participated in the interview automatically received a chance to win an Edible Arrangement valued at $50.00 through a raffle. Participation was measured in terms of anyone who participated in a phone interview.

Participants

This research consists of 16 completed surveys and 10 completed semi-structured telephone interviews. While this sample and model are modest, they reflect powerful findings. Table 1 lists Regional Center by pseudonym, geographic location, number of clients served, and their participation. Moving forward in this analysis, Regional Centers will be referred to by their assigned pseudonyms.

Data Analysis

Data were analyzed by coding the open-ended survey questions and interview questions while looking for themes and trends in demographics, frequency of requests, level of training, and general procedures. The results provide a quantitative and qualitative description of attitudes and opinions Regional Centers representatives hold regarding limited conservatorships.

Table 1: Participant Information

Regional Center	Area of California	Approximate Number of Clients Served	Completed Survey	Completed Interview
Cedar	Northern	20,000	Yes	Yes
Pecan	Northern	7,000	No	-
Sycamore	Northern	9,000	Yes	Yes
Cypress	Northern	8,000	Yes	No
Oak	Northern	3,500	Yes	No
Spruce	Central	17,000	Yes	Yes
Silk Oak	Central	19,000	No	-
Ash	Central	8,000	Yes	Yes
Maple	Central	15,000	Yes	No
Fir	Central	13,000	Yes	Yes
Olive	Central	12,000	Yes	Yes
Birch	Southern	12,000	Yes	No
Palo Verde	Southern	10,000	No	-
Willow	Southern	31,000	Yes	Yes
Pine	Southern	9,000	Yes	No
Evergreen	Southern	21,000	No	-
Pepper	Southern	19,000	Yes	Yes
Elm	Southern	23,000	Yes	Yes
Hazelnut	Southern	13,000	No	-
Mesquite	Southern	12,000	Yes	Yes
Juniper	Southern	8,000	Yes	No
Total: 21 Regional Centers	**-**	**Approx. 289,500 clients**	**16 Participants (76%)**	**10 Participants (62.5%)**

*Compiled from dds.ca.gov

FINDINGS AND DISCUSSION

In the first section of my findings and discussion, I start by reviewing current trends involving the frequency and types of conservatorships implemented by the Regional Centers. I do this by providing an overview of some of the most important findings of the study in table form. Table 2 identifies the highlights of the survey and Table 3 outlines the most common factors related to the limited conservatorship process noted by participants in their surveys and interviews.

In the second section of the findings and discussion, I consider the three main themes that emerged across all stages of study, which include three points, conflicting interpretations of the law, budget constraints, and non-individualized assessments. I begin with a focus on different interpretations of the law and how this leads to conflicting practices. I then turn the focus to budget constraints that worsen the gap between law and practice. I conclude by focusing on how, in reality, the assessment process for limited conservatorships in not individualized, as intended by the law. Considering these subthemes helps give meaning to the overall finding-- there is a gap between the law in the books and the law in practice.

Throughout this section I will refer back to Critical Disability Theory (CDT) and other concepts, such as discretion and Lipsky's (1985) Street-Level Bureaucrats. Relating these finding back to Critical Disability Theory and other previously discussed concepts helps to contextualize and provide meaning to the findings., the central tenants of CDT include: choice of model, multidimensionality, diversity, rights, voices, language, and transformative politics (Hosking 2008:5).

Current Trends

Results of survey (Table 2):

Table 2 highlights the main findings from the survey completed by 16 of the 21 Regional Centers. The results of the survey provide a basic glimpse into how participating Regional Centers approach limited conservatorships. Questions that focused on training requirements reflected that only seven, (44%) of participating Regional Centers require training on limited conservatorships for service coordinators, and managers. This is significant because it creates the potential for Service Coordinators to write assessments without adequate knowledge of what is at stake and what alternatives there are.

Questions that centered on reporting procedures reflect many differences among Regional Centers. One finding shows that 14, or 87% of participating Regional Centers require a meeting be held with a client prior to making recommendations to court. This is problematic because each individual is not necessarily provided an opportunity to voice their opinion on the matter, which directly contradicts CDT's idea of prioritizing the voices and experiences of people with disabilities.

Furthermore, 11, or 68%, of participating Regional Centers require that a client's wishes are honored in their report to the court. By including the client's wishes in the assessment Regional Centers validate the person by considering their input worthwhile. By withholding or ignoring client's opinions, Regional Centers contribute to silencing their voices.

Additionally, nine, or 53% of participating Regional Centers report that discussing all powers being requested with client is a requirement. For example, if a parent was requesting five out of the seven powers, the Service Coordinator is required to list and explain what all those powers are and what they mean. This not only contradicts CDT, but the Lanterman Act as well, which clearly prioritizes the importance of client's choices and preferences.

Based on the estimates provided, the participating Regional Centers had approximately 1,390[2] requests in 2015. Of these requests, about 1,000 of them were requested in southern California. Justice by geography, a concept developed by Barry Feld (1991), explains how the formality and interventions during court proceedings vary depending on county. My findings resonate with this concept, especially when remembering that Los Angeles County has seven Regional Centers, while all of northern California only has five Regional Centers.

These findings reflect a process that is not in sync with CDT's concepts of diversity and multidimensionality, but actually one that discriminates based location These findings show that people in southern California are more likely to be conserved than other areas. Discrepancies among counties within a single Regional Center's service area also shows great potential for disparities between those of different socioeconomic statuses.

Nine, or 60% of Regional Centers reported that the majority of limited conservatorships requests they receive were for all seven powers, and an additional three, or 20% report more than half the requests were for all seven powers. This reflects that the majority of requests for conservatorship are not individualized, because if they were, there would be a greater variety in requests that reflect *limited* power- meaning only two or three powers were being requested. These findings do not reflect individuality and expose a disturbing trend that requesting all seven powers is standard practice.

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[2] Survey provided a range for participating Regional Centers to indicate how many conservatorship requests they received in 2015. To find the approximate number I took the middle point of range for each participating Regional Center and added them together for overall total.

Table 2: Survey Highlights

Regional Center by Pseudonym	Area of CA	# of requests in 2015 (limited)	Majority of requests are for all 7 powers	More than ½ requests for all 7 powers	Require Training for SCs	Require Training for Managers	Require meeting with client before assessment	Honor client wishes in report	Discuss all powers with client
Ash	Central	40-59	No	Yes	No	No	Yes	Yes	Yes
Birch	Southern	20-39	No	Yes	Yes	Yes	Yes	No	No
Cedar	Northern	40-59	Yes	No	No	No	Yes	Yes	Yes
Cypress	Northern	60-79	Yes	No	Yes	Yes	Yes	Yes	Yes
Elm	Southern	120-139	No	No	No	No	Yes	Yes	Yes
Fir	Central	0-19	**N/A**	**N/A**	No	No	Yes	Yes	Yes
Juniper	Southern	0-19	Yes	No	No	Yes	Yes	Yes	Yes
Maple	Central	140-159	No	No	No	No	Yes	Yes	Yes
Mesquite	Southern	180-199	No	Yes	Yes	Yes	Yes	Yes	Yes
Oak	Northern	0-19	Yes	No	No	No	Yes	Yes	Yes
Olive	Central	40-59	Yes	No	Yes	No	No	No	No
Pepper	Southern	250-269	No	No	No	No	No	Yes	No
Pine	Southern	160-179	Yes	No	Yes	Yes	Yes	Yes	Yes
Sycamore	Northern	0-19	Yes	No	Yes	Yes	Yes	No	No
Spruce	Central	20-39	Yes	No	No	No	Yes	No	No
Willow	Southern	180-199	Yes	No	Yes	Yes	Yes	No	Yes
TOTAL 16	**-**	**Approx. 1390 requests in 2015**	**9 or 60% say yes**	**3 or 20% say yes**	**7 or 44% say yes**	**7 or 44% say yes**	**14 or 87% say yes**	**11 or 68% say yes**	**9 or 56% say yes**

Table 3: Most common factors mentioned by Regional Center representatives in Open-Ended Survey Answers and Interviews:

Regional Center by Pseudonym	Area of CA	Internal meeting with ID team	Lack Guidelines	Frequency Increasing	Receive mostly General	Outcomes Vary by County	Lack of Resources	Budget	Courts ignore report	Schools pushing
Ash	Central	•	•	•	•			•		•
Birch	Southern		•						•	
Cedar	Northern	•	•	•	•	•	•	•	•	•
Cypress	Northern	•								
Elm	Southern		•				•	•		•
Fir	Central		•	•	•	•	•	•		
Juniper	Southern							•		
Maple	Central					•	•			
Mesquite	Southern		•	•	•		•	•		
Oak	Northern									
Olive	Central		•	•	•	•	•	•	•	•
Pepper	Southern	•	•	•			•	•		•
Pine	Southern								•	
Sycamore	Northern	•	•				•	•	•	
Spruce	Central	•	•			•		•		•
Willow	Southern	•					•			•
TOTAL	**-**	**7**	**10**	**6**	**5**	**5**	**9**	**10**	**5**	**7**

Symbol Key:

•	**Mentioned**

Guide to Common Factors:

Internal Meeting with ID Team- Report to have an interdisciplinary internal meeting to discuss each request for conservatorships. Examples of team members include the proposed conservatee, family members, supervisors, psychologists, medical professionals and attorneys. **Lack Guidelines**- Report that their role in conservatorships is unclear and cite lack of streamlined requirements and expectations as a problem. **Frequency Increasing**- Reported that requests for conservatorships have been increasing in their areas. **Receive Mostly General**- Report that they mostly receive general requests for conservatorships**.** **Outcomes Vary by County-** Report that some counties grant conservatorships liberally, while others are conservative. **Lack of Resources**- Report that clients, families, schools and advocates are lacking access to quality resources on conservatorships and alternatives or that families are unable to afford fees associated with conservatorships. **Budget**- Report that budget constraints limit their involvement in conservatorship cases. This includes lack of staff, time. **Court Ignores Report**- Report that the courts generally ignore the recommendations or report that courts side with the petitioner no matter what. **Schools Pushing** - Report that local schools strongly push or even scare families into requesting conservatorships at the age of 18

Results of interview and open-ended survey questions (Table 3):

Table 3 summarizes the most common factors related to the limited conservatorship process noted by participants in their surveys and interviews. These factors present data that expose system factors, such as budget constraints, that influence how conservatorship policies are implemented.

Ten Regional Centers reported that they would like to see more resources and advocacy clinics created to assist with educating Regional Center employees, court employees, clients, families, and the general public. Additionally, nine Regional Centers reported that they are in need of guidelines. A staff member from Elm Regional Center stated:

> There's not a formal like lead module on training SCs on how to complete conservatorship letters, so that certainly might be one of the things that we need because it's done on a one-to-one basis, so maybe a formal lead module where a service coordinator is taken through how to complete a probate court assessment for conservatorship. That probably would be a great idea, and probably some of the other Regional Centers have it already.

Both of these findings, the need for more resources and clearer guidelines, show that not all Regional Centers have the resources they need to fulfill their responsibilities as advocates, as required by the Lanterman Act.

Additionally, six Regional Centers reported that they are seeing an increase in conservatorship requests. Ash Regional Center's representative offered this explanation when asked if requests were increasing:

> Yes it is. It is and it's disturbing that it's increasing. It's increasing quite a lot, I mean, we have seen an explosion… It probably sounds too cynical but it just seems to me that a lot of it is being pushed for convenience rather than necessity.

> That's a real problem. If we are moving in a direction in society where we want people to be more engaged in society, more self-directed and more independent then I don't understand the direction as far as conservatorships where they are increasing. We are actually moving backwards as far as that goes.

This is alarming when remembering that guardianships and conservatorships are considered very restrictive and should only be used as a last resort (Millar and Renzaglia 2002: Moye and Naik 2001).

Furthermore, five participating Regional Centers reported they receive mostly requests for general conservatorships. Cedar Regional Center reported that in 2015, they received 58 limited conservatorship and 187 general conservatorship requests. To review, general conservatorships are generally for the elderly, or fully incapacitated adults, and limited conservatorships are for adults with I/DD. This finding contradicts CDT's concept of multidimensionality as requesting a general conservatorship implies that being intellectually or developmentally disabled signifies an individual is totally incapacitated. The representative from Cedar Regional Center explained that this is a way families get around having Regional Centers provide the courts with an assessment and reported that general requests for conservatorships do not assign public defenders to the defendant:

> It's even the law that notice [of petition] of either type [of conservatorship] must be provided to the Regional Center, it's just that a report is only required for a limited [conservatorship]. Then it's optional for general… We object all the time. Several times a week we're filing objections to general conservatorship and recommending limited ones. The judges are getting a little bit more receptive to that, but the minimum that does is the court will appoint an attorney for the client.

> That's another thing you don't get when go through a general conservatorship proceeding. There's no one representing the client. Everyone else has an attorney.

The Cedar Regional Center representative went on to explain that "…it's not reflected anywhere. The advocacy organizations seem to think that most people don't seek general conservatorships, they don't really even address that." Such findings should serve as red flags that policies are not being implemented as they were intended, as limited conservatorships were specifically designed to protect the rights of this population (Hunsaker 2008); but general conservatorship requests continue to be made.

Conflicting Interpretation of Laws

Varying interpretations of limited conservatorship policies add to confusion and to misinformation being spread. A common theme found throughout this research revolved around ambiguous standards and contradictory interpretations of laws by the Regional Centers and different institutions. For example, seven participating Regional Centers discussed concerns that local school districts were pushing conservatorships during Individualized Educational Plan (IEP) meetings. A staff member of the Willow Regional Center explained,

> We also have ... an ongoing challenge sometimes with people misinforming families about the conservatorship process, or the need for a conservatorship. We especially see it when students are aging out ... I've heard school personnel tell the parent, "This student's going to be turning 18, and as soon as they do you need to become a conservator or you can't be involved in the IEP process anymore." I tell the families " that's not the case. You can be a member of the IEP as long as your son or daughter wants you to be"… But [it's] sometimes conflicting when the schools are misinforming families. The families get scared.

A representative of Olive Regional Center reported, “Some schools I think put the fear of God in families.” This sort of misinformation contributes to parents requesting conservatorships under the false pretense that it is the only way to have continued involvement in their adult child’s life. These findings mirror Jameson et al. (2015) that 50% of guardianship cases had been recommended by professionals, such as teachers.

Another area that reflects a lack of cooperation among agencies is reflected by the five Regional Centers that mentioned their local courts frequently ignored their recommendations and sided with parents regardless of the needs of clients. In a finding that resonates with Millar and Renzaglia (2002), Millar (2007), and Millar (2013), the representative from Olive Regional Center stated that the report submitted to the courts “in all honesty is not worth the paper it’s written on.” Cedar Regional Center staff member that I spoke to also cited concerns with the courts generally favoring the opinion of family members as opposed to the Regional Centers’ recommendations and described the following experience: “I've been at these hearings and they'll [the judge] say, ‘But the parents want this’… and [I] say ‘I'm not here to have the same opinion as the family.’ That's usually what the court listens to the most.” Having two different institutions working in opposite directions causes inefficiency as they both are serving their own agency’s interests. Such findings support Lipsky’s (1985) and Spade’s (2011) understanding of the problems of discretion in service delivery.

Another trend mentioned by five Regional Center representatives is how limited conservatorships are extremely hard to reverse and that reversals rarely occur. A representative from Pepper Regional Center explains that “…it’s very difficult to get a conservatorship reversed.” This also resonates with Lipsky’s (1985) and Spade’s (2011) concept of discretion as the law clearly requires that limited conservatorships are routinely reviewed for appropriateness.

The fact that reversals rarely happen reflect the level of discretion held by agencies like the Regional Center.

Finally, ten Regional Centers reported that they lack clear guidelines on how to approach and assess the need for conservatorship which resonates with Hafemaster and Sales' (1984) findings that professionals are granted absolute power over their clients when determining capacity. Only seven participating Regional Centers reported that they utilize an internal interdisciplinary approach that looks at the entire person as unique as opposed to trying to measure competency based on diagnoses or level of functioning. For example, Elm Regional Center staff welcomed a training module on how to assess for the need of a conservatorship and discussed problems with "…what's supposed to happen" and what does happen.

The common trend that is exposed with these findings is that Regional Centers and other institutions are free to interpret the law in the way that is best suited for them and their own needs, not the clients. This is reflected by Fir Regional Center being the only participating Regional Center who discussed Supported Decision Making (SDM) and its staff are actively exploring SDM models to follow. This reflects a high level of discrepancy left to the Regional Centers to decide the level of attention they give to exploring alternatives. This is contradictory because the Lanterman Act requires least restrictive measures, but all Regional Centers are not practicing least restrictive measures. A staff member of Ash Regional Center perfectly summarized their predicament by explaining "…it's really not consistent with our role as advocate to be taking people's rights away from them."

Budget Constraints

There are many reasons why all Regional Centers do not practice the law as intended. Budget constraints were a common concern that was cited by ten participants. A representative of Pepper Regional Center explained the impact of budget constraints:

> I think maybe about seven or eight years ago, I think our main goal was to try and see every proposed conservatee face-to-face, but given the fact that we don't have a specific, there's no budget for conservatorships and for Regional Centers' probate responsibility, it's just something that's expected without being funded, I don't have the staff support to do it. I have my designated service coordinators that are also carrying a standard case load, and doing that, and I haven't been able to get more designated service coordinators to kind of help fill in as we've had people who've left or who said they can't do the assignment any more or whatever else. So I only have three designated service coordinators now for the agency, which is a little tight.

This illuminates one of the ways gaps are created as not all Regional Centers can realistically absorb the cost it would take to create quality conservatorship assessments.

Budget constraints are also reflected in the fact only 44% of participants reported that training is mandatory for service coordinators and managers. Not having a designated budget for probate-related activities is setting up the Regional Centers to fail as advocates because they are not able to create the tools they need to be successful.

This is an example of the discretion each Regional Center has because they are at liberty to decide how many company resources they are willing to spend on conservatorship proceedings. The law requires they complete an assessment, but no law ensures that each Regional Center puts the same amount of time and consideration into these reports. This creates conflict due to economic restraints and leads to institutions prioritizing cost efficiency over individual needs (Carey 2009; Devlin and Pothier 2006; Lipsky 1985; Spade 2011; Turnball 2012). This results in alienation as clients are seen as a number, or object and not a human, which means that services are not individualized.

Non-Individualized Process

The final theme relates to general problems with the conservatorship process, which at best can be defined as a non-individualized process and mirror the findings of Millar and Renzaglia (2002) and Millar (2013) that reflect assessments as very standardized.

Findings show that 12 participating Regional Centers (80% of respondents) report that more than half, or the majority of limited conservatorship requests are for all seven powers. Such findings are should serve as red flags that policies are not being implemented as they were intended, as limited conservatorships were specifically designed to protect the rights of this population (Hunsaker 2008); but general conservatorship requests continue to be made. These findings uncover a strong disconnect between the intent of the law and its actual impact. My research reflects that the majority of conservatorship requests are for all 7 powers which reflects a major contradiction as they were created with the intent to *limit* the power held by the conservator (Hunsaker 2008) and thus does not follow CDT's tenant of preserving the rights of people with disabilities.

There were also five participating Regional Centers that distinctly brought up concerns regarding differences among various counties they serve. For example, a staff person from the Spruce Regional Center reported they serve six counties and that, "There are some counties that are more reluctant to do that [provide a public guardian] and other that are more willing to step forward…" Such differences open the doors for some to be left more vulnerable than others, based on which county in which they live. This resonates with Lipsky's and Spade's idea of discretion as in the end, one judge has the power to decide who is conserved and who is not. Additionally, these findings resonates with Feld's notion of justice by geography, as those living in southern California are placed under conservatorships more than people living elsewhere in the state.

This research has made a modest but powerful contribution to the field of sociology and disability. To my knowledge it is the first study to sample of the 21 Regional Centers in California and is one of the earliest to explore limited conservatorships in California on a sociological level. Additionally, it exposes a dire need for further research in this developing area.

RECOMMENDATIONS

It is hard, although not impossible, to ignore the blatant social inequities faced by people with intellectual and developmental disabilities. Inequality itself is problematic, but the stagnant progress society is making towards resolving the inequity is even more concerning. Our slow progress can be contributed to a variety of variables, but ineffective social service agencies, like Regional Centers, are an appropriate place to start. Government agencies are one place where we can lessen the impact of inequalities.

Before making specific recommendations it is important to consider how complicated human service delivery is. Lipsky (1985) points to America's entrenched system of bureaucracy as the primary reason individuals like judges and Regional Center service coordinators are able to violate laws mandating "least restrictive measures" without being held accountable. Lipsky argues that greater social change is needed before genuine progress can be made towards change. Until society changes as a whole he suggests the following 1) clients having influence over policies that concern them, 2) improving current practices by removing room for discretion, and

3) increasing professional development to spark change in behavior. He argues that doing such will strengthen the connection between worker and recipient and prevent discretion from being abused. Based on this research, Lipsky's suggestions and CDT, I recommend the following as a way to start addressing the issues highlighted.

To start California needs to acknowledge there is a problem and address the gaps in how Lanterman Act is written, and how it is implemented. By acknowledging the problem, California can start to address it. To start, providing each Regional Center with a budget designated to address conservatorships related needs. For example, trainings, alternatives, assessment workshops and court attendance could all be covered by the designated budget. This would help solve discrepancies between Regional Centers as each would have funds to manage their responsibility of making assessments. This resonates with critical disability theories concept of transformative politics as its providing the means to make change.

On a local level, I recommend that Regional Centers reach out to their own employees, courts, and schools with trainings on disability rights, and alternatives to conservatorships. This would help clarify the misconception that having an intellectual or developmental disability means that someone is incapable of making choices and educates other key parties to less restrictive alternatives, like supported decision making.

Additionally, I recommend that all Regional Centers individualize the process of assessing the need for conservatorship. This would include an interdisciplinary team consisting of the client, proposed conservator, the service coordinator, a psychologist, and community members like teachers and group home staff. The purpose of this team would be to discuss each power being requested and less restrictive alternatives that could be used. This would provide an opportunity for the team to consider the individual person and their personal circumstances prior to making recommendations to the court. Finally, I recommend that Regional Centers streamline limited conservatorship policies by adopting the same procedures. This would provide consistency and decrease the chances that justice will be impacted by location.

CONCLUSION

Clearly there is plenty of room for further studies to explore limited conservatorships in California. A study that looks at court sessions throughout the state would be interesting and could shed light on how Regional Centers could better prepare clients for this process. A study looking at reasoning, race, gender and SES would also contribute to a better understanding of who is being conserved and why. Finally, many Regional Centers mentioned that they rarely see conservatorships reversed or modified in any way. A study exploring how conservatorships have been reversed in the past could help us to understand why it is not happening more frequently. Gaining such understanding will help us develop effective policies that prioritize the maintenance of everyone's civil rights, regardless of ability.

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Appendix A: Survey

Hello and thank you for participating! My name is Barbara Imle and I am a sociology graduate student from Cal State University San Marcos and a former regional center service coordinator. I am currently conducting research on Regional Centers and how they implement limited conservatorship policies. This is a state wide survey of all Regional Centers in California and I am grateful for your support.

This survey will begin with general questions about you, the participant, and the regional center you are representing.

1. Which regional center are you representing?
2. How many individuals are served by this regional center?

   ○ 0-4,999
   ○ 5,00-14,999
   ○ 10,000-19,999
   ○ 15,000-19,999
   ○ 20,000-24,999
   ○ 25,000-29,999
   ○ 30,000-34,999
   ○ 35,000 or over, please specify

3. What is your job title? Briefly explain your responsibilities.
4. Please estimate, how many limited conservatorship requests were received in **2015**?

   ○ 0-19
   ○ 20-39
   ○ 40-59
   ○ 60-79
   ○ 80-99
   ○ 100-119
   ○ 120-139
   ○ 140-159
   ○ 160-179
   ○ 180-199
   ○ 200 or more, please specify

5. Please estimate, how many of those requested **all seven** powers?

   ○ almost all

○ more than half
○ about half
○ less than half
○ almost none
○ n/a

6. Please estimate, how many of those requests your regional center **supported**?

○ almost all
○ more than half
○ about half
○ less than half
○ almost none
○ n/a

7. Please estimate the **total** number of service recipients currently under limited conservatorship at your center:

o 0-499
o 500-999
o 1,000-1,499
o 1,500-1,999
o 2,000-2,499
o 2,500-2,999
o 3,000-3,499
o 3,500-3,999
o 4,000-4,499
o 5,000 or more, please specify

Next, I will ask about the training's offered to clients, families and service coordinators regarding limited conservatorships and their alternatives.

8. Is training on limited conservatorships **mandatory** for all service coordinators?

o Yes
o No

9. Is training on limited conservatorships **mandatory** for all case management supervisors?

o Yes
o No

10. Is training on *alternatives* to limited conservatorships **mandatory** for all service coordinators?

o Yes
o No

11. Is training on *alternatives* to limited conservatorships **mandatory** for all case management supervisors?

o Yes

- No

12. To whom does your regional center provide training on limited conservatorships? Check all that apply.

- Regional Center service recipients
- Parents/family members
- Regional Center vendors
- Other

13. To whom does your regional center provide training on *alternatives to* limited conservatorships? Check all that apply.

- Regional Center service recipients
- Parents/family members
- Regional Center vendors
- Other

The following section will focus on policies your regional center has when requests for limited conservatorships are made.

14. Who is responsible for writing regional centers assessment to the court?

- Assigned service coordinator
- Specially trained service coordinator
- Case management supervisor
- Psychologist
- Licensed clinical social worker
- other

15. Does your regional center require that report writer meets face to face with proposed conservatee prior to making assessment to court?

- Yes
- No

16. Do you require that each power requested is specifically discussed with proposed conservatee prior to making assessment to the court?

- Yes
- No

17. Does your regional center require that the proposed conservatee's wishes and input and is included in the assessment to the court?

- Yes
- No

18. What are some challenges your regional center faces regarding limited conservatorships?

Finally, this survey will close with questions pertaining to your interest in participating further in this research.

19. Is your regional center open to sharing materials related to training, policies and procedures on limited conservatorships and alternatives?

    ○ Yes
    ○ No

20. May I contact you directly with follow up questions about this survey?

    ○ Yes
    ○ No

Appendix B: Interview Questions

1) Walk me through the steps your RC takes once a limited conservatorship is request is received.

2) Does your RC receive many general conservatorship requests?

3) Would you say that the number of conservatorship requests is increasing or decreasing with time?

4) Do your staff ever attend the hearing?

5) What does your agency do if you do not agree with a limited conservatorship request or conservatorship that is already in place?

6) What resources do you have available to utilize when handling a challenging case? Like private fiduciaries, special needs attorneys, advocates.

7) Have there been any recent changes in limited conservatorship procedures at your RC? If so, please tell me about those changes and why they were made.

Appendix C: Links to Regional Center Websites

Alta California Regional Center- http://www.altaregional.org

Central Valley Regional Center- http://www.cvrc.org

Regional Center of East Bay- http://www.rceb.org

East LA Regional Center- http://www.elarc.org

Far Northern Regional Center- https://www.farnorthernrc.org

Frank D. Lanterman Regional Center- http://lanterman.org

Golden Gate Regional Center- http://www.ggrc.org

Harbor Regional Center- http://www.harborrc.org/

Inland Regional Center- http://inlandrc.org

Kern Regional Center- http://www.kernrc.org

North Bay Regional Center- http://nbrc.net

North LA County Regional Center- http://www.nlacrc.org

Regional Center of Orange County- http://www.rcocdd.com

Redwood Coast Regional Center- http://redwoodcoastrc.org

San Andreas Regional Center- http://www.sanandreasregional.org

San Diego Regional Center- http://sdrc.org

San Gabriel/Pomona Regional Center- http://www.sgprc.org

South Central LA Regional Center-http://sclarc.org

Tri Counties Regional Center- http://www.tri-counties.org

Valley Mountain Regional Center- http://www.vmrc.net

Westside Regional Center- http://www.westsiderc.org