“The Call is Coming from Inside the House:” Tracing Experiences in the Institutionally-Centered Process of Establishing Limited Conservatorships in California

by

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Abstract

In this institutional ethnography, multiple methods are used to explore California's process of establishing limited conservatorships, which are legal proceedings that limit or terminate civil rights of people with Intellectual and Developmental Disabilities (IDD). This research uses observations of 93 conservatorship hearings, 16 interviews with people involved in the conservatorship process, and an analysis of multiple documents related to these legal proceedings. These data are used to answer two questions: 1) what is the process of establishing a limited conservatorship in California; and 2) how is this process experienced by those involved?

Findings break down a complex process and contribute to an empirical understanding of how the combination of knowledge, policy, and institutional ideology shape the lives and freedoms of people with IDD. For example, of the 93 hearings observed, all 93 petitions for limited conservatorships were granted. This study reflects that the process is not individualized, and that people with IDD continue to be viewed as incompetent and unworthy of the civil rights many American adults take for granted. By mapping out the complex process, this research highlights areas for potential change and provides recommendations to make the process more person-centered, and one that prioritizes disability rights over institutional goals.

Dedication

Most importantly, this is for “Hal.”

This is also for me, and for all the other souls who our schools called “failures,” when in reality, the education system had failed us.

Finally, this is for Luke Robinowitz, who left us before completing his own doctoral research. You are missed, but not forgotten. Rest easy, friend.

Acknowledgements

Pulling this dissertation together took the work and support of my entire village. Those who know, know. Thank you for supporting me through this journey. I would not have crossed the finish line without you.

List of Acronyms/Terms Used in California's IDD Service Delivery System

Act	Lanterman Act
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ARCA	Association of Regional Center Agencies
CAA	Court-Appointed Attorney
CDER	Client Development Evaluation Report
Client/Consumer	Client/Consumer/ regional center service recipient used interchangeably
CHHSA	California Health & Human Services Agency
CMS	Centers for Medicare and Medicaid Services
DDS	California Department of Developmental Services
DRC	Disability Rights California (formerly Protection & Advocacy, Inc.)
DSS	California Department of Social Services
Generic Resources	Resources and services available through family other programs (Medicaid)
HCBS	Home and Community-Based Services
HSC or H&S	California Health and Safety Code
IDD	Intellectual and developmental disabilities
ID Notes	Interdisciplinary Notes, or T19 notes, for Target Case Management (TCM)
IEP	Individualized Education Program
IHSS	In-Home Support Services
IPP	Individualized Planning Process
LPS	Lanterman Petris-Short
LRA	Less Restrictive Alternatives to restriction/termination of rights
MCW	Medicaid Waiver (aka HCBS waiver)
OCRA	Office of Client's Rights Advocacy (w/DRC)
PD	Public Defender
Peer Advocate	Individual with IDD employed by RC to help other clients access services
PROB	California Probate Code
POS	Purchase of Services
RC	Regional Center
SC	Service Coordinator (regional center case manager)
SCDD	California State Council on Developmental Disabilities
SES	Socioeconomic Status
SIR	Special Incident Report
T17 CCR	Title 17 of California Code of Regulations
T19 units	Title 19 SSA/Target Case Management (TCM)
T22 CCR	Title 22 of California Code of Regulations
Vendor	Third party hired by RC to provide direct service(s) to RC clients
WIC	California Welfare and Institution Code

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CHAPTER 1: INTRODUCTION

> *This research begins with the story of Hal. Hal was in their late 40s, held down a job, lived relatively independently, and was diagnosed with mild intellectual disability and moderate anxiety. I was Hal's case manager at regional center and had worked with them for about two years before their family petitioned the court for a limited conservatorship (a legal proceeding that would remove Hal's rights and assign them to family), after having a disagreement with a medical doctor over a prescribed medication.*
>
> *As required by law, I, as their case manager, completed an assessment regarding the need for conservatorship. I submitted a report to the court stating I did not support this petition, as Hal was capable of making choices independently and had been doing so for over 20 years. I desperately tried to advocate on Hal's behalf with the court-appointed attorney assigned to defend and protect Hal's rights. My efforts did not produce any results. This attorney erroneously believed that people like Hal, who could not read, were not able to consent or make informed decisions in their best interest because they could not read language in contracts and agreements.*
>
> *During a public hearing observed by over 60 strangers, Hal stood in front of a judge and displayed signs of distress as they cried while responding to the judge's questions. Hal stated that this was a stressful process and that, yes, they did appreciate their family's support. As the case manager, I reiterated that a conservatorship was inappropriate because there were less restrictive ways to support Hal. In the end, and in under 10 minutes, the judge thanked everyone for their work and time, and delivered the final ruling, granting the limited conservatorship. Just like that, Hal had their rights terminated and assigned to an elderly father and older sibling.*

The above vignette is based on my experience working as Hal's case manager and is the motivation for this research. Participating in and witnessing a process that resulted in Hal's having their rights terminated left me feeling disheartened and defeated. I felt I had failed both Hal and as a case manager. I was also frustrated and angry that I did not have the support and resources to be able to do more. Anger eventually turned into curiosity. I wanted to understand how a person in their 40s could have their rights terminated so quickly and easily in spite of my protests and efforts. What could have been done to prevent this? Why didn't anyone else, particularly state-level disability service agencies, seem to care that this could happen? Was Hal's experience a fluke, or a common experience? Understanding Hal's experience—how an adult has their rights terminated despite the laws and agencies put in place to protect those rights—sparked this research. I aimed to answer the following questions: what is the process of establishing a limited conservatorship in California, and how is this process experienced by those involved? While this may present as an individual-level issue, adult guardianships carry significant risk and have serious consequences for larger society.

Research Motivation and Background

In 2017, 40.7 million people, or 12.7% of the population, reported living with one or more disability in the United States (Erickson et al. 2016). 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, the question will arise whether a person's disability is impairing their decision-making skills. Conservatorships, also known as guardianships, are judicial proceedings that result in civil liberties being legally restricted or terminated if a person is declared unfit or considered incapacitated and unable to manage their affairs (Hunsaker 2008).

This study focuses on the conservatorship process within California, specifically limited conservatorships. Limited conservatorships are designed especially for adults diagnosed with an intellectual and/or developmental disability (IDD). In section 4512 of Welfare and Institution codes, the State of California (2019) a defines a developmental disability as a chronic impairment that begins before the age of 18, such as autism, cerebral palsy, and intellectual disability. Not all these diagnoses involve cognitive impairment, and the inability to communicate verbally is not a reflection of having a cognitive impairment. Briefly stated, 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 access confidential records, 3) the right to marry or enter into a registered domestic partnership, 4) the right to contract, 5) the right to give or withhold medical consent, 6) the right to control social and sexual contacts and relationships, and 7) decisions concerning education.

This study looks at the whole process of limited conservatorships but pays particular attention to the involvement of California's local IDD service agencies, known as regional centers. There are 21 regional center agencies across California who are contracted by the state to coordinate services and supports for children and adults with IDD. The decision to focus on the regional center is based on my various experiences working for two separate regional centers, in two different counties, over a nine-year period. My experience, how it influenced this work, as well as the purpose, structure, and role of the regional center system, are addressed in detail in Chapters 4 and 5. However, I want to emphasize early in this research the admiration and respect I have for the people who work at the 21 regional centers statewide. Most of them, like me, entered the field to help people. They take this responsibility seriously.

My attention to the regional center system—its problems and its promise—comes from a place of care, dedication to the IDD service delivery system, and my belief that the regional center system has untapped potential to spark change. The purpose of this research is not to place blame on any individual, organization, or agency. Instead, my purpose is to explicate a complex process and then offer actionable, practical solutions to improve the process. The few studies that focus on California's conservatorship system (which are summarized next) indicate that there are statewide problems, and that the system is ripe for reform.

Studies on California's Conservatorship System

Studies on California's conservatorship system are scarce (Coleman 2021; Mildred 2015; Anders et al 2009; Kincaid 2012). However, while the literature may be limited, it reflects a consensus that the system has substantial, long-standing issues. Statewide budget cuts (Coleman 2021; Mildred 2015; Anders et al 2009), lack of statewide data (Coleman 2021; Anders et al 2009); and failing to utilize LRAs (Coleman 2014, 2017, 2019, 2021; Coleman & Baladerian 2015; Mildred 2015; Anders et al 2009) are consistent trends throughout the research. Work specifically on limited conservatorships in California and include the role of RC is even more sparse, and is summarized below.

Over the past decade, the Spectrum Institute, a nonprofit agency contributing to probate reform efforts, has conducted extensive legal research, and published over 14 reports on California's limited conservatorship process. Mildred (2015), in collaboration with Coalition for Compassionate Care of California, completed a study consisting of interviews that document regional center's role in the limited conservatorship process. Finally, work for my thesis (Imle 2016) utilized a survey sent to the 21 California regional centers. Sixteen regional centers responded, and 10 completed follow-up interviews. These studies all used different methods and occurred in different places throughout the state, but they all found similar problems.

Lack of training and a lack of consistent practices across the state were other trends found across studies. Mildred (2015:22) found "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 administrations, which are often vastly different from one to the next." Similarly, Imle (2016) found each regional center had very different approaches to implementing policies and procedures related to limited conservatorships, with only 44% of participating regional centers requiring training on limited conservatorship for staff and managers. Yet, despite ample evidence underscoring the need for more funding and guidance, these studies found the state of California has yet to take action and is largely missing from the process (Coleman 2014, 2017, 2019, 2021a; Coleman & Baladerian 2015; Imle 2016; Mildred 2015). These studies exposed some of the negative consequences lack of monitoring and oversight had on regional center clients, such as failing to ensure that conservatorships are used as a last resort when all other less restrictive alternatives have failed (Coleman 2014, 2017, 2019, 2021a; Coleman & Baladerian 2015; Mildred 2015).

To summarize, studies that have explored California's limited conservatorship process uncovered several problems that go beyond a single agency or person, pervading the system as a whole. Further, the research validates that my experience with Hal was not just a rarity in the system, or an isolated experience, and, as such, renders this an important site for further study. This study builds on this previous work by paying particularly close attention to regional center practices, which currently fail to live up to their great potential.

The title of this dissertation, “The Call is Coming from Inside the House” is a nod to 1979/2006 film *When a Stranger Calls*. It is horror movie featuring a teenager who receives threatening phone calls from a stranger while she’s babysitting. Eventually, a 911 operator informs the unsuspecting babysitter that, “The call is coming from inside the house!” The threat has been inside with her the whole time. In this study, the intent is to literally call on the regional centers to lead reform efforts because they are uniquely positioned to be able to make meaningful changes without waiting for new legislation or regulations.

Organization of Dissertation

In Chapter 2, I review literature focusing on historical and current approaches to IDD, challenges within human service delivery systems, and adult guardianships and conservatorships. These areas of research provide a foundation that improves understanding of this complex process. Chapter 3 lays out the theoretical framework of my research, and Chapter 4 details the methodological approach and tools (i.e., interviews, observations, text analysis). Chapter 5 provides detailed background information on California’s IDD service delivery system. In Chapter 6, I first present the findings from this research and then provide a discussion of their implications in Chapter 7. I conclude the dissertation by offering recommendations, a review of the study’s significance and limitations, and suggestions for potential research in Chapter 8.

CHAPTER 2: LITERATURE REVIEW

Reviewing current literature helps us understand why this study is important to sociology, disability rights, service agencies, and people with intellectual and developmental disabilities (IDD). Most of the literature I review is located within sociology, but I also pull from the fields of law, education, social work, and health. My focus is centered on IDD and concepts such as self-determination, choice, and autonomy. I explore how impairment is experienced and how access to support services can shape an individual's autonomy and ability to exercise rights of self-determination (Shogren et al. 2019; Stancliffe et al. 2011). The reason for this focus is to provide a solid foundational understanding of IDD rights and what it means to be presumed incompetent and dependent on governmental service agencies, as these are central components to this research, which explores the process of terminating or limiting the civil rights of adults with IDD in California.

I begin this chapter by reviewing literature that examines IDD, such as historical and dominant approaches. Following this, I consider literature that focuses on social/human services delivery systems, including work that explores power imbalances and gaps between the law on the books and the law in practice. I close by reviewing dominant literature relevant to adult guardianship and conservatorship, including the consequences, challenges, and barriers to policy implementation and the use of less restrictive alternatives (LRAs).

Research shows that people with disabilities continue to face higher levels of economic marginalization compared to nondisabled peers. In the Disability Status report, Erickson et al. (2016) reported that only 14.4% of disabled persons have a bachelor's degree compared to 33.8% of people without a disability.

The impact of ineffective education in addition to the stigma associated with disability have caused this population to be viewed as incapable of working. Erickson et al. (2016) also found that 23.9% of individuals with a disability work full time, compared to 59.4% of those without a disability. The same report also shows that the median annual income for households including a disabled person was $40,300, compared to $45,300 for households that do not include a disabled person. Other research finds that people with disabilities continue to be at higher risk of victimization (Erickson et al. 2016; WHO 2018) and abuse (WHO 2018; Erickson et al. 2016). Further, other studies expose how such abuse has long-term impacts on overall health (Hughs et al. 2019). In short, the variety of ways in which society continues to oppress persons with disability, particularly those with IDD, is well documented in the literature. Gaining an understanding of the different approaches to disability, which are reviewed next, helps us understand how people with disabilities came to experience such high levels of marginalization.

Conflicting Approaches to 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 approached disability as an individual-level issue. The social model was introduced during the Civil Rights Movement and aimed to create equality for people with disabilities by addressing structural barriers that kept people with disabilities from accessing society.

The medical model of disability. Prior to the 1900s, people with IDD generally lived within the community and were not viewed as a threat despite being considered deviant (Carey 2009). The extent to which 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 IDD 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) explained that "capitalism required the differentiation of able-bodied and disabled, productive and non-productive" (48). This form of rationalization established the belief 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 1900s 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 school of thought led to the beginning of segregation and dehumanization of people with IDD.

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, Colin, and Mercer 2013; Carey

2009). There is nothing inherently wrong with addressing negative symptoms of disabilities. In some cases, receiving medical treatment (e.g., speech therapy) can improve quality of life by increasing one’s ability to communicate their needs. However, if other factors are not considered, such as how a person experiences a disability, there is a risk of further marginalization. The medical model, for example, does not account for those who are unable to access or pay for speech therapy services.

The medical approach to disability relies on binary categories and labels to establish and guide treatment and support (Barnes et al. 2013; Pothier and Devlin 2006). Stewart and Ward (2008) argued, 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). The issue here is that diagnoses and definitions have serious, sometimes negative, consequences for people with IDD. A medical diagnosis can qualify individuals for access to services and support but can also exclude them from accessing services. For example, level of intellectual disability (i.e., mild, moderate, severe, profound) is categorized based on IQ score, which is used by disability agencies such as regional centers to determine eligibility for services. If a person’s IQ score does not fall at least two standard deviations below an average intelligence score of 100, that person does not qualify for services, even if their life was substantially impaired due to borderline intellectual disability and other life circumstances (Shakespeare 2014: 65).

Carey (2009) and Shakespeare (2014) both explained how the medicalization of disability has led to service agencies attempting to measure and define one’s competence, or ability to be productive. For example, Carey (2009:102) cited a study by Mickelson (1947, 1949), who studied the relationship between IQ scores and competence in parenting and found that IQ had minimal impact on parenting ability. The author also showed the importance of other factors (e.g., class, impairment) that need to be considered when assessing competence and ability.

Rigid categorical thinking can severely impact the extent to which people with IDD can exercise their civil rights. Being diagnosed with an intellectual or developmental disability brings an automatic assumption of incompetence, thus making rights to decision-making irrelevant (Stewart and Ward 2008). This is supported in studies that have found people with IDD are frequently denied opportunity to make basic choices, such as where they live or how they spend their free time (Stancliffe et al. 2011; Stewart and Ward 2008). These findings clearly show how generalized assumptions of incompetence actively contribute to the marginalization of people with IDD (Rood, Kanter, and Causton 2015).

The social model of disability. Approaches to disability began to shift in the 1970s, and the social model was developed in opposition to the medical model (Barnes er al., 2013; Harpur 2011). The social model argues that disabilities do not impair people—society does (Harpur 2011). For example, the social model, advanced by medical sociology theorists like Mike Oliver and Irving Zola (Barnes et al. 2013), views the lack of a wheelchair ramp as the problem, not the person in the wheelchair. 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; Pothier and Delvin 2006).

The social model places high importance on maximizing independence and promotes self-determination and autonomy (Barnes et al. 2013). While well intentioned, it does not provide enough protection for individuals who are more vulnerable than others (Carlson 2013; Shakespeare 2014; Stewart and Ward 2008). For example, disability rights advocates argue that intellectual disability is socially constructed, meaning that it would not be problem if society reacted differently. Shakespeare (2014) pointed out that this is accurate in cases of mild intellectual disability, but reminds us that intellectual disability is ontologically real, and argues that people with severe and profound intellectual disabilities will be negatively impacted, regardless of how accepting the culture is.

A study that examines the limits of the social model was conducted by Sapey et al. (2005), who surveyed over 1,000 people with disabilities, to explain why there had been an increase of people utilizing wheelchairs. Sapey et al. (2005) reported that 80% of those surveyed found wheelchairs liberating, and 48% agreed that environmental barriers made it challenging to accomplish things they wanted. The same study also found that 80% of respondents agreed that their disability had prevented them from doing things they wanted to do. Sapey et al. (2005) suggested that their findings demonstrate the validity of the social model, reflecting the importance of addressing structural issues like accessibility. However, the authors also give less weight to the finding that physical impairment can be just as restrictive as inaccessible environments (Shakespeare 2014). In other words, even if all physical barriers were removed, a person with severe autism may never be able to access society because of how they personally experience this impairment.

In summary, the social model ignores individual variations in impairments and other structural and systemic factors like class and complications of accessing services through disability agencies. For example, in a comparative case study by Millar (2008), the author contrasts the cases of two young adults with IDD (one with a guardian and the other without). Both had similar characteristics including gender, age, abilities/limitations, and both were eligible for similar disability services. Millar (2008) found that the individual under guardianship was more autonomous and independent with making choices—but this individual had a family of high socioeconomic (SES) status who assisted them in navigating the system and accessing services to which they were entitled. In contrast, the individual without a guardian had less access to services and independence—but had a family of low SES who were less able to help them find and access services. In other words, the individual without a guardian had less access to services because they were unaware of what was available, but their family was less able to help. Millar's (2008) study reflects how powerful external forces like class and familial support can influence the way disability and impairment are experienced.

Dualistic models of disability. As the literature shows, there are many approaches to disability, but most address disability on a singular level (i.e., individual/medical level or structural/social level) and do not address the many factors (e.g., individual needs, structural factors, systemic factors) that influence how disability is experienced. As suggested by others like Pothier and Devlin (2006) and Shakespeare (2014), I suggest that the critical realist (CR) perspective is a viable alternative model that incorporates central parts of the social and medical models and more effectively addresses issues related to service delivery.

A CR perspective to disability offers a holistic, pragmatic solution to the dominant, yet incomplete, other approaches. It balances medical, social, and cultural aspects of disability, and considers disability as an interaction between individual needs and structural conditions. Shakespeare (2014:78) explained that while CR models of disability can differ, they all address three key factors that influence the way disability is experienced: (a) individual factors, such as impairment and personality characteristics; (b) social factors, such as public accommodations and cultural beliefs about disability, and (c) factors within the systems that provide supports, such as disability-related services. Next, I explain in more detail these factors and the influences they can have.

Individual factors. Like the social model, the CR approach is critical of the binary approach to disability (i.e., disabled or not disabled; competent or incompetent). For example, how do you categorize someone who is technically “non-verbal” but is able to communicate through gestures and body language? To avoid essentialism, or categorizing diverse disabilities in the same box, CR perspectives acknowledge that disability is multidimensional. People can experience the same disability differently (Shakespeare 2014). For example, not all people with autism spectrum disorder are antisocial, and people with epilepsy (seizures) can experience impairment from this condition very differently and have different needs.

Additionally, CR perspectives include the concept of intersectionality to highlight how personal characteristics (e.g., level of support, race, class, gender, sexual orientation) can impact disability and how it is experienced (Carey 2009; Shakespeare 2014; Pothier and Devlin 2006). For example, two people with Down syndrome who have similar functioning levels can have very different needs depending on the level of resources they have access to within their circle of support. This was highlighted by Millar's (2008) aforementioned comparative case study.

Structural factors. CR also recognizes that disability is about politics, power, and control. CR perspectives directly challenge liberalism—the dominant ideology that organizes our society around concepts of individualism like autonomy, liberty, and choice—by recognizing the many ways it routinely fails to meet the needs of people with disabilities. Shakespeare (2014) explained how labels and social understandings of labels change over time and how this influences level of impairment experienced. Liberal ideology causes society to blame individuals for their marginalized status, as opposed to recognizing how our social structure creates and contributes to their marginalization, thus worsening the power imbalance already favoring the institution over the individual.

Individual rights and autonomy are also key concepts considered by CR approaches to disability. CR contextualizes these concepts by calling out the limitations of these liberal ideologies. For example, some people with severe disabilities have no other choice but to be dependent on others. Unlike liberalism, CR perspectives do not categorize dependency as a sign of not being autonomous, but acknowledge that all people are interdependent, and that having someone to depend on may actually increase one’s level of autonomy (Carey 2009; Shakespeare 2014). For example, a person with autism may not be able to communicate verbally, and thus may depend on a 1:1 aid to be able to communicate their needs when out in public. Liberalism would consider the need of a 1:1 aid as restrictive because the person with autism must depend on another person. In contrast, CR would consider the use of a 1:1 aid as a way to increase autonomy because now the person with autism is actually able to access the community while having their needs met.

Systemic factors. Issues of disability are connected to multiple systems of power (e.g., social values and norms, priorities of institutions, and the political climate). All these systems influence disability, and the responsibility (burden) of managing these systems falls on people with disabilities (i.e., the person needs rehabilitation). People with disabilities start out in a lower position of power, as they are in need of services in the first place, and rely on these intuitions to provide necessary supports. To address this power imbalance, CR takes a bottom-up approach by starting from the lived experiences of people with disabilities and exploring the challenges they face. This leads them to the source of power and their object of exploration (Pothier and Devlin 2006; Shakespeare 2014). In other words, this approach—by placing responsibility and accountability on society and its organization, rather than on individuals with disabilities—makes the organizations the focus of research.

Further, this approach points out the cost-benefit analysis associated with providing disability services. Service agencies like regional centers have the authority to determine which services they consider appropriate and to prioritize those services.

Policies driven by the social approach to disability mandate that people with IDD live and participate in society in the least restrictive environment possible, meaning they should be in the most independent setting possible (Carey 2009; Shakespeare 2014; Turnball 2012). However, the CR approach recognizes how budget constraints limit what 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 but in the most cost-effective manner. Such contradictory aims contribute to the agencies' power by favoring institutional needs over the individual's right to autonomy (Carey 2009; Turnball 2012). CR explains that no matter how accessible we make our society, a significant portion of people will continue to be excluded when using a cost-benefit analysis, since in many cases, the cost of their inclusion exceeds the benefits of their exclusion (Pothier and Devlin 2006:18).

This critical realist approach to disability is critiqued by positivists as being "non-academic," because it promotes the use of multiple ontological assumptions that contradict each other (i.e., taking a dualistic approach by using medical and social models). Shakespeare (2014:83) counters this by explaining that multiple approaches and methods are sometimes required in order to be able to fully understand disability. Disability studies that work within a CR framework are designed in a way that illuminates specific issues influencing how disability and barriers are experienced. For example, Frazee et al. (2006) used multiple approaches to study the way gender and disability are constructed and dictated by administrative/legal policies that influence the relationships between the institution and disabled service recipients. Frazee et al. (2006) conducted focus groups with disabled women and mapped elements located within institutional texts to identify how laws and regulations shaped the different ways women interacted with healthcare systems. They found that the state implemented tools of surveillance and discretion in ways that superseded legal protective measures in place to protect the service recipient's right to confidentiality. This example illustrates how a CR framework provides a solid foundation for understanding the way disability is influenced by multidimensional factors.

Challenges in Human Service Delivery Systems

People with disabilities are forced to navigate various state and federal institutions, including Social Security, Medicaid, and Department of Rehabilitation. Further, people with IDD frequently depend on disability service agencies like California's regional centers to provide them with services in the community. Service recipients of any human/social service agency automatically start in a position with little-to-no power when compared to the power of the service agency (Carey 2009; Pothier and Devlin 2006). This is supported by studies by Dowse (2009) and Ward and Meyer (1999), who found that professionals hold most of the control over the lives of people with IDD.

There is a large body of literature that raises concerns about the level of power professionals have over determining who is labeled incompetent. Work by Demer (2018), NCD (2018), and Moye and Naik (2011) raised concerns regarding professionals overly relying on diagnoses that presume incompetence. Dowse (2009) and Hafemaster and Sales (1984) examined concerns associated with state agencies' efforts to measure an individual's decision-making capacity. They pointed out that relying on professionals to measure one's capacity to make decisions results in "absolute discretion" being granted to the professional completing the competency assessment. 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 consists of a summary of the client's functioning level and whether it supports the need for conservatorship (CANHR 2014). This is an example of the high-level discretion that service agencies exercise.

Stancliffe et al. (2011) used data from a national core indicator survey, which is an instrument used to represent and measure the national goals of service provision for people with IDD. Stancliffe et al. (2011) examined these data to measure the degree of choice adults with IDD had in choosing where and with whom they live. The authors made comparisons across levels of disability (i.e., mild, moderate, severe). They found that 55% of participants were given no say in where they lived, despite numerous disability policies that require the service recipient's choice of living arrangement be considered. The same study also found that the level of choice one had in their living arrangement was significantly impacted by their level of disability. The authors looked at instances where "choice" wasn't really much choice at all, as in the example of an individual's being given a choice of living arrangement, but only between two group homes. Such findings suggest that agencies restrict the level of choice people with IDD have by only presenting them with limited options. This gives the appearance of honoring choice, when in reality, the choices presented are controlled by the agency.

Guardianships and Conservatorships

Every state in the United States has some form of policy for implementing conservatorships/guardianships. However, there is not a single federal law in place guiding the way states handle guardianship proceedings (Millar 2013; Moye and Naik 2011). Recent reports indicate that the lack of guidance and oversight can lead to negative consequences. For example, in an examination of guardianship and current practices across the nation, the U. S. Senate Special Committee on Aging (2018) reviewed over 100 solicited responses from states and courts across the country. It found that people under guardianship were at high risk for abuse (e.g., financial and neglect) and emphasized the need for (a) more reliable data on guardianship arrangements; (b) improved oversight of guardians, and (c) increased use of less restrictive alternatives, such as power of attorney.

In another study, the National Council on Disability (NCD 2018) published a report based on an extensive review of literature and 46 qualitative interviews with various participants, including people under guardianship, family members, service professionals, and advocates. Like the U. S. Senate Report (2018), NCD (2018) found that a lack of data hinders guardianship reform. It found several systemic problems related to implementation. One was failure to require that less restrictive measures be explored (e.g., supported decision-making or power of attorney). Another was how guardianships are rarely reversed, even though each state has processes in place that can restore rights removed unnecessarily.

A substantial portion of literature on guardianships focuses on the development of guardianship laws and policies and questions the overall impact they have on those with established guardians. Generally, this work focuses on the benefits and risks of guardianships (Arsenault 2017; NCD 2018). A non-academic news article published by the Associated Press (1987) exposed the high levels of abuse, such as isolation, neglect, and financial fraud that people under guardianship face. This led to an increase of legislation throughout the country that aimed to reform the broken system (Arsenault 2017). However, it is now 30 years since the Associated Press article, and people under guardianship continue to face high levels of abuse and neglect (NCD 2018; U. S. Senate Report 2018).

Greenwood et al. (2014) suggested that guardianships do not always protect people with IDD from harm and neglect. They found that implementation of guardianships alone cannot prevent abuse, and that well-intentioned guardians may unintentionally cause harm. Greenwood et al. (2014) conducted 16 interviews with guardians of women with IDD and found that guardians resisted taking their disabled family member for routine mammogram screenings because they felt this would unnecessarily traumatize their family member with IDD. The hesitancy to follow through with standard cancer screenings may have come from a genuine concern for the IDD person. Nevertheless, this resulting resistance to a healthcare screening can unintentionally place their family member at higher risk of dying from breast cancer due to lack of preventative care.

Other researchers have suggested that guardianships can benefit individuals by facilitating and supporting choices of that individual. Findings from Millar (2008) demonstrate how, in some cases, guardianships can increase one's ability to coordinate and access services that increase their level of independence. In contrast, a review of national survey data found that this goal is hindered for some, because IDD adults under guardianship are more likely to live in group homes and less likely to be involved in making everyday decisions about their lives (Bradley and Hiersteiner 2019). These studies demonstrate how guardianships can both increase and limit access to resources, as well as promote or hinder autonomous decision-making. However, they did not explain the processes that create these discrepancies.

Other literature on guardianship focuses on the overutilization of guardianships, regardless of many states' acknowledging that competence is not "all or nothing." Many states have enacted legislation authorizing limited guardianships, which, compared to a general guardianship, limit the powers given to a guardian (Carey 2009). This raises the question, how often and how appropriately limited guardianships are used when they are available. Millar and Renzanglia (2002) completed a content analysis of 221 Michigan court files and found that 100% of the requests for guardianships were granted and, of these, 54% were for full guardianship. Further, they noted that 13% of cases had requested limited guardianship but were granted full guardianship. These findings are consistent with those of Bradley and Hiersteiner (2019), who reported that 42% of adults with IDD living in the U.S. were placed under full guardianship, while 7% were placed under limited guardianship. These studies underscore the degree to which service and legal institutions in multiple states and jurisdictions still take a binary, “all-or-nothing” approach to measuring capacity and fail to consider multidimensional aspects of disability and impairment. The combined evidence reveals that states overutilize guardianships to support adults with IDD, but current studies do not address how this is happening and how it is experienced.

Another portion of literature examines systemic issues related to the process of establishing guardianships. Millar and Renzanglia’s (2002) content analysis, described above, found that of the 221 cases reviewed, the average length of time spent on a hearing was seven minutes. Other researchers have focused on processes related to utilizing less restrictive alternatives to guardianships. For example, Jameson et al. (2015) completed an online survey of 1,222 people involved in the guardianship system. This included parents and guardians of adults with IDD under guardianship as well as people seeking more information or training on guardianships and alternatives. The authors found that, of those surveyed, 58% had not received any training or education on guardianships and alternatives. The study also found that 41% of respondents said the idea of establishing guardianships had first been suggested by a trusted professional e.g., teacher, social worker, or attorney), who did not discuss any alternatives (Jameson et al 2015). These findings add weight to the argument that adult guardianships are favored over less restrictive alternatives and are overutilized.

Millar (2007) conducted focus groups with students, parents, and educators to explore the extent to which the participants understood guardianships and alternatives. The findings showed that the majority of participants had a very limited understanding of the responsibilities guardians have and were not well informed on less restrictive alternatives (Millar 2007). In a similar study, Brady et al. (2019) interviewed 10 siblings of adults with IDD and found they had insufficient knowledge of what guardianship actually means, as well as very limited knowledge about less restrictive alternatives available.

Other work focuses on the role external parties (e.g., medical practitioners, social workers) have in the process. For example, Gibson (2011) reviewed 240 clinical assessments for 80 court petitions seeking guardianship over older adults. In examining these assessments for comprehensiveness (e.g., consideration of LRA), he found they overwhelmingly relied on medical diagnoses to make recommendations. He found the assessment authors did not include imperative information like strengths, use of LRA, or rationale for recommendations. Similarly, in my thesis work (Imle 2016), only 44% of participating regional centers require training on limited conservatorships for service coordinators and managers, and only 68% require that the service recipient’s opinions and wishes be documented in the assessment they complete for the court.

A consistent finding across these studies is that a lack of institutional standards and lax oversight fail to ensure that guardianships are implemented only as a last resort. These studies also suggest that utilizing least restrictive measures is not a high priority for institutions and organizations. They do not, however, explain how policies that mandate least restrictive alternatives get overlooked or ignored in the process of establishing guardianships.

In summary, current literature shows that adult guardianship policies and practices are (a) applied inconsistently across states and even across counties; (b) lack resources, guidance, and oversight; (c) are overly restrictive/utilized, and (d) do not guarantee that the person under guardianship will escape abuse or neglect and may place them at greater risk of abuse. However, there is little information on how the actual process and practices operate when establishing a guardianship and how it is experienced by the multiple people involved. In other words, there is a gap in the literature that fails to connect how external factors (e.g., service delivery practices) shape individual experiences. This study addresses this gap by answering two research questions: what is the process of establishing a limited conservatorship in California, and how is this process experienced by those involved?

Institutional Ethnography (IE) offered the most complete and appropriate framework in which to accomplish this research, as it allowed me to explore and connect individual-level experiences to larger (macrolevel) external forces, such as governing agencies like the regional centers.

In Chapter 3, I discuss IE more fully as the theoretical framework for the current study. I first provide background and discuss ontology and epistemology for the theory. I then explain central IE concepts as well as how IE differs from conventional qualitative and ethnographic research.

CHAPTER 3: INSTITUTIONAL ETHNOGRAPHY (THEORETICAL FRAMEWORK)

The most appropriate research strategy to answer my research questions was Institutional Ethnography (IE), which can be understood as its own distinct sociology with its own epistemology and ontology (Smith 2005, Smith 2006). IE is a critical feminist “mode of inquiry” developed by Dorothy E. Smith, to understand how individual experiences are organized and subordinated to larger institutional factors. IE is a powerful tool that can be used to spark social change and support activism. The main goal of IE is to create practical and accessible knowledge about institutional forces that will benefit the marginalized group who depends on them for services or resources (Campbell and Gregor 2004; Smith 2005; Smith 2006).

IEs begins with a specific problem or an issue from the standpoint of those subordinated. The object of inquiry is the institution, and the goal of research is to critically explore how institutional social relations and practices are organized in a way that produced the problems experienced on the individual level. Exploring the functions of institutions and the interconnected ruling relations sheds light on how our lives are organized by language and texts (Smith 2005:68).

Ontology and Epistemology

What is unique about the IE framework is that it focuses the lens on macrolevel institutional processes and power dynamics, but from a microlevel viewpoint of lived experiences (Smith 2005:68). IE can be described as “combining Marx’s materialist method and Garfinkel’s ethnomethodology with insights from the feminist practice of consciousness raising" (Smith 2006:16). This is an unconventional, anti-positivist approach and requires radical "ontological shift" (Stanley 2018:23).

Central IE Concepts

Three central IE concepts aid the researcher in making the shift needed to explicate relations and practices between macro- and microlevels. These concepts are (a) standpoint, (b) ruling relations, and (c) texts/discourse.

The first concept central to IE is standpoint. Standpoint is a concept located within feminist epistemology, or way of knowing (Smith 2006; Stanley 2018). Standpoint stresses that knowledge is socially constructed and is not neutral, as knowledge is a tool that can be used to enforce power/domination over a subordinate by excluding their own knowledge and experiences as "subjective" and not "fact." Standpoint privileges lived experiences over abstract theory and challenges essentialism's tendency to value so-called "objective" science over lived experience (Campbell and Gregor 2004; Smith 2006). This allows IE researchers to draw from and include their experiential knowledge in their work and rely on personal and individual experiences as the point of entry into their investigation of larger (macrolevel) processes (Deveau 2008). Smith (2005) refers to these processes as ruling relations.

Ruling relations is the second key concept to IE and has roots in Marx's materialist approach, "which understands that the everyday world (the material context of each embodied subject) is organized in powerful ways" (Smith 2006:17). IE retains the assumption that humans are social beings and that our lives are socially organized through social relations and activities (Campbell and Gregor 2004; Smith 2006). Smith reframed this Marxist ontology, expanding the concept of social relations, which refers to "the coordinating of people's activities on a large scale, as this occurs in and across multiple sites, involving the activities of people who are not known to each other" (Smith 2006:17). This reframing introduces her concept of ruling relations, which refers to the social relations (macrolevel) that organize and control the activities of actual individuals at the local level (microlevel). Smith (2005) defined ruling relations as activities or venues such as institutions, laws, or procedures that "activate" practices and actions that govern and organize how work is carried out. The purpose of ruling relations is "to co-order and coordinate the activities of people in and across various and multiple settings" (Deveau 2008:3). In other words, ruling relations are actions and practices that govern, control, generate power, and maintain social order (Rankin 2017a).

Ruling relations take form through a variety of instruments or tools such as established institutions (e.g., schools), texts, laws and policies, and practices. Texts are materials (e.g., websites, books, manuals, assessments, intake forms) that can be replicated and circulated across time and locations, and are instruments used to administer work (Rankin 2017b). Texts are one of the main ways institutions are able to shape experiences and lives. Smith (2001) argues that texts are "essential to the objectification of organizations and institutions and to how they exist" (160).

Deveau (2008) examined a police report as a tool of ruling relations used to summarize/document the death of his mother, developing certain facts and knowledge to determine what actions, if any, would be taken (e.g., determine cause of death as homicide or natural causes). This is an example of textual mediation (Smith and Griffith

2014), or how what is or is not included in the official accounts can dictate different sets of actions and consequences. In other words, texts act as tools that an IE researcher can use to trace individual-level actions back empirically and physically to regulatory texts and can act as a tool that subtly operationalizes systems of oppression.

How IE Differs from Conventional Qualitative and Ethnographic Research

Smith (2005, 2006) is very clear that IE is a theoretical approach distinct from traditional qualitative and ethnographic research. Smith resists IE's being lumped into qualitative research because doing so constrains the researcher's tools. For example, qualitative research begins with and is framed by theory. Final analysis in IE also takes a different form from conventional qualitative methods that code data based on predetermined themes and concepts, as this reduces a person to a piece of data to be counted or to represent an abstract theory (Rankin 2017; Holstein and Gubrium 2003. In IE, the data are indexed or categorized, and organized around settings, steps in process, threads, and documents (Campbell and Gregor 2004, Stanley 2018).

To distinguish their work from conventional methods, IE researchers avoid determining and causal language such as "structures," "influences," or "impacts." Instead, they use words like "connects," "links," "frames," "shapes," "channels," "paths," and "threads." IE researchers also refer to interview participants as informants, participants, or a sample of population. For this reason, IE research does not gather typical demographic information like gender, race, or class (Holstein and Gubrium 2003). Smith's argument for not including these factors in research design is to ensure that the focus of inquiry remains on governing institutions as the suspected source of the problem and thus the object under investigation, not the individual informants (Holstein and Gubrium 2003).

There is not a standardized way to conduct an IE, as the approach is committed to being fluid and reflexive, leaving the researcher free to adapt as the research process evolves. Methods that IE employs for data collection most commonly include interviews, observations, and text analysis ((Rankin 2017; Smith 2006; Deveau 2008).

Analysis in IE is centered around explication of information gathered and is congruent with data collection. The goal of explication (final analysis) in IE is to explain/detail a process, not to generate a new theory or support for a theory. IE does not aim to highlight gaps, but aims to identify issues and highlight potential sites for change (Rankin 2017; Smith 2006; Deveau 2008; Turner 2014).

Next, in Chapter 4, I discuss the methods utilized for this study.

CHAPTER 4: METHODS

Positionality Statement

This research is extremely personal and is influenced by my life experiences. Therefore, it is imperative to acknowledge my positionality and discuss how this influenced my research. To start, I myself have disabilities and can relate to many of the struggles faced by people with IDD, including the effects of presumed incompetence, being segregated from peers in educational settings, and being forced to rely on and navigate bureaucratic service systems. Further, I have spent nearly 20 years working in California’s regional center system. Over nine of these years were spent working as a case manager at two different regional centers in two different counties. My duties included assessing the needs of and coordinating services for an average of over 85 people with IDD, as well as handling administrative tasks such as writing reports, record keeping, and filing.

Since this research was motivated by personal experiences, I want to begin by recognizing my many positive experiences with the caring, dedicated professionals who work in regional centers, DDS, probate courts, and elsewhere within the system. To this day, I consider many of these people to be my closest friends and chosen family. I hold the mission of and the people working within the system very close to my heart. It is where I feel most at home and want to be. The sole intent of this research is to explicate a complex process in order to identify issues and develop practical solutions. My attention to the regional center system and its challenges comes from a place of care. If I did not genuinely care for and believe in the regional center system, I would not have spent nearly 20 years working within it and an additional seven years researching it. In other words, I am critical because I care.

My time working at two regional centers not only provided extensive hands-on experience with the process of establishing a limited conservatorship, but also exposed flaws within the system that had negative consequences for the clients. While both regional centers were following the same state laws, they implemented those laws in very ways. The first regional center I worked for had designated case managers given specialized training to assess the need for conservatorship and to make recommendations to the courts. Strict procedures were in place that guided the assessment process, and attending the court proceeding was required. My second experience was very different. At the second regional center, the assigned case manager was responsible for assessing the need for conservatorship and responsible for make recommendations to the court. Training on conservatorships was not mandatory, there were lax procedures guiding the process, and attending the hearing was not required.

These two very different experiences not only motivated me to return to graduate school to study implementation of guardianship policies but also shaped this study. For example, I knew from experience that limited conservatorship hearings were open to the public. So, I knew where to go and what to expect while conducting observations. Additionally, my experience working as a service coordinator meant that I was already familiar with many of the documents and texts involved in the process. I also had a fundamental understanding of the work involved with limited conservatorship requests.

This experience aided me in developing interview questions and in targeting the focus of my attention.

The remainder of this chapter focuses on the methods employed in this study, which aims to understand the process of establishing limited conservatorships in California, while paying specific attention to the role regional centers have in the process. First, I examine the organization and implementation of practices for establishing limited conservatorships across multiple sites throughout California. The guiding questions of this study were as follows: 1) what is the process of establishing a limited conservatorship in California; 2) and how is this process experienced by those involved?

I decided on the regional centers as my main site of inquiry because IE frames experiential knowledge as the lens through which to explore. As discussed above, I benefited from my knowledge of and connections within the California service delivery system. My experiential knowledge aided with designing my methodological approach and also facilitated easier access to the site.

Data Collection

For this research, I employed the methods typically utilized in institutional ethnographies, including observations, interviews, and text analysis. The majority of the data was gathered concurrently over a 19-month period, from January 2020–July 2021. The final analysis and writeup took place between August 2021–October 2022.

In total, the research results described in this dissertation consist of 27 hours of observing limited conservatorship hearings, 16 semi-formal interviews with 18 informants, analysis of over 40 texts (e.g., forms, websites, manuals) related to the conservatorship process, and numerous casual conversations with people I met throughout the research process. All participants, locations, and agencies involved in this research remain confidential, and informants are solely referred to by titles/agencies to protect identities and locations.

Interviews

I completed 16 semi-structured, informal interviews with a total of 18 informants between April 2020—July 2021. To locate informants, I utilized a purposive and snowball sampling process, which means that I asked participants to assist me by connecting me to other potential participants they knew. This also helped ensure all participants fit within the scope and nature of the study. I started by recruiting those I already knew through professional work experience. I initiated contact by emailing them an invitation to participate along with an information sheet that explained the purpose of the study. To encourage and increase chances of participation, I entered all interviewees in a raffle to win a $50.00 incentive. The drawing was held in September 2021, and the winner, a vendor of the regional center, chose a Starbucks gift card as their incentive. This was mailed to them the following week. These techniques were appropriate and effective, as I was able to secure 16 interviews with 18 informants. Saturation, which is the point at which data no longer generates new information (Guest et al 2006), was met after completing 16 interviews. When responses to interview questions became predictable, I felt confident that I had reached saturation. For example, after 16 interviews, I knew to expect that lack of state guidance was an issue that was going to continue to be raised by most, if not all, informants. Informant details are described next.

Informants. All informants met the following criteria: (a) over the age of 18; (b) live in California; (c) have knowledge of and experience with regional centers and the process of establishing limited conservatorships; (d) able to participate in a telephone/virtual interview, and (e) able to understand and consent to participating in research. No participants were turned away from participating in this research for any reason, as all interested informants met participation criteria. Verbal consent/assent was obtained as needed. See Table 1: for a description of informants.

Table 1: Informants

Site	#	Informant Title/Role	Years of Experience
Regional Center	1	Service coordinator	15+
Regional Center	2	Service coordinator	20+
Regional Center	3	Service coordinator	10+
Regional Center	4	Manager	15+
Regional Center	5	Manager	5+
Regional Center	6	Vendor (conservatorship services)	20+
Regional Center	7a*	Peer advocate/conservatee	20+
Regional Center	7b*	Parents/conservators	20+
Regional Center	8	Peer advocate	20+
Regional Center	9	Parent/activist	20+
Nonprofit	10	Director/activist	20+
Probate Court	11	Other	20+
Probate Court	12	Attorney	10+
Probate Court	13	Attorney	5+
Nonprofit	14	Director/activist	15+
Nonprofit	15	Director/activist	5+
Regional Center	16	Vendor (psychologist)	20+

*Note: *Interview 7a/7b was a single 3-person interview*

Two informants were peer advocates (individual with IDD employed by regional center to help other clients access regional center services), and three were parents/conservators of regional center clients. The other 13 informants were various professionals representing a range of roles within the service delivery system. Their occupations include five regional center employees (three service coordinators, known as SCs, and two managers), three probate employees, two regional center vendors, and three reform activists/nonprofit founders/directors. IE researchers also avoid the use of pseudonyms (Holstein and Gubrium 2003), as this might risk identifying informants by continued use. In this research, informants are referred to by their work settings and/or roles (e.g., “a regional center service coordinator”). Pseudonyms are used only for the names of the two counties where observations took place.

Interview structure. Interview questions were semi-structured and included both closed and open-ended questions. Interviews were casual in nature. Interviews lasted between 45 minutes and two hours, with an average of about one hour. All interviews were conducted over the phone or via Zoom. I began with a list of questions, but the process was fluid and emergent, allowing me to improvise and adapt questions as needed. The questions were designed to elicit responses that helped explore the process of establishing a limited conservatorship, including what work is required, what that work looks like, and how it’s experienced by the people involved (see Appendix A for sample interview questions). I generated the questions based on my previous knowledge and experience, observations, document reviews, and previous interviews.

I contacted all informants via email with an information sheet, scheduled the interview, then sent a follow-up email with virtual meeting details. I began the interviews by reminding informants of the voluntary nature of the study, that they could decline to answer any questions, and could stop the interview at any time. I adapted interview questions as needed based on the individual's experience and expertise. All interviews were recorded and professionally transcribed by Gotranscript.com. Once transcripts were received, I read through them twice to get a general feel and then uploaded them into MaxQDA for analysis.

During interviews, I took note of the time on the recorder and wrote this on the interview sheet. This aided in being able to locate specific parts of the interview quickly and easily. After each interview concluded, I immediately wrote an account with a summary, my thoughts, and memos summarizing important moments.

Observations

In total, I spent 27 hours observing new requests for limited conservatorship hearings in the Superior Court of California—Sunny County and Lovely County (both pseudonyms). Overall, I observed a total of 93 judgments on new petitions for limited conservatorship. In Sunny County, three probate departments are overseen by three different judges. The one department I observed in Lovely County is typically the same judge. However, this judge was absent for an extended period, so my observations included temporary judges filling in for the regular judge. Lovely County is also one of three counties in California that uses public defenders (PDs) to represent proposed conservatees. In this county, I always observed the same public defender, except for one day when an assistant public defender sat in their place. In Sunny County, the probate department utilizes a panel of attorneys who are approved to serve as the court-appointed attorney (CAA) to represent proposed conservatees. In Sunny County, I observed numerous CAAs, but did not gather data on how many I observed, since they were not the focus of this research.

I was able to complete one in-person observation at each site before the COVID-19 pandemic shut everything down in March 2020. (I expand on how the pandemic impacted my methods at the end of this chapter.) The remaining hours of observations were conducted virtually via Microsoft Teams or Zoom. Because of my previous work experience, I was easily able to identify and find the exact probate departments I wanted to observe. I started by accessing the websites for each Superior Court I planned on observing. From there, I followed the appropriate links to their probate departments, to locate the judges who hear limited conservatorship petitions and then to access their probate courtroom calendars.

Sunny County probate court schedules most limited conservatorship hearings on Thursdays, in three different departments overseen by three different judges throughout the day. For example, in Department “A,” court sessions (or calendar sessions) begin at 10am and 1:45pm, and in Department “B,” sessions are scheduled to begin at 10:30am and 1:30pm. In Lovely County, limited conservatorship hearings are primarily heard in just one department, and these sessions are regularly scheduled on Tuesdays at 1:45pm. The number of cases being heard varied, and I did not gather specific data, but I estimated a typical calendar session had about 60 items/cases on the docket in Lovely

County and 10-to-30 items/cases on the docket in all three departments in Sunny County. It is important to note that these sessions included two types of conservatorship requests (i.e., general and limited). Sometimes, cases with existing limited conservatorships were being heard to add co-conservators, or for other reasons. As a result, many of the cases on the docket were not relevant to my research, as this was not my focus. I gathered data only on the new petitions for limited conservatorships. After locating the probate courtroom calendars, all that was required was to show up, as most probate hearings are open to the public. Although, in Lovely County, one judge explicitly stated they were holding off on "complicated cases" until the end of session and removed all those not directly involved in such cases from the virtual courtroom without advance warning or further explanation.

I used two research tools during observations (i.e., in-person and virtual). The first was a steno pad used to write down general observations. The second was an Observation Data Collection Tool (see Appendix B), a custom log sheet that I created to document the outcome of each case I observed. With this tool, I documented (a) type of request (how many powers were requested); (b) if a regional center assessment was received; (c) if the regional center report supported the petition; (d) if a regional center representative was in attendance; (e) how long the hearing lasted; (f) how involved the proposed conservatee was (for example, present? spoken to?); (g) final decision (e.g. what specific powers were approved?), and (h) miscellaneous memos (e.g., if the attorney had objections, if the proposed conservatee was still a minor). After completing my observations, I wrote a brief journal entry summarizing what I had observed and noting moments of particular interest, as well as any questions I had. Once all my observations were complete, I took my handwritten field notes and the log sheet Observation Data Collection Tool and typed out everything that had been documented. Once all notes were typed, I had a total of 25 pages of single-spaced field notes.

In-person observations. Both of my in-person observations were conducted in January 2020, before the COVID-19 shutdown. I observed one department and one session in Lovely County and two departments (two different judges) and two sessions on the same day in Sunny County.

For the in-person observations I arrived at the courthouse early to allow time to explore and observe the general setting. I dressed in professional casual clothing (i.e., slacks, plain tee, and cardigan), which helped me blend in with the other attendees. When the sessions were called (i.e., when the bailiff calls everyone into the courtroom) I queued up with everyone while we filed into the room. For all in-person observations, I chose seats that were toward the back and as far against the wall as possible, so that people directly involved in the hearing had access to the seats closer to the aisles. This also allowed me more privacy to take field notes. For the most part, I went unnoticed, but in Lovely County, I was asked by one bailiff, “What matter are you here for?” I responded that I was “just observing,” and that was the end of the exchange. At most observations, while waiting for the judge to arrive, I would typically chat with other attendees. Some of these chats proved to be useful for my research. For example, I sat next to the same woman twice while observing in two different departments in Sunny County. She recognized me while we were waiting for the second department to be called to order and asked if I was there to complete observation training as well. I told her I was not and explained the research I was doing. She said she was a court-appointed attorney “in training,” and observing hearings as part of her requirements. We chatted for a few minutes, and I was able to get her opinion on specialized areas where she wanted more training (e.g., how to communicate with people who have IDD and how to assess one’s level of understanding if the person is non-verbal).

Virtual observations. Accessing virtual hearings was more challenging than accessing them in-person. Both counties had temporary court closures because of COVID-19 from March 2020–June 2020 and then resumed hearings (virtually) in mid-June. I started my virtual observations in October 2020. Each county had a different approach to virtual hearings. For example, Lovely County started out using MS Teams and later transitioned to the Zoom platform, while Sunny County used Zoom throughout. Finding the links to access the virtual hearings was extremely tedious and time consuming in both counties. Once links were found, it was relatively easy to access and join all virtual sessions. Virtual hearings, which I observed from my home office, were more time-efficient and provided several advantages that in-person attendance could not. I kept my video off and remained muted at all times (unless the court asked why I was there). This removed the risk of my appearance or actions influencing the people or events I was observing. Virtual observations also enabled me to take notes constantly without being scrutinized by court employees.

These hearings are public, but I met other advocates who had been asked to leave court sessions for just observing. On the few occasions I was asked why I was there, I responded by saying, “I am a member of the public here to observe.” This response was never met with a negative response, although on one occasion, I heard one court employee remark, “Who the heck would want to spend their time observing these?”

Text analysis

I selected texts (see Table 2) to analyze based on my previous knowledge of the process. Observations and interviews also helped to provide or identify documents for analysis. For example, two texts I used were provided by informants. One was obtained from a limited conservatorship clinic I visited during in-person observations. (It should be noted that this clinic, available to the public for help with limited conservatorships, dealt exclusively with how to obtain one and not how to terminate one or restore rights to a conservatee.) Text analysis was an ongoing process in the research between January 2020–September 2022.

Most documents gathered were publicly available online and do not contain any private or identifying information. Documents provided by informants had confidential information removed. Analysis included several conservatorship-related documents, websites for California codes of law and code of regulations (Prob, WIC, HSC, Title 17); Superior Courts of California website, and 25 IDD service agency websites including all 21 regional centers, the Department of Developmental Services, State Council on Developmental Disabilities and Disability Rights California. These agencies frequently upload regional center documents to their websites. The intent of exploring these sites and documents was to understand how these agencies organize information and the amount and content of information publicly available on the topics of limited conservatorship and LRAs.

Table 2: Documents Included in Analysis

Document Originator	Document Name
Regional Center (RC)	Conservatorship assessment report template (see Appendix C)
	Individual Program Plan (IPP)
	Client Developmental Evaluation Report (CDER)
	Service coordinator training manual
	Service coordinator performance evaluation
	Regional center performance contracts
	HCBS Waiver Primer and Policy Manual
	Special Incident Report (SIR)
Probate Court	Petition for Appointment of Probate Conservator (see Appendix F)
	Petition to Terminate Conservatorship
	Confidential Supplemental Information (see Appendix G)
	Probate investigation report
	Capacity Declaration (see Appendix H)
	Court-Appointed attorney training manual
	Judge's Handbook
Websites	Source of Documents
	Separate websites for each of 21 RCs (see Appendix)
	Department of Developmental Services
	CA State Council on Developmental Disabilities
	Disability Rights California/Office of Client's Rights Advocacy
	Association of Regional Center Agencies
	California Code of Regulations (Title 17 & Title 22)
	California Codes of Law (Prob, WIC, H&S)
	Superior Court of California (Probate Division)

Final Analysis/Explication

I structured my final analysis around particular stages of the process and sources of tension in the process, rather than interpretive/thematic coding used in conventional ethnographies. I gathered and separated documents and combined them with field notes, interviews, and observations so that I could investigate connections between sites. By organizing data by site or by moment of time within the larger process (i.e., establishing a limited conservatorship), I was able to explore regular practices and ways in which this work is accomplished. I was also able to examine some of the ways text's structure their work. This allowed me to map the connections among regional center employees who do work related to limited conservatorships, the texts they use for this work, and the institutional ideology that guides the work located in the larger, overall process (i.e., petition, assessment, hearing, and monitoring).

Tools used to assist in analysis included indexing with MaxQDA, a qualitative data analysis software used to index, organize, and categorize data. I developed index categories, refined multiple times, based on locations of actions, the phase in the process, issues related to single sites, and those that are experienced across all sites. I also used IE mapping techniques, such as mapping the sequential steps of the process (Turner 2014) of establishing limited conservatorships, as well as small hero diagram (Smith 2006:3) of the different sites/institutions (individual, probate court, regional center) where the processes take place. I explored how staff at each site performs in relation to each other. I then considered the textual aspects of each site and finally, examined interpersonal/ideological dynamics that are present at each site and that enable the work of the system to be accomplished.

Overcoming the Unexpected

A global pandemic that closed down public areas was a challenge I did not plan to encounter during the proposal phase. The pandemic did not impact interviews, since those were already arranged to be through telephone or Zoom. However, shutdowns related to the pandemic did halt all limited conservatorship hearings from March 2020–

June 2020. This is when the courts converted to virtual hearings through Zoom or Microsoft Teams.

Overall, changes required by the pandemic were not very disruptive to this research. There were both negatives and positives. The process suffered from more delays than usual. The Zoom learning curve varied significantly for probate court participants and could delay the start of a virtual hearing. Another negative is that I lost the spontaneous opportunities provided by in-person observations, where I could chat with people and explore the limited conservatorship clinic in Sunny County. On the plus side, virtual hearings were easier to access, requiring less time and expense to attend, since I did not need to pay for gas or parking. These also provided the privacy of being hidden behind a screen, allowing me to take more notes than I did in in-person observations because I did not have to risk causing notice and influencing the proceeding.

The pandemic aside, other unexpected challenges arose from the level of complexity and bureaucracy related to limited conservatorships. There were moments when this academic research felt more like investigative journalism. For instance, locating one policy in writing could take hours longer than expected, causing delays in progress and overall completion. One example is that it took over three hours to locate the petition to terminate a conservatorship. This crucial form initiates the process to restore a conservatee’s rights, and was not included with the 60+ other probate forms available on the Superior Courts of California website. Another example is my time-consuming efforts scrutinizing the probate codes to gain an understanding of the

Confidential Supplemental Information form, a key court document that remains a mystery to most parties other than the petitioner and the judge.

Maximizing Trustworthiness

Institutional ethnographies can receive criticism from positivists for not being generalizable and not being replicable. To overcome this, my goal was to maximize trustworthiness of data, meaning the research is valid and empirically sound (Connelly 2016). I accomplished several different ways. Most of the data can be easily verified. For example, limited conservatorship hearings are held throughout the state and are open to the public. So, a similar study could take place elsewhere in the state and would likely produce similar results. Further, most of the documents and texts I examined can be easily verified for accuracy because they are public and easily accessible online. I took additional steps to ensure accuracy by making sure all informants had the opportunity to review and verify data obtained during their interviews before analysis was complete

Finally, to maximize transparency, I kept a complete log of websites I reviewed and maintained a journal in which I recorded, in detail, how research was conducted and why I why made the choices I did (Creswell 2006). All these steps maximized the trustworthiness of this study, ensuring it was reliable and empirically sound (Connelly 2016).

Next, Chapter 5 breaks down California’s IDD service delivery system as well as the limited conservatorship process.

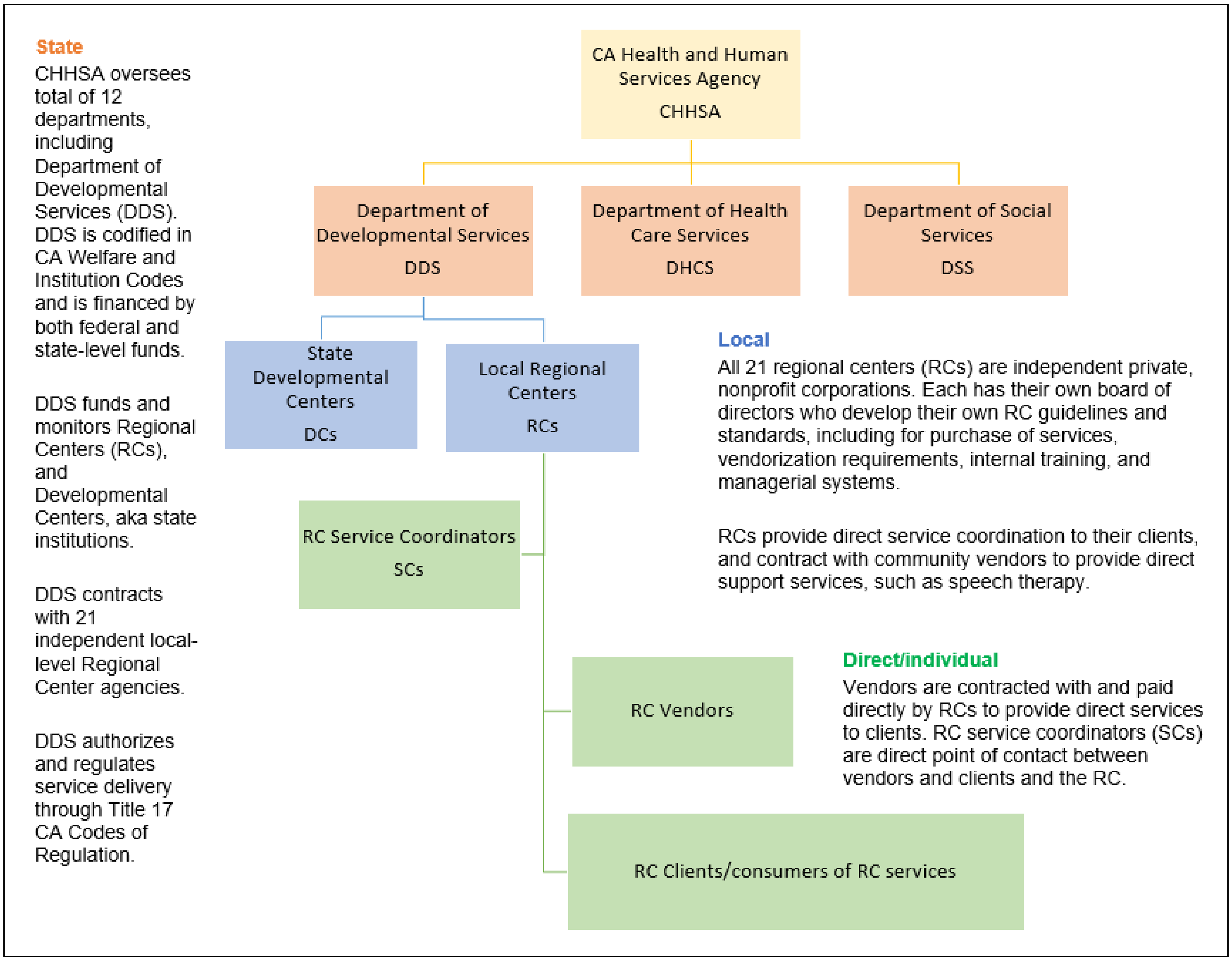
CHAPTER 5: BACKGROUND OF CALIFORNIA'S IDD SERVICE DELIVERY SYSTEM

It is helpful to have a basic understanding of how California's IDD service delivery system and probate systems are organized and work together within the overall process. Therefore, in this section, I break down the various agencies and functions within a complex system of service delivery.

California's IDD Service Delivery System

According to state websites, such as that of the Department of Developmental Services (DDS 2022), legislation known as the Lanterman Act made California the only state in the nation that guarantees its residents with IDD access to services enabling them to live in a most inclusive setting. California delivers this guarantee through a system of state and local-level organizations (see Figure 1). These include the Department of Developmental Services (state-level) and 21 local/county-level regional centers (county-level).

The Lanterman Act (1969). The Lanterman Act, often referred to as "the Act," is the foundation of California's service delivery system—a network of numerous interdependent agencies (DDS, regional centers, vendors, and departments that are funded by federal and state governments. The Lanterman Act is codified in the California Welfare and Institution Code (WIC) sections 4500-4906. It is these sections of law that entitle Californians with IDD to services that foster their inclusion and participation within the community. This law guarantees that Californians with IDD are entitled to the same rights as all other citizens. The law provides for additional protections entitling this population to state-funded, community-based services in the least restrictive environment that fosters independence, inclusion, and autonomy (State of California 2019). The various entities established by this law (DDS, regional centers, and vendors of the regional center) are primarily regulated by Title 17 of California Codes of Regulations (T17 CCR).



State

CHHSA oversees total of 12 departments, including Department of Developmental Services (DDS). DDS is codified in CA Welfare and Institution Codes and is financed by both federal and state-level funds.

DDS funds and monitors Regional Centers (RCs), and Developmental Centers, aka state institutions.

DDS contracts with 21 independent local-level Regional Center agencies.

DDS authorizes and regulates service delivery through Title 17 CA Codes of Regulation.

Local

All 21 regional centers (RCs) are independent private, nonprofit corporations. Each has their own board of directors who develop their own RC guidelines and standards, including for purchase of services, vendorization requirements, internal training, and managerial systems.

RCs provide direct service coordination to their clients, and contract with community vendors to provide direct support services, such as speech therapy.

Direct/individual

Vendors are contracted with and paid directly by RCs to provide direct services to clients. RC service coordinators (SCs) are direct point of contact between vendors and clients and the RC.

Figure 1: Organization of California's IDD Service Delivery System

California Department of Developmental Services. DDS, referred to as “the Department,” is the primary state-level agency responsible for governing, organizing, and monitoring the deployment of government resources designated for Californians with IDD. The Department is one of 12 departments (e.g., other IDD-related departments deal with social services, rehabilitation, healthcare services) overseen by the California Department of Health and Human Services (CHHSA). An IDD foundation (SCAN 2013) explained why the California system is organized as it is:

> The Legislature intended for the network of regional centers to 'be accessible to every family in need of regional center services' and because the services are 'special and unique in nature... (they) cannot be satisfactorily provided by state agencies.' Therefore, the statute requires the state to contract with these community agencies to respond to local needs. DDS contracts with 21 regional centers across California that serve as the 'single entry point' into the developmental disabilities service system, providing or funding a range of services that assist individuals and their families in accessing services and developing individualized plans.

Regional centers. The Lanterman Act is implemented by regional centers, which, according to DDS (2019) are "nonprofit, private corporations that contract with the DDS to provide or coordinate services and supports for individuals with developmental disabilities." Each community-based regional center provides such services as medical assessments, advocacy, referrals, and funding for direct services provided to children and adults with developmental disabilities. Each regional center has its own board of directors and geographic service area. Each one implements its own service guidelines for purchasing direct services for service recipients (i.e., determining who gets what and how much), hiring/training standards, and policies and procedures. All of this is guided by the Lanterman Act and related state/federal laws (DDS 2019).

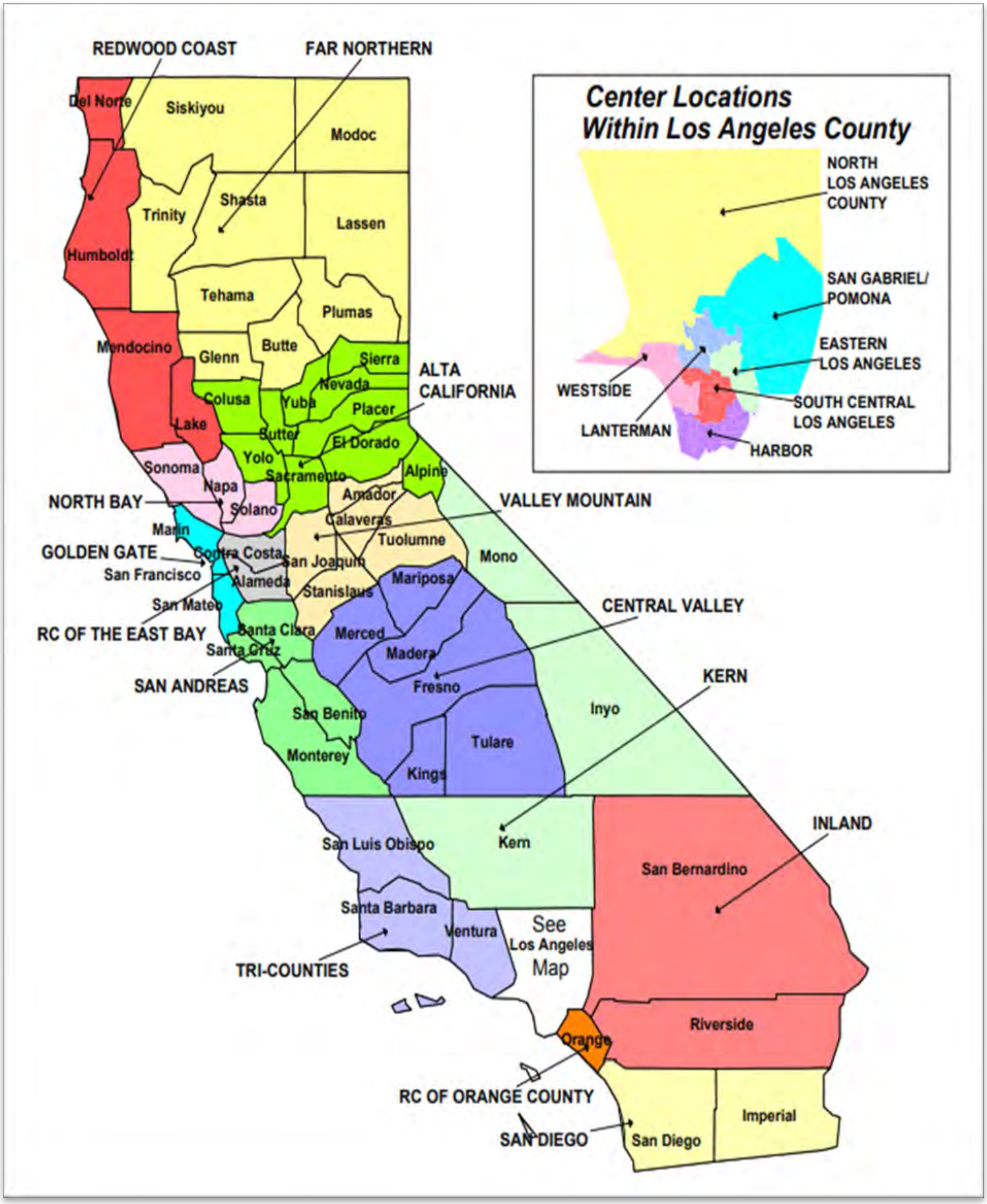


Figure 2: Map of regional center service areas

**Image retrieved from DDS 2019. Colors correspond to areas served by each center.*

There are 21 regional centers located throughout California that have their own designated service areas (see Figure 2). All the regional centers are required to implement the Lanterman Act, but each is free to decide how they implement it. There is a common saying in the system, “21 regional centers and 21 ways.” In other words, all regional centers have the same duties, but they each choose how they carry out those duties. This is important, considering that Los Angeles County alone has seven regional centers. The services offered could be different for people living within the same county because the address of the service recipient dictates which regional center will provide that person with services. A regional center coverage area is determined by population and geographic locations.

Other agencies that make up the system include The Association of Regional Center Agencies (ARCA); Disability Rights California and the Office of Clients Rights Advocacy (DRC/OCRA), and California State Council of Developmental Disabilities (SCDD). ARCA is a nonprofit agency that represents all 21 regional centers to DDS, state legislatures, and other interested parties. ARCA’s board consists of representatives from all 21 board of directors as well as the executive directors of each regional center. DRC and SCDD are state-level protection and advocacy agencies established by federal law. Both are responsible for protecting and advocating for IDD rights and monitoring DDS, regional centers, and vendors (ARCA 2020).

Vendors of the regional centers play a pivotal role in service delivery. They provide direct services to clients of the regional centers. Vendors range from a single individual providing consultation services to nationwide agencies, such as Goodwill

Industries. Each regional center has its own vendor process and requirements. Vendored services include community living arrangements like group homes, day programs, speech therapy, and independent and supported-living services. All vendors are required to follow state laws and Title 17 regulations. The regional centers are responsible for monitoring compliance and ensuring quality assurance. Conservatorships can shape actions of vendors and the direct services they provide. For example, before a service provider can set up a mammogram appointment for a conserved adult with IDD, they must obtain consent from the assigned conservator. This places service providers in a difficult situation because if the conservator doesn't to consent to the procedure, the service provider then must produce documentation as to why the regional center client has not received all recommended medical procedures.

The Lanterman promise. Many people within the service delivery system refer to "the promise" of the Lanterman Act and its guarantee ensuring that Californians with IDD continue be entitled to services that promote independence, inclusion, and self-determination. Central to the system are concepts and principles that foster person-centered and individualized services and implement the Act's intent—that rights, access, inclusion, and self-determination are prioritized in the most inclusive environment. The Act also dictates that the regional center will be the payer of last resort after other "generic" resources (services like speech therapy services, which can be paid for by other sources such as health insurance, or respite services being provided by "natural" resources like one's family) have been exhausted. Regional center services are required to be outcome-driven, as measured by agreed-upon goals.

The Lanterman Act is clear about its mission to empower and advocate with and for Californians with IDD. Regional centers, as the designated “experts” on IDD, are a single point of entry into a complex service system. It is the expert-level designation that crucially legitimizes their authority and involvement in the process of establishing limited conservatorship. The regional centers’ role in the process is further explained in the next section, where I summarize the legal portion of the process.

California Probate Departments and Conservatorships

Probate courts are generally designed to assist with the transfer and management of private real estate and inheritance. How it happened that in California, limited conservatorships came to be heard in probate court is beyond the scope of this paper. However, a probate attorney informant noted, “These are social issues that we are attempting to remedy through probate court. You have to think of it from that context of it really. We are dealing with somebody's fate, but not very much thought has been put into it.” There are 58 superior courts in California, each with one-to-55 branches. Probate is guided by California Rules of Court, which apply to all 58 Superior Courts. Additionally, there are local court rules, which vary by county and then department-specific rules, which vary within each local court. For example, in Sunny County, there were three separate probate courtrooms, each with their own “rules.”

Types of Conservatorships in California

There are two main types of conservatorships in California: probate and Lanterman Petris-Short (LPS). LPS conservatorships (commonly referred to as a “5150”) are used when adults with serious mental health issues, like chronic mental illness, are a risk to themselves or others, and as such, can be involuntarily committed to a mental hospital (CANHR 2014). There are two kinds of probate conservatorships: general and limited. Hunsaker (2008) explained that general conservatorships are utilized for adults who are considered completely incapacitated and are typically used for elderly adults no longer able to manage their affairs. Limited conservatorships are used only for adults (18 years or older) with IDD.

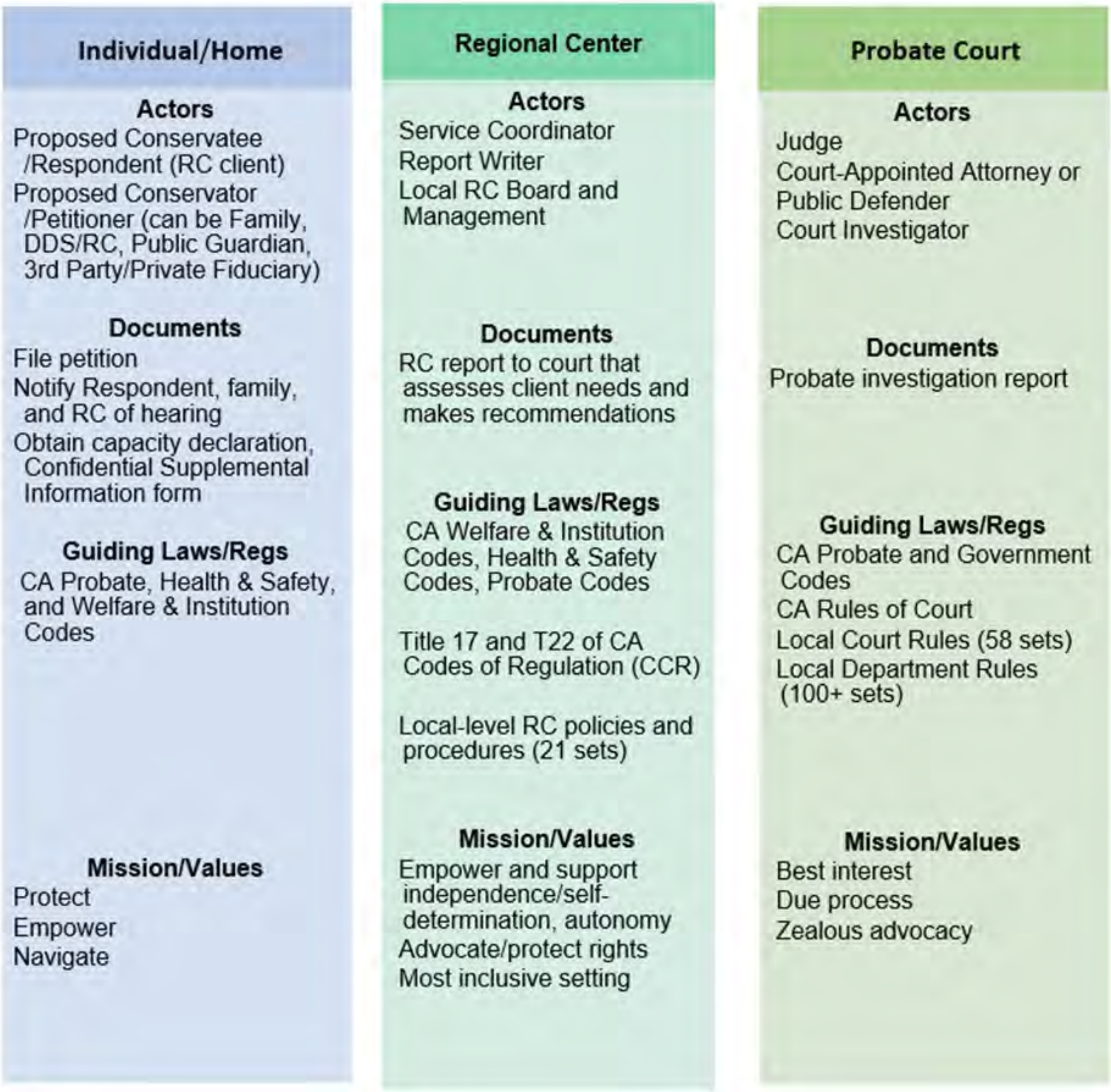
The reason for the different types of conservatorships is an attempt by the state to safeguard rights and to make sure that conservatorships are being used in a way that acknowledges the unique conditions and impairments of people with different disabilities. For example, there is a significant difference between someone experiencing a temporary and situational crisis that requires medical intervention and someone experiencing long-term effects of age-related dementia. According to training material obtained from a regional center informant, there are several key differences when comparing a limited conservatorship to a general conservatorship. When a petition is requesting a limited conservatorship, there are specific institutional obligations: (a) more attention and inquiry into the level of functioning of the proposed conservatee; (b) required regional center involvement and report preparation, and (c) a requirement that seven categories of powers (level of control) be evaluated separately (reviewed below). The petitioner (proposed conservator) must prove the need for being granted each power requested on the petition.

Hunsaker (2008) explained limited conservatorships were specifically designed to limit a conservator’s control to only certain decision-making powers, not to the whole person. This is because IDD impacts everyone differently. In other words, California recognized that not all people with IDD need help making choices and, if they do 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 individual's unique circumstances.

Limited conservatorships designate seven powers, or rights, of a conservatee (the person with IDD) that can be terminated and assigned to a conservator. According to Probate code 2351.5(b) the proposed conservator can petition the court to take control over all or some of these seven rights, to: (1) fix the conservatee's residence or dwelling; (2) access the conservatee's confidential records or paper, (3) consent or withhold consent to marriage on behalf of the conservatee; (4) enter into contracts on behalf of the conservatee; (5) give or withhold medical consent on behalf of the conservatee; (6) select the conservatee's social and sexual contacts and relationships, and (7) make decisions to educate the conservate. Additionally, at the limited conservatorship hearing, the judge makes a ruling on whether the proposed conservatee's right to vote is also taken away, but this is not designated as a specific power.

Establishing a Limited Conservatorship in California

The process of establishing a limited conservatorship is complex and involves multiple actors across multiple sites, with varying levels of involvement. I begin this section by describing each setting and the actors and laws involved within each (see Figure 3). I close this section by laying out how the process is supposed to work in theory, followed by what the process looked like in practice for Hal, whose story I shared in the introduction chapter.



Individual/Home	Regional Center	Probate Court
Actors	**Actors**	**Actors**
Proposed Conservatee /Respondent (RC client) Proposed Conservator /Petitioner (can be Family, DDS/RC, Public Guardian, 3rd Party/Private Fiduciary)	Service Coordinator Report Writer Local RC Board and Management	Judge Court-Appointed Attorney or Public Defender Court Investigator
Documents	**Documents**	**Documents**
File petition Notify Respondent, family, and RC of hearing Obtain capacity declaration, Confidential Supplemental Information form	RC report to court that assesses client needs and makes recommendations	Probate investigation report
Guiding Laws/Regs	**Guiding Laws/Regs**	**Guiding Laws/Regs**
CA Probate, Health & Safety, and Welfare & Institution Codes	CA Welfare & Institution Codes, Health & Safety Codes, Probate Codes Title 17 and T22 of CA Codes of Regulation (CCR) Local-level RC policies and procedures (21 sets)	CA Probate and Government Codes CA Rules of Court Local Court Rules (58 sets) Local Department Rules (100+ sets)
Mission/Values	**Mission/Values**	**Mission/Values**
Protect Empower Navigate	Empower and support independence/self-determination, autonomy Advocate/protect rights Most inclusive setting	Best interest Due process Zealous advocacy

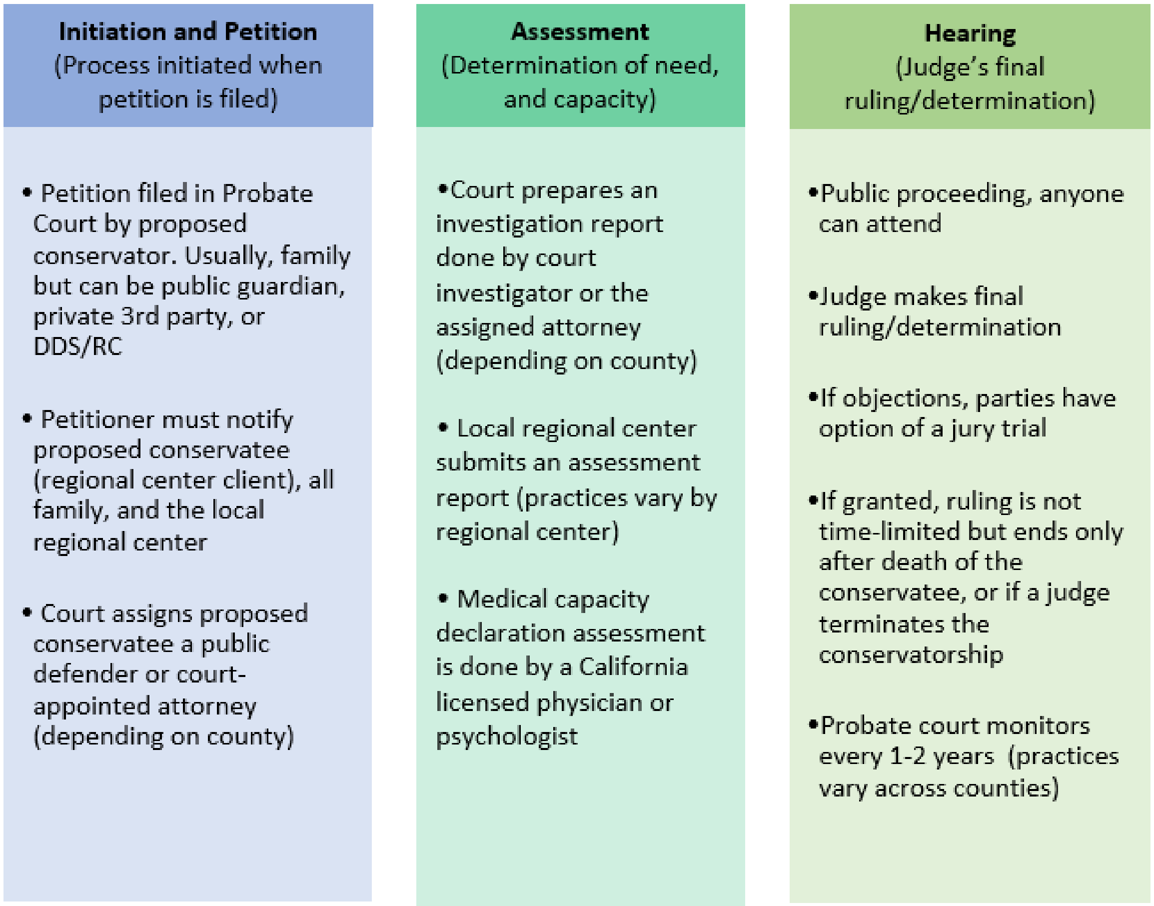
Figure 3: Actors/Settings of California's Limited Conservatorship Process

The main settings (see Figure 3) in the process include (a) individual/home setting, (b) regional center setting, and (c) probate setting. The individual setting incorporates the general everyday life and circumstances of the proposed conservatee/regional center client, including interactions with their families, assigned local regional center and designated service coordinator, the report writer, and medical provider completing the capacity declaration. The regional center setting incorporates work that is regulated and generated across different sites within the disability service system at different levels: local, county, state, and federal agencies/laws/regulations. This study centers on the regional centers.

Last, the probate setting includes multiple probate actors, including the local court, assigned department, judge, assigned attorney (court-appointed attorney or public defender, depending on the county) for the proposed conservatee, and a court investigator. Some local courts have three or four probate departments, each assigned their own judge.

Process in Theory.

The conservatorship process (see Figure 4) 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). Nonprofits, 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). Once someone has petitioned the court for conservatorship over an individual, a formal hearing is scheduled. The proposed conservatee is assigned a public defender or court-appointed attorney who is selected from a panel of attorneys who serve as counsel for proposed conservatees (California Probate Code 1471; Hunsaker 2008).



Initiation and Petition
(Process initiated when petition is filed)

- Petition filed in Probate Court by proposed conservator. Usually, family but can be public guardian, private 3rd party, or DDS/RC
- Petitioner must notify proposed conservatee (regional center client), all family, and the local regional center
- Court assigns proposed conservatee a public defender or court-appointed attorney (depending on county)

Assessment
(Determination of need, and capacity)

- Court prepares an investigation report done by court investigator or the assigned attorney (depending on county)
- Local regional center submits an assessment report (practices vary by regional center)
- Medical capacity declaration assessment is done by a California licensed physician or psychologist

Hearing
(Judge's final ruling/determination)

- Public proceeding, anyone can attend
- Judge makes final ruling/determination
- If objections, parties have option of a jury trial
- If granted, ruling is not time-limited but ends only after death of the conservatee, or if a judge terminates the conservatorship
- Probate court monitors every 1-2 years (practices vary across counties)

Figure 4: The Stages of Establishing a Limited Conservatorship

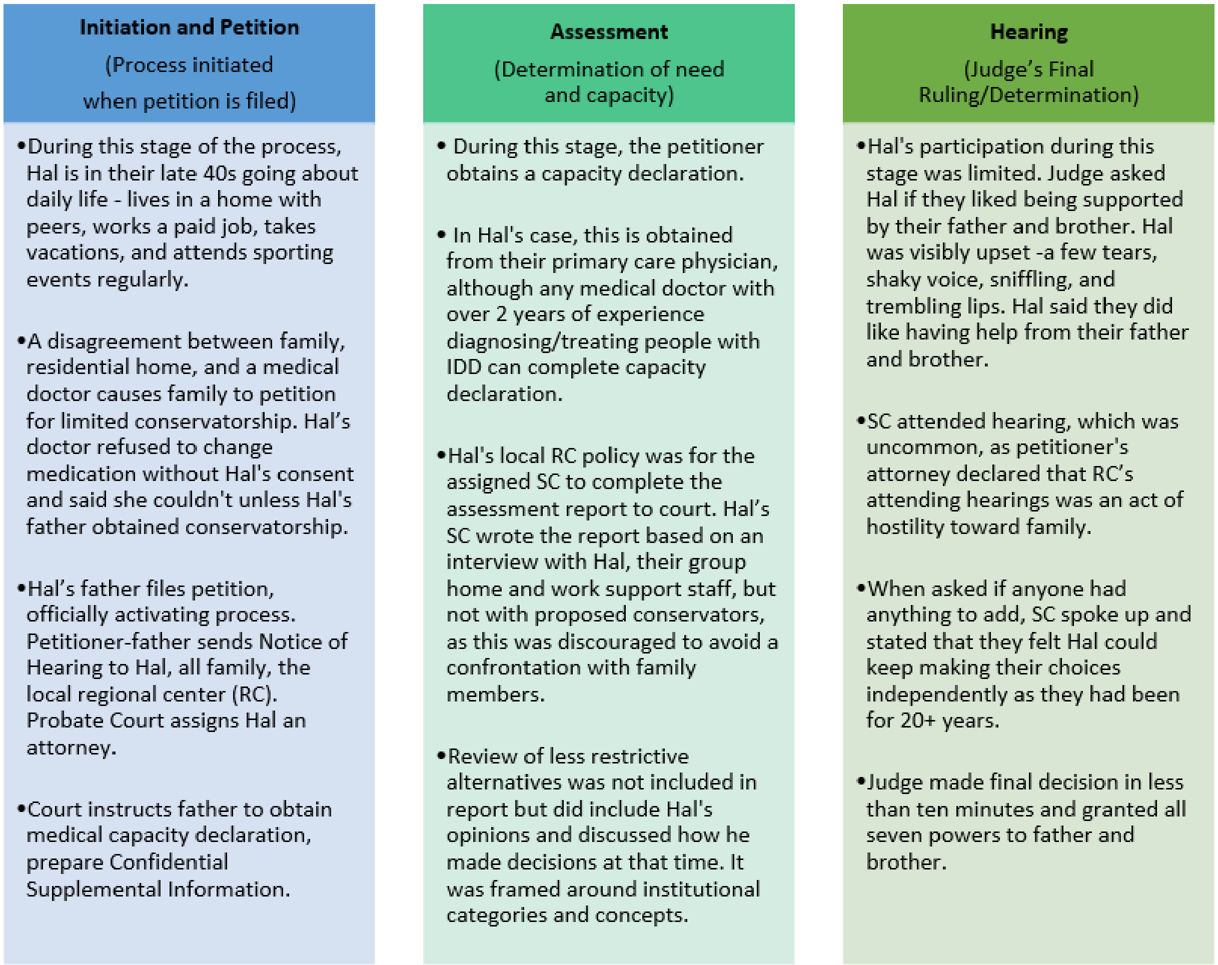
A court investigator is also assigned to conduct an investigation for the court (California Probate Code 1826; Hunsaker 2008). The court investigator is responsible for explaining the petition and court process to the proposed conservatee. The investigator also makes assessments and recommendations to the court regarding the petition (Hunsaker 2008). California Probate Code 1827 requires the appropriate regional center submit a report to the court prior to the hearing (Hunsaker 2008). This report consists of a summary assessing the client’s functioning level and whether 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 outcome of the petition. Hunsaker (2008:5) explained 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.” The judge primarily relies on three main documents to make their decisions: regional center assessment, probate investigation report, and medical capacity declaration. These hearings are public proceedings and become part of the public record (CANHR 2014).

On the surface, this process appears to recognize the law’s intent to be person-centered and individualized. However, Hal’s experience (see Figure 5) shows us that, in practice, this is not always the case, as discussed below.

Process in Practice: Hal’s Story.

Hal was in their late 40’s, held down a job and lived in a group home with their peers. Their family petitioned the court for a limited conservatorship after having a disagreement with a medical doctor over prescribed medication. I completed an assessment on the need for conservatorship and submitted a report to the court saying the limited conservatorship was not needed. Hal was doing well making his own decisions. The probate assessment was not conducted by a trained probate investigator. The assessment was conducted by Hal’s CAA, a lawyer who believed that illiteracy was an indicator of incompetence.



Initiation and Petition

(Process initiated when petition is filed)

- During this stage of the process, Hal is in their late 40s going about daily life - lives in a home with peers, works a paid job, takes vacations, and attends sporting events regularly.
- A disagreement between family, residential home, and a medical doctor causes family to petition for limited conservatorship. Hal's doctor refused to change medication without Hal's consent and said she couldn't unless Hal's father obtained conservatorship.
- Hal's father files petition, officially activating process. Petitioner-father sends Notice of Hearing to Hal, all family, the local regional center (RC). Probate Court assigns Hal an attorney.
- Court instructs father to obtain medical capacity declaration, prepare Confidential Supplemental Information.

Assessment

(Determination of need and capacity)

- During this stage, the petitioner obtains a capacity declaration.
- In Hal's case, this is obtained from their primary care physician, although any medical doctor with over 2 years of experience diagnosing/treating people with IDD can complete capacity declaration.
- Hal's local RC policy was for the assigned SC to complete the assessment report to court. Hal's SC wrote the report based on an interview with Hal, their group home and work support staff, but not with proposed conservators, as this was discouraged to avoid a confrontation with family members.
- Review of less restrictive alternatives was not included in report but did include Hal's opinions and discussed how he made decisions at that time. It was framed around institutional categories and concepts.

Hearing

(Judge's Final Ruling/Determination)

- Hal's participation during this stage was limited. Judge asked Hal if they liked being supported by their father and brother. Hal was visibly upset -a few tears, shaky voice, sniffling, and trembling lips. Hal said they did like having help from their father and brother.
- SC attended hearing, which was uncommon, as petitioner's attorney declared that RC's attending hearings was an act of hostility toward family.
- When asked if anyone had anything to add, SC spoke up and stated that they felt Hal could keep making their choices independently as they had been for 20+ years.
- Judge made final decision in less than ten minutes and granted all seven powers to father and brother.

Figure 5: Hal's Experience with the Conservatorship Process

I attended Hal's hearing, as this had been standard practice at the regional center I had previously worked. When I said 'hello' to Hal, the family's attorney asked to speak to me privately. They pulled me aside and said 'you must be new, because you obviously don't know that regional center never attends these.' I explained that I came from a different regional center, and that I planned to attend all hearings for my clients, even if that wasn't common in this area. To this, the family's attorney declared that I was a "hostile and confrontational" service coordinator and was not acting in Hal's best interest. I agreed to disagree, and we went separate ways until court was called to session.

The public hearing was stressful. Hal struggled to answer questions loud enough to be heard by the judge. When given the opportunity, I stated for the record that as his service coordinator I found the assignment of a conservator was unnecessary. Hal had a well-documented history of making excellent decisions and LRA available. Hal's CAA however, argued the opposite. They argued that Hal was unable to care for themselves independently. Further, Hal was high risk for financial exploitation because they could not read. The judge expressed appreciation for my advocacy efforts, but followed the advice of Hal's CAA— and granted the petition. In less than ten minutes, Hal's rights (all seven powers) had been terminated and granted to his family.

Hal lost their rights in a process that was sadly predictable: cursory, incomplete, not person-centered, and not a reflection of the law's intent for people like Hal. The vignette also demonstrates how any efforts of regional center workers to advocate on behalf of their clients may be futile, as was true in Hal's case. Hal's experience is one of many. In practice, California's limited conservatorship process operates inside a vast, complex—and inherently diverse— system of 21 independent and autonomous regional centers with 44 branch offices and 58 superior courts, each with one-to-55 branches and a total of 1,498 judges across the state of California. The potential for varying practices is infinite.

In Chapter 6, I discuss findings that provide clarity and details to each stage in the process. I discuss, in broad sections, Stage 1: Initiation/Petition; Stage 2: The Assessment and Stage 3: The Hearing. I conclude the chapter with a discussion of the process overall.

CHAPTER 6: FINDINGS

The lives of people with IDD and their families are commonly dominated by specialized disability service agencies (DDS, regional centers) and the various laws and regulations that organize the system. This research uncovers further evidence that demonstrates how these governing institutions coordinate and shape the lived realities of people with IDD as well as the work practices of the professionals they rely on to access critical services and support. Findings presented in this chapter are based on data gathered from observations of 93 limited conservatorship hearings, 16 interviews with 18 informants, and analysis of over 40 texts/documents. This research was designed to answer two guiding questions: 1) What is the process of establishing a limited conservatorship in California? and 2) How is the process experienced by those involved?

This research uncovered how institutional priorities and work conditions within and between IDD service delivery agencies and professional discourse organize the process of establishing a limited conservatorship around the needs of the government institutions, as opposed to the needs of the people they serve, contributing to their marginalization. This chapter contains two main sections. Section 1 is sequentially organized by the three stages in the process of establishing a limited conservatorship: (1) initiation/petition, (2) assessment, and (3) the hearing. Section 1 includes a description of who does what and highlights analytically significant moments/sites where most issues arise. Section 2 contains an analytical discussion on the sources of tension (i.e., work conditions, culture, and practices).

Review of Key Elements

The data presented in this chapter involve multiple actors across multiple sites with varying levels of involvement. As was previously discussed, there are three main settings/sites where the process of establishing a limited conservatorship takes place, including (a) individual/home setting, (b) regional center setting, and (c) probate court circumstances of the proposed conservatee/regional center client. This includes interactions with their families, local regional center, assigned service coordinator, and designated report writer, the medical provider completing capacity declarations, and others.

The regional center setting incorporates work being completed across many sites within the disability service system in general, including local, county, state, and federal agencies/laws/regulations. However, the primary focus of this research is on the local regional center. The probate setting involves multiple actors, including the local court, assigned department, judge, proposed conservatee’s assigned attorney, and the probate investigator. Figure 6 provides a visual representation of the way the IDD service delivery is structured. The body icon represents a regional center client receiving services in their individual/home setting. This setting is shaped by laws and practices at all jurisdictional levels: local, county, state, and federal.

California laws clearly state that limited conservatorships are the most restrictive option and should be implemented only as a last resort. Therefore, before petitioning for a limited conservatorship, a decision must be made as to whether a limited conservatorship is needed, or if less restrictive options are available and appropriate (Probate Code

1851.5). The other laws and regulations that guide the process include California H&S code, Probate code, and WIC.

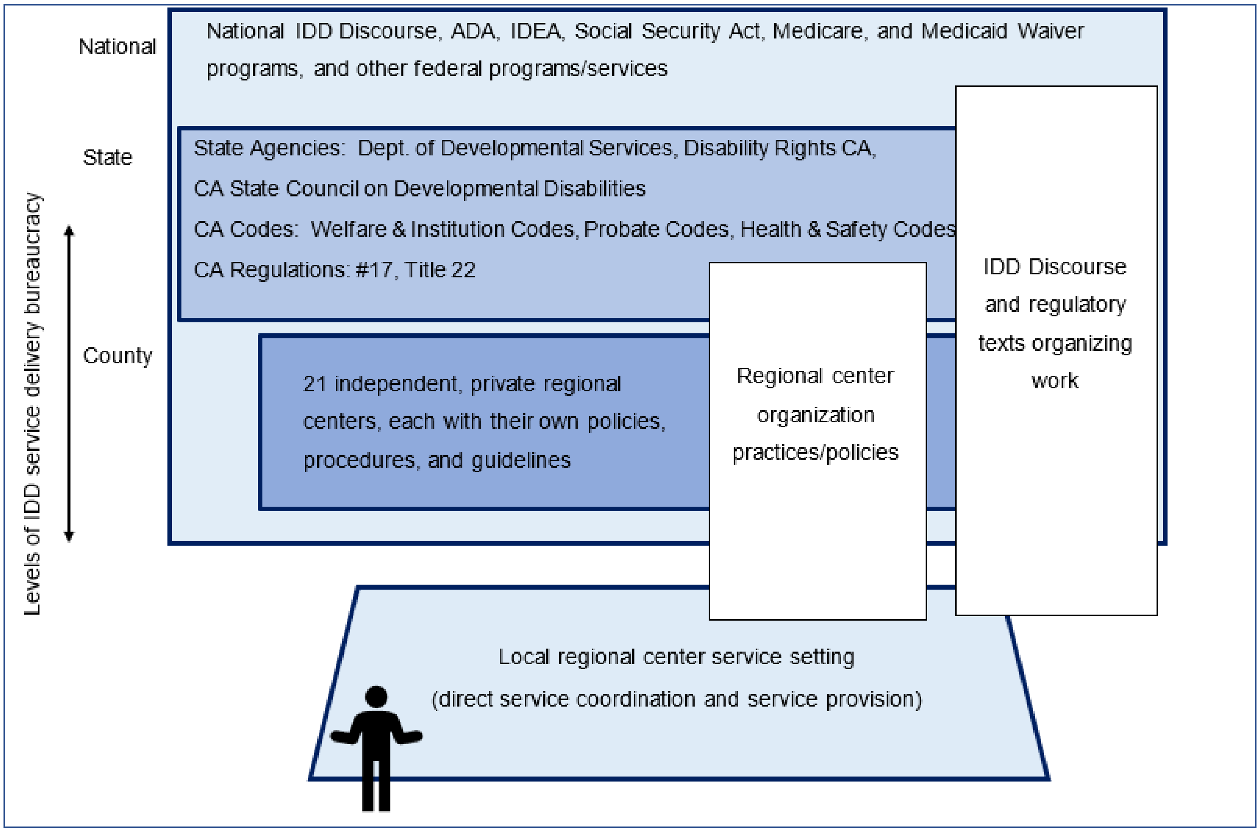


Figure 6: Textual Organization of California's IDD Service Delivery System

This section includes a detailed account of what the process of establishing a limited conservatorship looks like and how it is experienced. Figure 7 provides a visual representation of this complex process. The colored circles represent the three different settings: green is probate, purple is regional center, and turquoise is the individual/home setting. The rectangles are texts that guide the process (petition, assessment reports). The thin arrows indicate where documents are sent.

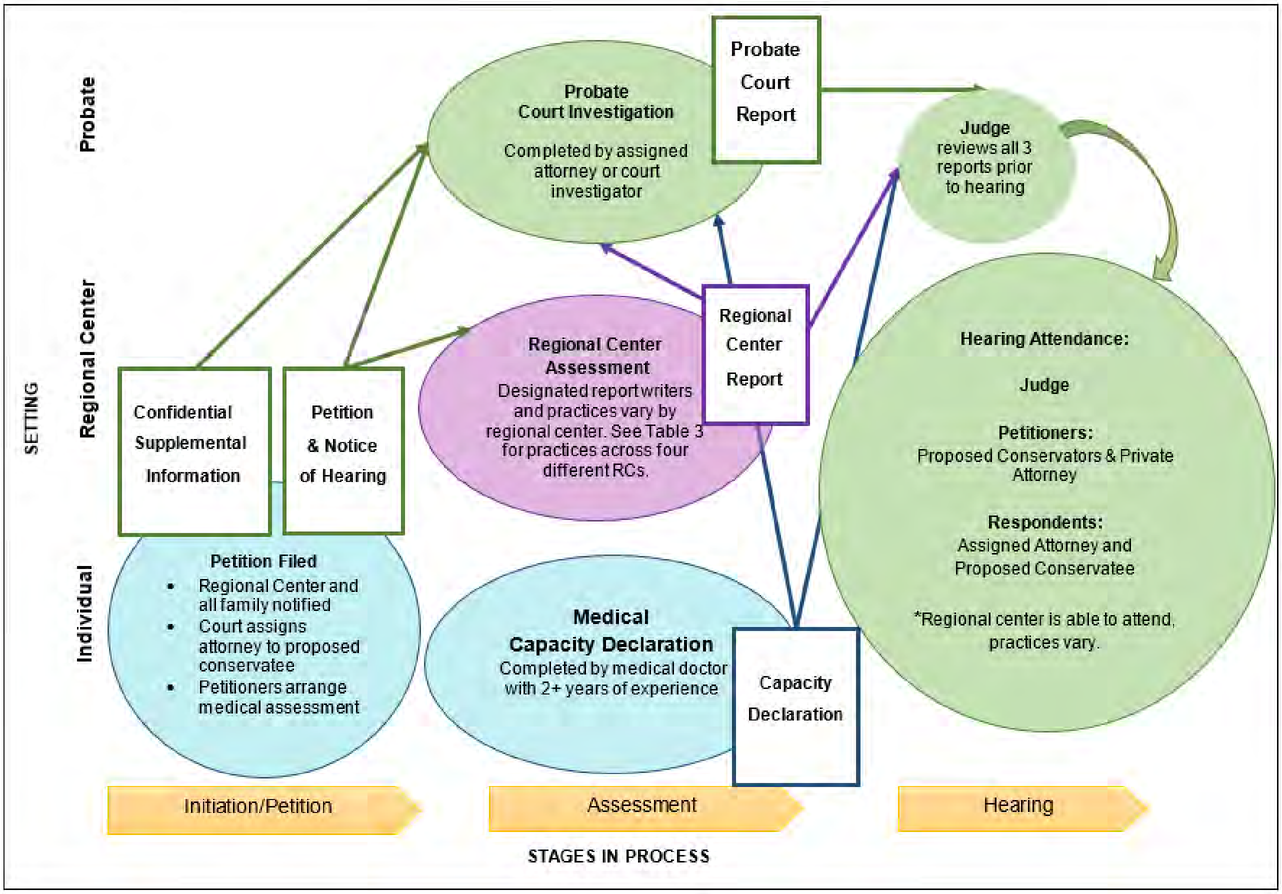


Figure 7: Process to Obtain a Limited Conservatorship

Stage 1: Initiation and Petition

In the following section, I break this process down by each sequential stage and describe who does what. I also explain how the process is experienced by the various actors in the process.

Initiation. Findings from this research suggest some common factors that lead to a petition’s being filed for limited conservatorship. These include fear of abuse or concerns about the proposed conservatee’s inability to exercise sound decision-making. Overall, there is a relentless presumption that having an IDD makes one incompetent. A caretaker’s fears can become disproportionate to the reality. Additionally, the caretaker has an understandable desire to remain involved in the process of accessing and coordinating disability services and medical care for their loved one, now reaching adulthood.

This study found that paternalism, caretaker concerns, and convenience—coupled with a lack of knowledge about the disadvantages of establishing a limited conservatorship or the availability of less restrictive alternatives—drive petitions for limited conservatorship. These factors more commonly propel the process than the need of the individual with IDD to be protected from the risk of their being abused or making poor decisions.

*Paternalis*m. A glaring, yet predicable, finding highlighted in this study is the large role fear plays when deciding whether to pursue a limited conservatorship. Moreover, various disability service professionals drive this fear. More than 62% (10/16) of the informants shared concerns that parents of people with IDD are advised by professionals that obtaining a limited conservatorship is the best, and sometimes the only, way they can protect their child and remain involved in decision-making after the child reaches the age of 18. One parent explained, "It started when my child was a teenager. The vice principal told us that if we wanted to be included in meetings in the future that we had to get a conservatorship. If we didn't, all the decisions would be made between them [the school] and my child. As a parent, that was terrifying to hear." A probate attorney acknowledged this fear faced by parents, saying, "I've come to see that schools, doctors, or regional centers sometimes even say that conservatorship is the way to go as opposed to trying to find somebody to help with power of attorney or a supported decision-making agreement." As a result, informants reported that many limited conservatorships are initiated around the time the proposed conservatee has just reached, or is about to reach, the age of 18. One regional center worker explained, "Most conservatorships are done when the client is about to turn 18 because school districts are notorious for really pushing conservatorships when the client is about to hit age 16, 17, as they tell parents that they will not be legally entitled to have a seat at the table without one. So, the parents really freak out." Observations conducted for this research also provide evidence that this is a common issue, with at least 24/93 (approximately 26%) of observed petitions for limited conservatorship being initiated when the proposed conservatee was still a minor. This percentage is potentially higher, because the age of the proposed conservatee was not mentioned in most hearings.

Twelve informants indicated they believe the vast majority of petitioners are well intended and wish to remain involved in their adult child's service planning and protect them from potential abuse. They believe this choice is best for their adult child with IDD, as explained by a regional center manager:

> I think I would say in probably 98% of cases, parents have the best of intentions. In most cases, I think it is the parents who are just genuinely trying to make sure that they can continue to assist their child and that their child is protected.

However, as explained by one probate attorney, "Just because you think it's best doesn't mean it's necessary. Conservatorships are the bluntest tool in the box, but just because it's available doesn't mean you should use it." This is not to suggest that people with IDD are not more vulnerable to abuse, as this is already solidly documented in the literature.

However, the all-too-common practice of terminating a person’s civil rights prior to or as they turn 18—before they have ever had an opportunity to exercise or learn to exercise those rights—does indicate that limited conservatorships are not being implemented as designed. The limited conservatorship was designed to be a “last resort,” after less restrictive alternatives failed. Further, the inappropriate removal of civil rights is inherently abusive. An activist explained, “You don’t take away the right to walk when all you need is a crutch.”

The “knee-jerk” reaction, as described by one regional center service coordinator, to conserve people with IDD as soon as they reach adulthood reflects a larger issue: there is an all-too-common assumption that people with IDD are incompetent. As mentioned by the parent earlier, many parents rely on advice and guidance from the professionals that work in the IDD service delivery system. Parents seek the opinions of teachers, case managers, and doctors because they are so often overwhelmed by the task of navigating a complex service system while wanting to protect and empower their child. The facts and discourse surrounding the parents’ efforts to help their child convey a consistent message: an adult with IDD needs to be conserved. This is reflected throughout countless online resources, including regional center websites, many of which encourage parents to obtain a limited conservatorship when a child with IDD is about to turn 18. This sends the message that an IDD makes a person incompetent and, therefore, unable to make—or learn how to make—their own decisions. One probate reform activist explained:

> Most 17-year-olds are not ready to make ‘good’ decisions without considerable outside support from other adults, but just because you’re not ready at 17 or 18, doesn’t mean that you can’t make decisions for yourself

> down the road. It takes practice and experience to make good choices, but these kids aren’t even given a chance to mature before they have their rights taken away.

Disempowering messaging is found abundantly on websites of “special needs” law firms and disability service centers. The sources engage in discourse relying on the outdated medical model approach to disability, where capacity and competence are treated as binary concepts. A person is either capable or not. The fluidity of disability, level of impairment, and personal circumstances are seen as irrelevant. For example, during a conference for special education issues related to transitioning to age-of-majority sponsored by her local school district, an informant asked the presenter if her children (who communicate with Augmentative and Alternative Communication [AAC] devices) would be allowed to use their devices during conservatorship assessments and proceedings. The presenter giggled and said, “No, we just assume that you’re incapacitated if you have a communication device.” One should challenge this presenter’s prejudice with the example of Dr. Stephen Hawking, among others. The presenter should be reminded that the inability to communicate verbally or vocally does not necessarily indicate cognitive impairment or the inability to make sound decisions.

C*onvenience*. Convenience was another commonly mentioned reason to petition for a limited conservatorship. As discussed in other sections, the IDD service delivery system is undeniably complex, and navigating the system is challenging (Smith and Grifith 2014; Vogel et al 2019). A limited conservatorship can be an effective way to cut through layers of red tape that constrain a caretaker’s ability to effectively advocate for their loved one. According to one parent, “The only good thing that I've seen is just the convenience, so that they can negotiate things with the schools, negotiate with doctors, and sign contracts and things like that." The same sentiment was expressed by both a self-advocate/regional center client and their parent/conservator. The two spoke about their own decision-making process when considering a limited conservatorship:

> *Self-Advocate:*
>
> The whole reason why I agreed to have my dad as my conservator is because I didn't want the responsibility of me being my own conservator. I felt like it would be easier for me to have my dad be my conservator rather than me being my own conservator, at least for the time being. I didn't want the responsibility of signing different documents. I didn't want the responsibility of everything else that comes [with] managing money and signing contracts. I wanted my dad to do that. I could focus on advocacy and starting my nonprofit. So far, everything has been going well since I made that decision.
>
> *Father/Conservator:*
>
> [Name redacted] had been targeted and scammed by cyber hackers. [Name redacted] is a very ingratiating and polite and loving person and will cut everybody slack, even people that are looking to hurt him. Even if he knows they're looking to hurt him, he'll still understand them and try to tolerate it because of the goodness in him, which is a beautiful thing if you want to be a saint. But [name redacted] will not speak up and say 'No, I don't want to do it that way.' If I wanted to be able to protect [name redacted], I didn't have the legal authority to do it. It became a question of who then does the documents for him and how do we get the world to respect that?

Informants reported multiple barriers they confront after their son or daughter turns 18, including the inability to communicate with medical insurance and being denied access to records relevant to their child's services and benefits. A regional center manager explained, "Insurance and medical providers will tell a parent that they are required to obtain verbal consent from the adult child prior to discussing anything. If we are talking about a child who is nonverbal, this is an impossible requirement to fulfill." Another informant, who works as a probate attorney, gave their perspective on what drives limited conservatorship petitions:

> A lot of it comes from either the school or the doctor. Those are the agencies that say that it's needed, and they said that it's needed more as a liability protection than anything else. Everything gets complicated. A violation of HIPAA can lead to a complaint on somebody's medical license, and it leads to tens of thousands of dollars' fine. A power of attorney or release of information can be revoked at any time so a doctor is not going to want to run the risk of a HIPAA violation when a conservatorship covers them.

Sometimes institutions like the regional centers are forced to petition for limited conservatorship over their client because it is the only way they can legally intervene when a parent or other relative is abusing their client. A regional center service coordinator explained:

> It's tough. Sometimes the parent is so hard to work with that they cause utter chaos for the staff and group home owner. Eventually, if the client's mental health and the stability of that home is jeopardized, they [the home] have to choose between serving a client or risk losing their license.

> If that parent is refusing to comply with licensing requirements like providing receipts for items they purchased with the client’s money, or don’t give the client their medication when in their care, the whole home and all the other clients living there are at risk. That kind of stuff is really dangerous for a group home because they can and will be shut down if there is a repeated pattern of medication and financial errors.

Not only do federal laws like HIPAA commonly result in institutions protecting themselves over the clients they serve and represent. Sometimes such laws force parents and institutions to terminate the rights of their child or client to ensure that the person can get the necessary services, benefits, and support to which they are entitled.

One parent discussed the unintended benefit of having established a limited conservatorship over his adult son, saying:

> Now that I'm conservator, I'm looking into things and I'm seeing in plain English a lot of money being spent for [my child] that isn't actually being spent on [my child]. It's being spent for people who were supposed to take care of [my child], who aren't doing it. Lot of money is being spent behind the scenes without accountability. Now I have the power to find it out, fix it, and do something about it.

Being denied access to records alarmed this informant and reconfirmed their decision to establish a limited conservatorship. It granted the parent easy access to records they were not entitled to before, and this helped the parent be a stronger, more effective advocate.

The experiences recounted in this section help explain why the decision to pursue a limited conservatorship is frequently driven by the desire to effectively navigate the complex, legally safeguarded service delivery system. Clearly, without a limited conservatorship, access is a challenge.

Lack of knowledge. Lack of knowledge—about less restrictive alternatives and the disadvantages of limited conservatorship—is another hidden force that leads parents to request conservatorship over their adult child. One parent described their decision process, saying, “I don’t remember any alternatives discussed. I guess I should feel somewhat guilty. I didn’t know that alternatives were supposed to be considered and of course, I didn’t know of any alternatives. I was just trusting and following the suggestions of the professionals because that’s what we are taught to do.”

Multiple informants reported that parents generally receive information on limited conservatorships from online sources such as “special needs” law firms and regional center websites. Findings (see Table 3) from the textual analysis of online resources available from primary IDD service agencies revealed very little guidance or resources to help families make decisions about a limited conservatorship or consider less restrictive alternatives. For example, DRC was the only agency who had developed and made available a simple resource designed for regional center clients that educates them about limited conservatorships, LRAs, and tips on what to do if the conservatee is not happy with an assigned conservator.

The websites of only nine regional centers (out of 21 statewide) provided information for petitioners/parents on how to establish a limited conservatorship or file the paperwork, and/or offered informational workshops. Only five had resources and information on less restrictive alternatives (LRAs). These five provided links to LRAs such as supported decision-making websites, forms for establishing power of attorney,

Table 3: Website Information on Limited Conservatorship from State/Local Service Organizations

Website Information of State and Local Organizations	Intended for Proposed Conservatees	Intended for Proposed Conservators	Less Restrictive Alternatives (LRAs)	Conservatorship Reform Initiatives	Cost-Shifting "Generic" Resources	Included in Purchase of Service Guidelines
State Level Entities						
DDS	-	-	-	-	✓	n/a
ARCA	-	-	-	-	✓	n/a
SCDD	-	-	-	-	✓	n/a
DRC/ORCA	✓	-	✓	✓	✓	n/a
State Entity Totals	**1 (25%)**	**0**	**1 (25%)**	**1 (25%)**	**4 (100%)**	**n/a**
Regional Centers						
Alta	-	✓	✓	-	✓	✓
Central Valley	-	-	-	-	✓	-
East LA	-	✓	-	-	✓	-
Far North	-	-	-	-	✓	✓
Lanterman	-	✓	-	-	✓	-
Golden Gate	-	-	-	-	✓	-
Harbor	-	✓	✓	-	✓	-
Inland	-	-	✓	-	✓	-
Kern	-	-	-	-	✓	✓
North Bay	-	✓	-	-	✓	✓
North LA	-	-	-	-	✓	✓
Redwood	-	-	-	-	✓	✓
East Bay	-	-	-	-	✓	-
Orange County	-	✓	-	-	✓	-
San Andreas	-	✓	✓	-	✓	✓
San Diego	-	✓	✓	-	✓	✓
San Gabriel/Pomona	-	-	-	-	✓	-
South Central LA	-	-	-	-	✓	✓
Tri-Counties	-	✓	-	-	✓	✓
Valley Mountain	-	-	-	-	✓	-
Westside	-	-	-	-	✓	✓
Regional Center Total	**0**	**9 (42%)**	**5 (24%)**	**0**	**21 (100%)**	**11 (52%)**
Combined Totals	**1 (4%)**	**9 (36%)**	**6 (24%)**	**1 (4%)**	**25 (100%)**	**n/a**

and/or offered training on alternatives. Eleven did not provide any information on limited conservatorships. About half, 11 of the regional centers, included conservatorships in their Purchase of Service (POS) guidelines. These guidelines describe what services regional center will pay for, and under what circumstances, but they do not discuss how to evaluate the options when considering a conservatorship or alternatives. None of the regional centers provided information on active probate reform legislation.

Additionally, looking at the state-level or “extra-local” agencies, only one, DRC/OCRA, provided resources on four of the five information categories (resources designed specifically for regional center clients on how to prevent or object to a limited conservatorship or restore rights, resources on LRAs, and information on generic resources, as well as active probate reform legislation). All others (DDS, ARCA, SCDD) provided no information on limited conservatorships. Overall, only six, or 24%, of the 25 websites analyzed, contained resources that address the disadvantages of conservatorship or offer information about alternatives.

However, all 25 websites had extensive information on the mandated policy requiring the “utilization of generic and natural supports,” clearly documenting the institutional priority placed on this budget-conscious topic. It was important enough to be featured prominently on every single website—DDS, DRC, SCDD and ARCA—and all 21 regional centers. “Generic and natural supports” refers to community services funded by sources other than regional center. One example is daycare. Another is Medi-Cal. Before the regional center can pay for behavioral services requested by a family, that family must first receive a denial from Medi-Cal. Information on “generic resources” is both ample and accessible on every website, in many different formats and in multiple locations. The message is clear: cost shifting is a very high priority at regional centers.

To summarize, the analysis suggests that limited conservatorships and the termination of regional center clients' rights is not a major concern and is, in fact, a low priority for the governing institutions. This is evident in the quality and quantity of institutional information available to the public. It is organized in a way that presents limited conservatorships as the best and most acceptable option available versus less restrictive alternatives that preserve more client rights.

What many parents do not understand—and what is usually not explained in the publicly available information—is that a limited conservatorship is not a magical shield. It cannot guarantee their adult child will not be abused, and it cannot always be enforced. A regional center attorney explained, "If your [adult] child is walking out the front door and getting in a car with someone, you are not going to be able to call the police and show them, 'Look, I have conservatorship,' and physically restrain them from going off with someone. That's not how it works." Further, a limited conservatorship does not give the conservator total authority over the conservatee. For example, if a conservatee communicates that they do not want to live where their conservator is making them live, and the two are unable to reach an agreement, they have to go back to court. A regional center manager put it bluntly: "By seeking a limited conservatorship, you are inviting the court into your life to monitor parenting decisions."

Additionally, many parents are also unaware of the risks they personally face of being removed as conservator, and possibly having a third party or private attorney assigned as their child’s conservator. Three informants shared different experiences where one or both parents were removed as conservators and replaced by a third party, such as a nonprofit or private law firm. A parent explained, “If I had known there was a chance that a law firm would be given control over my kid’s rights, I never would have considered conservatorship as an option. Who would?” In another example, a regional center manager explained that something as minor as not completing paperwork can lead to removing a parent acting as conservator: “Not filling out a change of address notice with the court can turn into this whole thing where a judge sets an order to show cause as to whether the conservator should be removed and ask the regional center to nominate the director of DDS to act as conservator.”

Further, every one of the parent-informants was unaware they do not have the power to designate a successor to replace them as conservator. One explained, “They [the courts] don’t even ask my opinion. It’s just a fresh start all over again, as if nobody was ever conservator. I can’t appoint my own successor. I don’t even have influence on who might be next in line.” Another explained the significant consequences of not being aware of this fact:

> They [parents/conservators] are in great danger because when they get old, they're going to want to leave money for their child [conservatee] through a special needs trust, and identify someone like a sibling to be the trustee and replacement conservator. What they don't realize is that because there's money in that trust, the court will appoint a professional instead. The professionals and their attorneys are then free to bill the trust for their work and will likely exclude the sibling from any involvement.

This fact—if parents knew about it—could influence their decision about petitioning for a limited conservatorship. Understandably, they may not want to take the risk of having a third-party unknown to them gain control of their adult child’s special needs trust—and be paid out of that trust—and to exercise control over that adult child’s decisions. Every parent considering a limited conservatorship for their adult child at least deserves to know not only the advantages of a limited conservatorship, but also the disadvantages. Otherwise, they cannot make a fully informed decision.

Finally, many parents are also unaware that terminating limited conservatorships can be extremely challenging, even if both the conservator and conservatee agree it is no longer needed. A psychologist explained that she is frequently contacted by parents looking for assistance in finding an attorney to help get their adult child out of a conservatorship they had established themselves. She has to tell them, “They [the conservatee] no longer have the right to hire or fire any attorney. That was taken away when they were conserved and lost their right to contract.”

The information that organizations like DDS, DRC, and regional centers choose to disseminate and make accessible through their websites carries great weight as a trusted source and reflects Smith’s (1990) concept of the social organization of knowledge. Because these are state-supported IDD experts and professionals, with the authority to establish priorities, values, and standards, their information is more likely to be accepted as factual and therefore more persuasive. What the experts say (or don’t say) about a topic subtly but forcefully shapes the perceptions and experiences within the regional center community. There are very real consequences for the lived experiences of people with IDD and their families, as this is the information on which decisions are based and actions taken.

The Petition.

Regardless of the age of the proposed conservatee, or reason for pursuing a limited conservatorship, all petitioners face the challenge of completing and submitting a petition to the court. The petition officially activates the process of establishing a limited conservatorship. At a glance, the petition stage appears to be relatively straightforward. However, data obtained from observations, text analysis, and informants all offer evidence to suggest this is not the case.

The California Superior Court website explains that before the appropriateness of limited conservatorship is assessed, the petitioner must file the following three documents with the court: Petition for Appointment of Probate Conservator, Confidential Supplemental Information, and a Notice of Hearing. The Petition is eight pages and provides important information, including the proposed conservatee's preferences related to the proposed appointment, documentation supporting the allegation that proposed conservatee is unable to care for themselves, and the specific powers the petitioner is requesting. The Notice of Hearing is very straightforward. Its purpose is to inform other parties there will be a hearing to decide if a limited conservatorship will be established and lists the date and time of the scheduled hearing. The Confidential Supplemental Information form is the third required probate document. It expands on the reason why the petitioner is convinced the proposed conservatee cannot make decisions in their best interest. This document also reports on less restrictive alternatives, that they were explored and why they were deemed not appropriate. Once the petitioner completes these documents, the petitioner is required to notify all family members and their local regional center 30 days before the scheduled hearing by mailing them copies of the Petition and Notice of Hearing—but not the Confidential Supplemental Information.

On the surface, the petition and Confidential Supplemental Information documents appear to be person-centered, providing many opportunities for individualized information to be presented. However, a closer look at the language used reveals some of the problems. Both documents focus on the deficits of the proposed conservatee, not their strengths, or the circumstances leading up to the petition to terminate their rights. The petitioner is instructed to document behaviors, overall functioning levels, and ability to complete Activities of Daily Living (ADLs) such as bathing, dressing, and cooking independently. The focus on deficits does not inform the court of what the proposed conservatee can do and how they can do it. For example, the ability or inability to prepare a meal independently does not indicate one's ability to decide what type of home they would like to live in (e.g., group home, family home, their own apartment). It indicates only whether the individual needs assistance preparing meals. A more relevant person-centered focus would be to ask, can and how does the person currently access meals, and will they continue to have access to these meals without a conservatorship?

Confidential Supplemental Information Form. The Confidential Supplemental Information is a probate document completed by the petitioner making the argument that the proposed conservatee in unable to provide properly for their own needs (e.g., food, clothing, shelter), as well as the allegation that the proposed conservatee is unable to manage their finances or “resist fraud and undue influence.” Section 5 in the document (see Appendix G) of this document contains particularly useful information regarding less restrictive alternatives. This is where the petitioner documents other options they have considered and found to be “unsuitable or unavailable to the proposed conservatee.” This form lists six alternatives to a limited conservatorship that must be addressed by petitioner, including: voluntary acceptance of informal or formal assistance, limited power of attorney, durable power of attorney for health and estate, trust, and other. Each alternative is followed with a prompt, directing the petitioner to “give reason this [alternative] is unsuitable or unavailable.”

The Confidential Supplemental Information form is a highly significant document. It aids the judge in making an appropriate ruling. I was shocked to learn about this form for the first time during the course of my research for this study. I had been an “expert” at a regional center, where I specialized in limited conservatorships. I had never seen such a document. Sadly, I learned during this research, that most parties to the limited conservatorship process (except for the petitioner) also don’t know of its existence or their right to obtain a copy. While this document must be filed with the court to initiate a petition for conservatorship, it is standard practice for this information not to be shared outside of the court. It is not attached to the copy of the petition sent to the notified parties: proposed conservatee, family members, and regional center. Probate code 1821 (a) includes a statute that states:

> The supplemental information form shall be separate and distinct from the form for the petition. The supplemental information shall be confidential and shall be made available only to parties, persons given

> notice of the petition who have requested this supplemental information or who have appeared in the proceedings, their attorneys, and the court. The court shall have discretion at any other time to release the supplemental information to other persons if it would serve the interests of the conservatee. The clerk of the court shall make provision for limiting disclosure of the supplemental information exclusively to persons entitled thereto under this section.

This statute makes very clear that people who received the Notice of Hearing are entitled to receive a copy of this key document—if they request a copy. However, the statute does not specify how to request a copy. Further, it gives no explanation why this information isn’t shared by default. This practice is problematic for a few reasons. First, it limits access by requiring the form be requested. Unless an interested party has scrutinized many pages of dense probate codes, they may not know this form exists. Even if they become aware of the form, they would probably not know they are allowed to request it unless an “insider,” like the conservatee’s counsel, told them they could. An experience shared by a regional center service coordinator highlights how this practice can have a negative impact on a proposed conservatee:

> I didn’t even know there was an additional form submitted by the family that addressed things like this. I assumed everything I needed to know was in the copy of the petition sent to us [the regional center]. I didn’t think that the fact she couldn’t drive or take public transit independently to program was something that mattered. Why would it? Had I known that her mom was arguing that she [proposed conservatee] needed a conservatorship because she depended on others to help her with things, I could have challenged that. I would have argued that the fact she is

> currently accepting support indicates that she is capable of caring for herself. Accepting the ride and getting into the van every morning to go to work is an example of her [proposed conservatee] being capable of getting her needs met.

Withholding such important information denies a level playing field to the individual with IDD and their supporters. They have no opportunity to rebut or refute disempowering assertions if they don’t even know such an important court document exists or have never seen it. For example, if a petitioner reports that the proposed conservatee is unable to secure clothing, food, and shelter for themselves on the Confidential Supplemental Information document, the person writing the regional center assessment could counter that assertion. Their assessment could describe how the proposed conservatee effectively manages such tasks as an active regional center client entitled to and receiving those supports and services.

Additionally, requiring that this form be requested by interested parties, like the regional center, hinders full consideration of less restrictive alternatives like supported decision-making. If the court relies on this Confidential Supplemental Information Report—provided by only one party, the petitioner—the judge may grant a limited conservatorship without hearing from other experts who might have made a compelling case for a less restrictive alternative. Regional centers are considered the experts on IDD and related IDD services. One must question why the court would not want to seek their expertise more actively by automatically sharing all pertinent information with them. For example, if a petitioner indicates that option 5(a) “Informal and formal assistance” is unavailable or inadequate, the regional center would know they need to provide examples of situations where the proposed conservatee has accepted informal assistance, such as accepting a ride to work or being a client of the regional center.

Limiting access to this text certainly does not benefit the proposed conservatee. The court relies on professionals for expert opinions, but those professionals are not provided all the information needed to complete a thorough, meaningful assessment. This system failure constrains the effectiveness of advocacy that regional centers can provide. In other words, this text holds power because not having access to it triggers one set of actions, while having access to it could trigger a different set of actions, which could result in very different outcomes (e.g., civil rights retained versus terminated).

Petition patterns. A problem found during the petition phase is that the specific powers requested in petitions for limited conservatorships all too predictably follow precedents reflecting highly local/county standards and expectations, rather than focus on individual circumstances and needs of the proposed conservatee. In Sunny County, a full 100% (44 cases) of all new petitions filed requested all seven powers. In neighboring Lovely County, most petitioners knew their local court rarely grants all seven powers and, accordingly, the vast majority (80%) of petitions observed in that county were requests for only five of the seven powers (the excluded two powers were always control over the conservatee’s right to marry and their right of social/sexual relations). This strongly suggests that petitions are being structured to suit the preferences/expectations of the local court and judge as opposed to the needs of the proposed conservatee. This is also a clear indicator that limited conservatorships are not being utilized as they were designed to be. If they were, there would be a larger variation in the number of powers requested. This is an example of ruling relations unknowingly leaking into everyday experiences. The choices and actions conform to the invisible blueprint designed by a governing institution, which is, in this case, the local probate court. An unspoken mechanism is in place, where the default is to request the maximum number of powers that a particular county is known to approve.

Multiple informants across multiple agencies and counties reported that each Superior Court had their own unique philosophy regarding which powers are acceptable to request. This was generally determined by the specific judge appointed to that department. An informant working for the regional center in Sunny County stated, “All the petitions are for all seven powers. I don’t recall seeing one for less than that.” Another informant who works in a different regional center catchment area reported the same, stating that petitions “almost always request the max [all seven powers], even when not necessary.” One probate attorney expressed surprise when discussing trends across different counties. When informed that one county very rarely grants marital and social/sexual powers, they said, “That's so interesting. I’m glad you told me that because I feel so uncomfortable doing that for a lot of my clients. I'm glad to hear that [redacted] County says the five, because here it's presumed essentially the seven.” These experiences consistently demonstrate that it is common practice to request the maximum level of power as possible— one activist compared this practice to “Taking care of a housefly with a nuclear bomb.” Further, such experiences suggest these specific local practices and patterns go unchallenged and are accepted as “the way it is.”

To summarize, multiple issues arise during the initiation and petition stage that work against the interests of the proposed conservatee—and against the intent of the laws protecting their civil rights. The process pivots on a lack of knowledge about limited conservatorships and their disadvantages, in addition to poor or no understanding of alternatives. Foundational to the process is a bias based on outdated, incorrect stereotypes about adults with IDD being unable to make decisions. Inadequate document sharing hinders collaboration and opportunities to present the judge with complete information. And finally, the number of rights taken from an individual has more to do with the local court's patterns and practices than with the merits of any individual case.

Stage 2: The Assessments

Once a petition has been filed and a hearing scheduled, the assessment stage begins. There are typically three assessments completed during this time: the probate court's investigation, the medical capacity declaration, and the regional center assessment. There is no particular order for completing these assessments, but all three must be completed and filed with the court at least four days prior to the hearing so the judge can review them. The assessments the court relies on to inform their final judgment have different specialties and goals, but all are centered on similar concepts, such as diagnoses and functioning level. The intent of these reports is to provide the judge with professional, expert opinions regarding an individual's functioning level and ability to make informed decisions. The reports also inform the judge of any extraordinary circumstances or urgency (e.g., probate codes, health and safety codes).

Medical and Probate Assessments

The Medical Capacity Declaration. The medical capacity declaration is required by probate codes and must be completed by a California licensed physician or psychologist with at least two years of experience diagnosing or treating people with major neurocognitive disorders. The intent of this assessment is to medically confirm that the proposed conservatee is legally incapacitated and to determine whether the proposed conservatee is medically able to attend the hearing. The medical capacity declaration is structured around concepts and categories such as official medical diagnosis, IQ, ADLs, and ability to reason and understand consequences. One informant stated, “Essentially, it’s a bunch of check boxes. Do they have capacity or not? If only it was that simple.”

This binary, medical approach to determining capacity leaves out other critical areas that should be included when determining the need for conservatorship. For example, a person with IDD may not be able to independently read or fully comprehend a medical document listing the risks involved with a medical procedure, in order to consent to that procedure. However, if that person has a family member or friend who can explain it to them in a way they understand, they could make an informed decision. In other words, even if someone has been declared “incapacitated,” if they have a support system in place that keeps them safe, healthy, and happy, then establishing a limited conservatorship is unnecessary. Their needs are being met organically with the support of others— without stripping them of their civil rights.

Probate Investigation. Once a petition for limited conservatorship is filed, the proposed conservatee is assigned legal counsel by the probate court. This is either a public defender or a court-appointed attorney, a topic that will be elaborated on later. The probate department of the local Superior Court starts their formal investigation. Training requirements and investigation practices vary across each Superior Court and probate department. The probate court's investigation report, which must be submitted to the judge, includes assessment of the proposed conservatee's communication skills and whether they can attend the hearing in person. Probate lawyers working as court-assigned attorneys in this specialized area are required to obtain a minimum of three hours of training related to IDD—and even this requirement was mandated as recently as 2019.

An analytic point of interest is the difference in training standards for different professionals. Two years of experience are required for medical professionals completing capacity declarations, compared to the three hours of training for court-appointed legal representation. A probate informant noted that, "It's very telling, as the courts aren't holding themselves to the same standards they set for other professionals." The other probate informants expressed similar concern that this was not enough. For example, an attorney offered:

> 2019 was when the law was passed that actually added these required three hours of training for court-appointed attorneys. I don't know if I would say that's enough but I would say it's better than none. To handle juvenile cases in the state you have to have eight hours of training. The three is getting to where it should be.

Another probate attorney gave the following response when asked if they received adequate training before starting to work in probate:

> Oh, no. [laughs] God, no. You learn trial by fire. It was like, ‘This is what you need to do. Go say that, go file that.’ No, nothing comprehensive, [chuckles] it was like, ‘Come with me real quick and watch. [pause] All right, you got that? K, go for it.’

The quality and quantity of attorney training hours have direct consequences on the proposed conservatees and the quality of representation they receive. A probate attorney explained, “So much depends on the attorney you get, and how they’ve been trained.” They expanded on what the lawyer for the proposed conservatee is supposed to do to represent their client:

> In theory, what you're supposed to have is an interview with the proposed conservatee. You're supposed to check out the home. You're supposed to look at all of the information. You're supposed to explore, tell them what their rights are in a way that they're able to understand. Not using legalese, you’re supposed to explain what it means in a practical sense, and then see what it is that they want to do. This doesn’t always happen.

The research found consistent examples where the tasks assigned to the attorney did not always unfold that way. An activist shared that some counties waive the probate investigation altogether and rely on the regional center assessment instead. A probate attorney explained, “I really normally don't get involved until the week before the case is set to begin. That's just reality and a function of probate work.” This experience resonated with another informant’s knowledge of probate investigation practices varying across the state who said, “I'm in four counties. In some counties, they actually do it. In most counties, they don't.” These data illuminate a high level of variability in probate practices, which can have serious consequences for regional center clients.

Failing to meet with and interview conservatees prior to the hearing was also discussed by an activist who raised concerns that it is becoming “common practice for court appointed attorneys to not meet the proposed conservatee in person until the day of the hearing.” This practice was what I observed during the one in-person court session I attended. I observed five attorneys meeting their clients for the first time 20 minutes before court was scheduled to be called into session. They were observed introducing themselves, shaking hands, and apologizing for not meeting sooner.

This section highlights the importance of regional center assessment reports. These reports are key because evidence here indicates that probate and medical assessments do not reflect the person behind the petition. The regional center has the opportunity for their report to fill informational gaps that otherwise would not be presented to the judge. This section also highlights how critical it is for regional center to step in, since medical professionals and lawyers cannot be expected to have the same level of knowledge and understanding of IDD as regional center workers. Regional center workers are the “experts” and have a responsibility/opportunity to complete assessments that reflect the multidimensionality of IDD and emphasize the human and the context that are excluded from medical capacity declarations and probate court investigation reports.

Regional Center Assessment. Probate Code 1827.5 and Health and Safety Code 416 require that local regional centers submit their assessment of limited conservatorship to the court. The regional center assessment is intended to provide the judge with a "professional/expert" opinion on the level of impairment the regional center client experiences and their ability to make decisions in their own best interest. H&S code 416 dictates that the report should address the nature and degree of disability as well as relay any concerns about the proposed conservator(s). As mentioned earlier, all 21 regional centers are independent and autonomous nonprofit organizations contracted by the State of California. This means that, unless given specific guidance or direction, each regional center is at liberty to establish policies and guidelines that will suit the needs of their own unique catchment area. For example, DDS T17 regulations state that regional center must complete Individual Program Plans (IPPs) for clients at least every three years. DDS requires certain information be included, but each regional center designs their own form and has their own way of completing it. DDS, as the state-level agency that monitors and partially funds regional centers, provides 200+ pages of Title 17 regulations. These regulations are designed to guide, coordinate, and streamline regional center services. However, there is no mention of practices related to limited conservatorship petitions.

21 regional Centers, 21 ways. The way these assessments are completed varies greatly from one regional center to another. There are several forces at work: the overall philosophy of the local regional center, the level of training provided, and local policies and procedures. An informant who works as a vendor with various regional centers, explained, "How they handle limited conservatorships is a regional-center-specific philosophy. Some initiate limited conservatorship petitions themselves, and others don't really believe in it.” Table 4 illustrates reported differences between regional center practices.

Table 4: Comparing Practices Across Four Regional Centers

Process Phase	RC 1	RC 2	RC 3	RC 4
Training	Offered but not mandatory	None offered	Basic training for all, but not comprehensive	Covers rights history and alternatives for all; Additional training for designated report writers
Initiation and petition support	RC supports petition if client is nonverbal	Support all petitions, "Don’t want to rock the boat"	Oppose request for marital, social/sexual powers but support other 5 powers if client is nonverbal	Oppose all petitions unless there is a substantial risk to client’s safety and well-being
Assessment of client	Contract with external vendor psychologist to complete assessment and write report	Assigned to SC regardless of their experience. SC sends IPP instead of a report with a brief letter of recommendations	Legal Dept. handles all petitions and reports. Assessment usually is based on records only. Interviews done only for high-profile cases	Designated SC with specialized training writes report and is required to interview both conservatee and conservator
Probate hearing participation	Report writer decides whether to attend	Never go, "Don’t want to get involved"	Go when disagreeing with petitioner	Always attend hearing, send legal support if needed
After-hearing monitoring	None known	None known	None known	None known

The columns represent regional centers practices that were either observed or shared by informants. However, since each regional center has their own policies and procedures, practices at any one regional center could be a combination of any of the four practices provided in the examples. Further, there may potentially be other differences in practices that are not documented here. The intent of the comparison is to broadly illustrate how different practices can be across regional centers. Table 4 presents four different ways regional centers can complete the work required of them, which is to submit a report to the court with basic diagnostic information regarding the proposed conservatee, and their recommendations regarding the powers requested in the petition.

The table captures how service coordinators are guided by different procedures and practices, depending on where they work. For example, one service coordinator reported that their regional center generally supports all requests, to avoid conflict with family members. Another said that their regional center generally does not support requests without documentation of substantial risks. The designated report writers have varying experience and training. Some have no training or experience, whereas at one regional center, a single individual writes all reports and has specialized training in the legal department. At another, the assigned case manager writes the report and has never received any training. Still other regional centers contract with psychologists to complete the assessments on their behalf. A service coordinator explained:

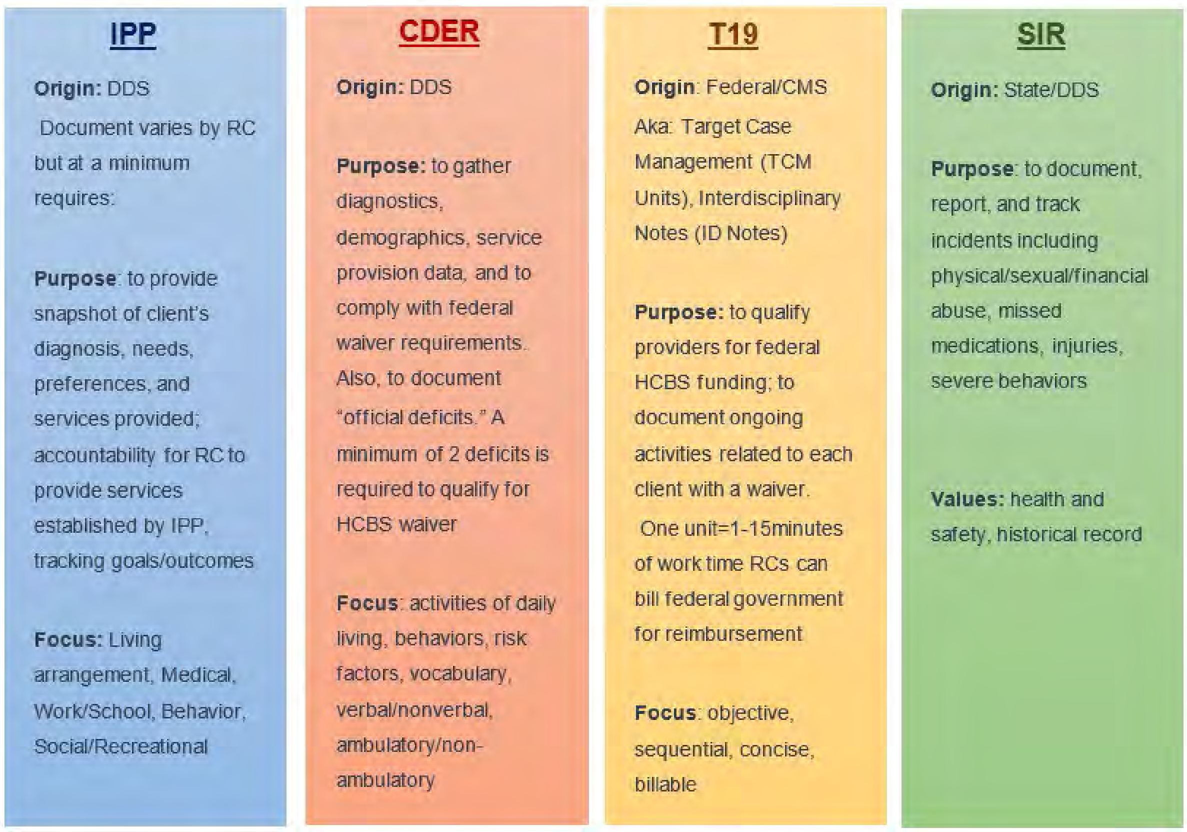
> I’ve never gone to a training. I was given some templates. There's not a whole lot of guidelines that the service coordinators are given when doing these reports or making these recommendations. When I think about it, it's rudimentary.

Differences between regional centers’ overall philosophy and approach to limited conservatorship requests are evident as well. A vendor explained the way limited conservatorships are handled appears to be a “regional-center-specific philosophy,” where they either believe in it or they don’t. For example, at one regional center it is customary and expected by management to “not rock the boat” with families/petitioners. However, a parent and their adult child had the opposite experience with their regional center, where the general approach was to rarely support a petition, even when it was being requested by the client with a record of being a strong self-advocate with outstanding verbal communication skills. The parent explained:

> We discovered was that on the legal side of the regional center there seems to be, according to our lawyer, a political attitude—a term she used more than once. They have a political agenda, she said, to block all attempts to conserve any of the regional center clients. I found that almost hard to believe. Why would that be? It had nothing to do with [their child] individually, or me, or any of us. It wasn't individualized. Apparently, it's an automatic.

An Overreliance on Institutional Texts. Each regional center also has varying policies and procedures dictating who writes and how assessments are written. All regional center informants indicated they primarily rely on four regional center internal documents (see Figure 8) to write their reports: the IPP (Individual Program Plan); the CDER (Client Developmental Evaluation Report); Title 19/T19 Interdisciplinary (ID) Notes; and SIRs (Special Incident Reports). The purpose of these documents varies, but generally concern obtaining financial reimbursement or accessing funds.

According to DDS (2020) the IPP is a contract between the regional center and the client/consumer they serve. It lists all services paid for by the regional center, including the contractual details such as goals/objectives/desired outcomes of service (i.e., the goal service will help client meet), service provider details, dates, and an approval number. The IPP also provides a snapshot of the client and their current needs/circumstances, such as their living arrangement, diagnosis, and age. The IPP is a state-required document developed by DDS and implemented by each regional center. All regional centers are required to have an IPP for every client, but what the IPP looks like and includes varies across regional centers. The template provided by DDS includes the following categories: Living Arrangement, Health, Education/Employment, Social/Recreational, and Activities of Daily Living (ADLs). These are the categories required to be addressed in an IPP, but regional centers can add other sections as well. A few examples of nonmandatory IPP categories are emergency preparedness or end-of-life planning. Of note, the IPP, which, according to DDS, ARCA, and DRC, is designed to be



IPP

Origin: DDS
Document varies by RC but at a minimum requires:

Purpose: to provide snapshot of client's diagnosis, needs, preferences, and services provided; accountability for RC to provide services established by IPP, tracking goals/outcomes

Focus: Living arrangement, Medical, Work/School, Behavior, Social/Recreational

CDER

Origin: DDS

Purpose: to gather diagnostics, demographics, service provision data, and to comply with federal waiver requirements. Also, to document "official deficits." A minimum of 2 deficits is required to qualify for HCBS waiver

Focus: activities of daily living, behaviors, risk factors, vocabulary, verbal/nonverbal, ambulatory/non-ambulatory

T19

Origin: Federal/CMS
Aka: Target Case Management (TCM Units), Interdisciplinary Notes (ID Notes)

Purpose: to qualify providers for federal HCBS funding; to document ongoing activities related to each client with a waiver.
One unit=1-15minutes of work time RCs can bill federal government for reimbursement

Focus: objective, sequential, concise, billable

SIR

Origin: State/DDS

Purpose: to document, report, and track incidents including physical/sexual/financial abuse, missed medications, injuries, severe behaviors

Values: health and safety, historical record

Figure 8: Regional Center Documents Used in Assessment Stage

“person-centered” and reflect the strengths and dreams of the client, primarily includes diagnostic information, deficits, and limitations.

According to DDS’s 2015 field manual, the Client Developmental Evaluation Report (CDER) is a state-mandated form designed by DDS to primarily serve as a management tool for budgetary purposes and for tracking data across the state, including demographics of clients and service outcomes. Unlike the IPP, the CDER has a consistent format, and the same document is used across regional centers. Additionally, the CDER catalogs diagnostic codes, use of psychotropic medications, living arrangement, maladaptive behaviors, “and other measures of client functioning” (DDS 2015:3). Regional centers use the CDER to assess a client’s overall status/condition—and to qualify for state funding.

Special Incident Reports (SIRs), according to DDS (2020), are required and governed by Title 17 regulations. These reports apply to all regional center clients, regardless of age and living arrangement. SIRs were designed to track incidents that threaten the health and safety of regional center clients, ranging from death or abuse of a client to a client’s displaying incidents of physical aggression or missing a medication. SIRs were designed to track/monitor actions like patterns of abuse behaviors that may place the health and safety of the client or others at risk. SIRs were also designed to assist DDS with ensuring that service agencies followed up and took steps to prevent similar incidents in the future. For example, if a client living independently has multiple SIRs for missed medication, an appropriate response would be to increase the level of services and supports to enable more time for medication assistance and management.

Interdisciplinary Notes (ID) notes, also known as T19 Notes, are a federal requirement found in Title 19 of the federal Social Security Act. They are part of the federal waiver program, which reimburses regional centers for case management activities that are reported billable units of time, as documented by T19 Notes (Vogel et al 2019). The Home and Community-Based Services (HCBS) waiver is very complex, but it allows regional centers to access federal funds for clients who have a minimum of two deficits that would qualify that person for placement in a state institution. Instead of placing the individual in an institution, which federal funds would cover, the federal government will pay for the services to be provided in home/community setting through the regional center. This is a more cost-effective and inclusive way to support people with IDD. Accessing these funds requires extensive documentation. The process is confusing and highly regulated. A regional center service coordinator explained how they officially document their time:

> The requirement is to have at least 400 'billable' units every month. One unit is equal to 15 minutes. It doesn't seem like much but things like filing paperwork, attending mandatory trainings and staff meetings… We can't even bill for mandated things like for quality assurance monitoring. So, it's actually hard trying to account for all that time [laughs] unless you run into a group of 'em [clients] in one spot. Then it's like cha-ching. I just got five [units] in one! Well, we aren't supposed to, uh, double-dip like that but you have to do what you have to do.

The focus of these documentation requirements overwhelmingly serves institutional priorities (i.e., securing funding, achieving cost efficiency). The documents present selected facts about the client the regional center deems worthy of inclusion, such as diagnoses, impairments, and deficits. The information from these documents is then summarized and included in the assessment report provided to the court as “objective facts” relating to the proposed conservatee’s ability to make decisions for themselves. Unless the regional center employee writing this report has met with the proposed conservatee and the proposed conservators (not required by each regional center), and thoroughly discussed the meaning and implications of being placed under a limited conservatorship, the client’s wishes and preferences may or may not be included in this assessment. The template used to structure their report does not always address subjects such as legal rights (including their voting rights) or decision-making. This is one example of external ruling relations (e.g., federal, and state-level practices) subtly, yet substantially shaping the everyday experiences of regional center employees. The result is a report that may be limited in how accurately it reflects the subject’s strengths, needs, and life circumstances.

The Report to Court. The assessment report that regional centers submit to probate courts varies across regional centers. Typically, however, the reports contain similar information because report writers rely upon the same documents to conduct the assessment. A sample template provided by one informant can be viewed in Appendix C. It is a training document provided to service coordinators. It illustrates what their assessments should include. This is only one template from one regional center and is not generalizable across regional centers.

The template analyzed for this study is organized into four sections. The first section,” Recommendations,” provides a short summary of their report’s recommendations. The next section, “Identifying Information,” summarizes the basics about the proposed conservatee, such as age, diagnosis, description, and dates of most recent medical assessments. The “Findings/Assessment” section describes the subject’s overall “current status of functioning level,” or what they are like socially, behaviorally, cognitively, and emotionally. It also includes information like CDER deficits (such as behaviors, high level of assistance), diagnoses, and description of how they spend their time (e.g., whether they attend school or day program). This is also where the proposed conservatee’s level of independence (e.g., independent or needs assistance) with ADLs (Activities of Daily Living) is summarized. Finally, this section lists each power requested by the petitioners/proposed conservators and regional center’s recommendation as to whether the petitioner be granted such power. For example, after each requested power, there is a statement saying, 1) this regional center recommends granting this power, or 2) this regional center recommends [client’s name] retains their right, and that this power should not be granted.

It is very important to pay attention to the information not included. For instance, does the document answer the question, why are the supports that met the client’s needs before the age of 18 no longer adequate? Or, have LRAs been tried and failed? If so, how, and why did they fail? The focus is instead placed on categories and labels attempting to measure capacity as binary. This approach simplifies a complex problem by reducing the concept of decision-making ability to a standardized, limited number of pre-selected categories.

An additional problem found with regional center assessments is the absence of discussion regarding LRAs such as supported decision making. Conservatorships are considered the most restrictive option. Considering LRAs first is mandated by numerous laws including Probate, WIC and H&S. Least restrictive measures are mentioned throughout the Lanterman Act, and regional center "mission and values" statements all prominently feature language about "empowering regional center clients to meet maximum independence and autonomy." Yet such concepts are not required to be included in the reports submitted to the courts.

Whose job is it to review and document how all LRAs were tried and failed? I asked four informants that question and got four different answers: the judge, the assigned attorney, the petitioner, the regional center representative. This lack of clarity made the point that a sincere effort to consider LRAs is not a high priority for the institutions involved in the limited conservatorship process. If it were, there would be a documented procedure/policy dictating exactly who has responsibility to provide information on how LRAs failed to meet the needs of the proposed conservatee.

Workload issues. As mentioned earlier, the lack of time allotted to a regional center report writer was a common concern among regional center informants. Not having enough time to complete assessments led to impersonal, standardized reports that did not reflect the actual needs of the proposed conservatee. A peer advocate employed by a regional center explained, "There's some really fine service coordinators that are setting very high standards, but with caseloads being so high, they're not able to invest themselves into individual clients as much." The amount of time service coordinators can dedicate to limited conservatorship assessments varies greatly, depending on the position the writer has within a regional center. For example, an employee responsible for limited conservatorship assessments said they were overwhelmed with increasing requests for limited conservatorships and that they “no longer have the resources to be able to meet them [proposed conservatees] all in person. So unfortunately, we’ve had to move toward conducting assessments just based on the client file [official records IPP, CDER, ID Notes, SIRs], which is not ideal.”

Further, all regional center informants who work as service coordinators reported that conflicting demands and lack of time made it hard—if not impossible—to prioritize limited conservatorship assessments. The two biggest issues reported were caseloads exceeding the state-mandated ratios and excessive federal and state documentation requirements. Regional center informants reported that, at a minimum, they have the following monthly responsibilities: scheduling and leading IPP meeting for clients born that month; updating the CDER; writing up the IPP and dispersing it to all required recipients; documenting 400 “billable units” in T19/ID Notes (equivalent to about 25 hours of work); renewing POS (Purchase of Service) contracts before they expire, and managing any crises that arise. An additional stressor is that all documentation has to match, or the documents will be out of compliance up the chain with local, state, or federal requirements. Documentation must be done carefully, then reviewed closely, to ensure accuracy and to avoid repercussions during performance evaluations. A regional center service coordinator explained:

> Working here is like playing an extreme version of Whack-a-Mole. With 96 clients, it’s an exhausting and depressing job that feels impossible. I am literally drowning in paperwork and doing the best to stay on top of the regular routine stuff like CDERs, SIRs and POSs, but the fires just keep popping up. When I have to choose between spending time writing a limited conservatorship report, which probably isn’t even going to be read by the judge, or getting caught up with paperwork…[pause] I’m going to prioritize paperwork because I don’t want to be out of compliance and risk losing my job. It’s not even a choice, more like a matter of survival. It’s sad but true. We can only do so much.

The urgency and demand to comply with documentation requirements is a burden that originates from federal-level requirements and cascades through all levels, down to regional centers. It shapes individual experiences by diverting the service coordinators’ attention from tending to other job responsibilities, such as advocating for client rights and completing meaningful assessments that accurately reflect the human being beyond their diagnosis and case number.

Regional centers’ level of participation and input from the client are shaped by extra-local regulations such as federal and state documentation procedures, as well as by local-level practices like training requirements. Based on actual experiences of regional center employees, and the analysis of regional center assessment documents, the data uncovered here do not reflect assessment practices are “person-centered.” Instead, current practices are organized around institutional documentation requirements and procedures. If the regional center limited conservatorship assessments were “person-centered,” meeting with proposed conservatees would be a requirement, and the proposed conservatee’s preferences and LRAs would be reviewed and included in the report to the court. The absence of such considerations silently removes the humanity from the objectified “professional accounts” they submit to the courts. Their clients—the people they want to serve and are legally obligated to serve—suffer the consequences of a system that places more value on institutional priorities.

In summary, current assessment practices are organized in a way that fails to personalize and individualize the process as intended. Excessive workloads and compliance demands make it clear that institutional priorities prevail. In the next section, the implications of current practices come to the surface as the focus shifts to the hearing stage. Final judgments are made based on the assessments reviewed in this section.

Stage 3: The Hearing

General hearing observations and patterns. Observational data (see Table 5) present a clear picture that the standardized approach and current institutional practices are failing to acknowledge the proposed conservatee as a person with multidimensional needs and circumstances. Table 5 presents descriptive data of the 93 rulings observed.

Observational data is shown for the pseudonymous Lovely County (Column 1) and Sunny County (Column 2). Rows provide frequencies, by each county and in total, for the following: new petitions for limited conservatorship requested and final ruling; the number of judges observed in each county; the powers requested and granted to conservator; conservatee attendance

Table 5: Probate Court Hearing Observations

Judgment Hearings Observed	California County (Pseudonyms) (1) Lovely	California County (Pseudonyms) (2) Sunny	Combined
Judgments Observed	49	44	93
Number of Judges Observed	4	5	9
PETITIONS GRANTED	49 (100%)	44 (100%)	93 (100%)
Powers Requested/Approved			
Powers Requested:			
All 7 powers	10 (20%)	44 (100%)	54 (58%)
5 powers	39 (80%)	0 (0%)	39 (42%)
Powers Approved:			
All 7 powers	1 (2%)	43 (98%)	44 (47%)
5 powers	46 (94%)	1 (2%)	47 (50%)
3 powers	2 (4%)	0 (0%)	2 (2%)
Hearing Attendance			
Proposed Conservatee:			
Present, spoken to	0 (0%)	15 (34%)	15 (16%)
Present, not spoken to	31 (63%)	11 (25%)	42 (45%)
Not present	18 (37%)	18 (41%)	36 (39%)
Regional Center Representative:			
Present, spoke	0 (0%)	0 (0%)	0 (0%)
Present, did not speak	0 (0%)	2 (4%)	2 (2%)
Not present	49 (100%)	42 (96%)	91 (98%)
Other			
Length of Hearing:			
5 minutes or less	39 (80%)	29 (65%)	68 (73%)
More than 5 minutes	10 (20%)	15 (34%)	25 (27%)
Conservatee's Voting Rights:			
Retained	49 (100%)	31 (70%)	80 (86%)
Terminated	0 (0%)	13 (30%)	13 (14%)
Objections by Conservatee's Atty.	9 (18%)	2 (5%)	11 (12%)
Less Restrictive Options Discussed	0 (0%)	0 (0%)	0 (0%)
ADA Accommodations Requested	0 (0%)	0 (0%)	0 (0%)
Conservatee Not Yet Adult (18 yrs.)	7 (14%)	17 (38%)	24 (25%)

*Percent discrepancies caused by rounding and participation; regional center representative attendance and participation; length of the hearing (over/under five minutes); whether voting rights were terminated or retained, and frequency and kind of objections from conservatee's attorney.

Table 5 contains a number of powerful descriptive findings uncovered through observations of these hearings petitioning for a new limited conservatorship. Most importantly, results show that in both counties, petitions were granted 100% of the time—a total of 93 judgments observed and 93 limited conservatorships granted.

There was some variation by county in the number of powers requested and granted. In Sunny County (Column 2), all 44 petitioners (100%) requested all seven powers. In every case but one (2%), all seven powers were granted to the conservator. By contrast, Column 1 shows a different practice in Lovely County. (Lovely County is where informants uniformly described the court's preference for "the standard five"—withholding from petitioner powers over the proposed conservatee's marital and sexual/social rights.) The findings for Lovely County confirm this practice. Unlike in Sunny County, in Lovely County there were 39 petitions— (80%) of the total 49— that limited their request to five powers. Judgment outcomes confirmed Lovely County's "standard five" characterization made by informants familiar with that system: Five powers were granted to 46 out of 49 total petitions (94%). It should be noted, however, that while the two counties differed in the number of powers routinely granted (five in Lovely versus seven in Sunny), practices and outcomes in both counties can be accurately described by the statement, "Petitioners asked for the maximum number of powers allowed and they got them."

In both counties, a majority (68 out of 93 total) of the judgment hearings (73%) lasted five minutes or less. The proposed conservatee—the individual whose rights were terminated at least partially in every case—was present (in person or virtually) in only 57 judgment hearings (61% of the time). Of those 57 instances where the person with IDD did show up, only 15 (16%) were spoken to, and these were all in Sunny County.

Regional center failed to show up, even though they submitted an assessment to the court as the “experts” on IDD and arguably the party who knew the proposed conservatee better than any other non-family participant. A regional center representative was present for only 2 judgments out of 93 total (2% of the time).

There was a second noticeable distinction between outcomes in the two counties. In Sunny County only, the judge terminated the voting rights of 13 out of 44 individuals with IDD (30% of the time). This occurred even though state law strengthened voting rights protections for individuals with IDD and conserved citizens in 2015 (CA Election code 2102 and 2208). In those 13 instances, did the individual case circumstances justify such a move by the judge in Sunny County? Why did this not happen to any of the 49 individuals whose petitions were filed in Lovely County? Answers to those questions lie beyond the scope of this study but warrant further inquiry.

As for the legal counsel representing the interests of the individual with IDD, and whose rights were at stake, in only 11 (12%) out of total 93 observed hearings did appointed representation make any objections. All of these objections were limited to certain powers requested, but not to the limited conservatorship overall. All other observed hearings (88%) proceeded without objections to powers.

Patterns of Judicial Preference. A consistent pattern that was observed and discussed by nine informants is that practices within Superior Court, and even in departments within the same court, vary. An informant with experience in multiple probate departments said:

> I've read the law, but the interpretation of it is widely different across jurisdictions and judges. Usually, you might have to do x, y, and z, and it has to be submitted in this time. But then another court will say, 'I don't care so much about x, y, and z, and just make sure you do a, b, and d.' It's like 'Okay, but I can't keep track of who wants what.'

Table 5 does not compare outcomes on an individual-judge basis. In total, nine were observed (four in Lovely County, five in Sunny County). However, background field notes and the Observation Data Tool used in this study show that seven out of the nine judges observed made the same decision on every case, regardless of whether regional center reports were received and reviewed during the hearing, and regardless of the regional center reports' recommendations. These findings also help to understand why some regional centers do not see value in improving the quality of their assessments since they are frequently disregarded.

The language observed at limited conservatorship hearings was telling—in fact, predictive. One public defender observed in Lovely County and described above consistently used the phrase, "No objections to the 'standard five,' Your Honor." This communicates that, in this court's department, it was standard practice to approve removal of "the standard five" powers (i.e., living, contracting, access to records, medical, education). The observations noted in Table 5 about Lovely County's hearing judgments bear this out. Another informant shared an experience consistent with these observations:

> The different courts across California have their own philosophies about conservatorships. Then you’ve usually got one-to-three judges assigned to the probate department, depending on the size of the court. They normally issue [grant] the powers the same way across the board. No matter what a person needs, they're going to get x, y, and z.

Clearly, this does not reflect an individualized approach. It demonstrates that the standard practice of individual judges, and the county in which the petition is filed, substantially determine the number of powers granted under a limited conservatorship. This is alarming, considering there are 58 superior courts in California, each with one-to-55 branches and a total of 1,498 judges. Of limited conservatorship proceedings in two California counties studied for this research, one generalization applies to both: at the most local level—a specific judge in a specific department in a specific county—hearing outcomes are largely predictable without having to know anything about the proposed conservatee or their circumstances.

The evidence provided in this section demonstrates how the hearing, at least in the counties observed, is more of a pro forma performance to give the illusion due process is being followed. The conservatee’s participation is not encouraged or supported, as witnessed by the substantial number of proposed conservatees (39%) who did not attend their own hearings, as well as the minimal level or total absence of their genuine participation in the proceedings. The lack of participation of proposed conservatees demonstrates that they are not receiving sufficient support or the accommodations they need to meaningfully participate in the hearing.

This section also highlights a pattern that rulings in limited conservatorship hearings conform to the standards and practices established by each local court and individual judges. One activist summarized how far the actual hearing departs from the intent of the laws protecting the rights of individuals with IDD:

> We have courts that are taking away rights without due process. For me, that's the key issue. According to the State Constitution we have these rights, and then according to the probate codes there has to be clear and convincing evidence. There is no clear and convincing evidence in a three-minute hearing. People come in with a few allegations and the judge signs off on it. Once it's happened, you know how hard it is to unwind.

Trends with attendance and participation. While observing, I paid close attention to the role regional center employees played in the process. Of all 93 cases, only two service coordinators were observed attending hearings for their clients. Neither of them provided input when asked if they had anything to add. Further, two of the three informants employed as regional center service coordinators admitted they had never attended a hearing after making their recommendations to the court. When asked if they had attended hearings, one service coordinator responded:

> Amazingly, no. I know you would think that after 16 years I would have, but no, I have not. I asked to go to a few but was told I couldn't go because that would open the opportunity for me to be called and put on the witness stand to defend my report, and that could create issues.

An informant explained a potential consequence of regional centers' lack of participation in limited conservatorship proceedings, "Frankly, it says they don't give a damn."

Having the regional center attend not only shows they care, but also that they take these proceedings seriously. It also shows they stand behind their recommendations enough to explain them at the hearing. It also provides the opportunity for the regional center representative to speak up about LRAs. If they attended, they could also assist their client in accessing available, yet underutilized, ADA accommodations that would facilitate the client's participation. An accommodation, for example, could be to request that the hearing take place in closed chambers, for clients who have sensory sensitivities.

Of those 57 proposed conservatees who did attend their hearing, only 15 were spoken to or engaged with by the judge and/or the attorneys. Yet even when proposed conservatees did attend their hearings and were capable of expressing their desires, it did not mean that their preferences or desires would be considered or honored. A regional center service coordinator shared an experience while attending the hearing of a client:

> It was cold. Very brief and impersonal. It must have lasted less than four minutes and that person, in this particular case, the client was high functioning and was able to speak to the judge himself, but the judge didn't seem to take advantage of that. He only asked basic questions like how old he was and who he lived with. It was just like conversational questions, not really for designed to illicit their [regional center client's] honest opinion on the matter." It was all pretty superficial.

However, a regional center vendor reported that in their experience, "For the most part, judges do try to figure out what the conservatee wants. I think the judges are attentive". These contradicting data are further evidence that experiences are shaped depending on the county they reside in, and not their needs.

During one in-person observation in Lovely County, a case was being heard without the conservatee present. The judge reported that there was a note indicating that the conservatee had been repeatedly contacting the probate help desk claiming they did not want the conservatorship and that the regional center report was opposed to the court's granting any powers other than financial. When the judge asked the public defender if they had any objections, the public defender responded with, "No objections to the 'standard five,' Your Honor." The judge proceeded to grant all five powers to the conservator. There was no discussion or inquiry regarding the proposed conservatee's not being present or expressing a clear desire to maintain their rights. Essentially, this conservatee had their rights terminated because the court did not believe their desires and input were significant enough to warrant a continuance. This could reflect the realities of an overburdened system that causes judges and conservatees' appointed counsel to make hasty decisions, but it does an injustice to the conservatee.

In summary, observations and informants in this section consistently demonstrate the predictable outcomes and non-individualized nature of limited conservatorship hearings. Petitions and judgments conformed predictably and unchallenged to patterns previously established by a particular county, department, and even judge. As for the person whose rights were at risk of being terminated—and were, in fact, terminated, at least partly—there is a similarity across sites: proposed conservatees were too-often absent or discounted, even if they were present and self-advocating.

Overall Process and Sites for Intervention

These findings uncovered how, in an attempt to “get things done” in this dysfunctional system, many agencies have turned to “one-size-fits-all” practices that flout the intent of California’s laws protecting the rights of people with IDD. The result is a process that has become institutionally centered. Additionally, the process is textually mediated, guided by a series of institutional documents designed to categorize unique individuals into predetermined, “objective” boxes. While such texts may serve the purpose of time efficiency and legal standardization, a rigid, binary approach to defining unique individuals fails to take into account the fluid and multidimensional aspects of IDD. These documents—non-individualized, too infrequently challenged or even shared, giving insufficient attention to the human being whose life may be changed forever by the outcome—are the dominant force in an unequal power dynamic that determines if someone’s most basic rights will be terminated, retained, or restored.

Figure 9 presents the overall map of the limited conservatorship process with sites of interventions. It illustrates moments/sites where most of the issues discussed in Chapter 6 arise. Dash circles and arrows represent potential for participation. For instance, the Confidential Supplemental Information is not automatically shared with the regional center as the other forms are. This map highlights five particular moments/sites where regional center has an opportunity to intervene to make the process more person-centered and individualized. These moments/sites are labeled with orange starburst shapes numbered one through five.

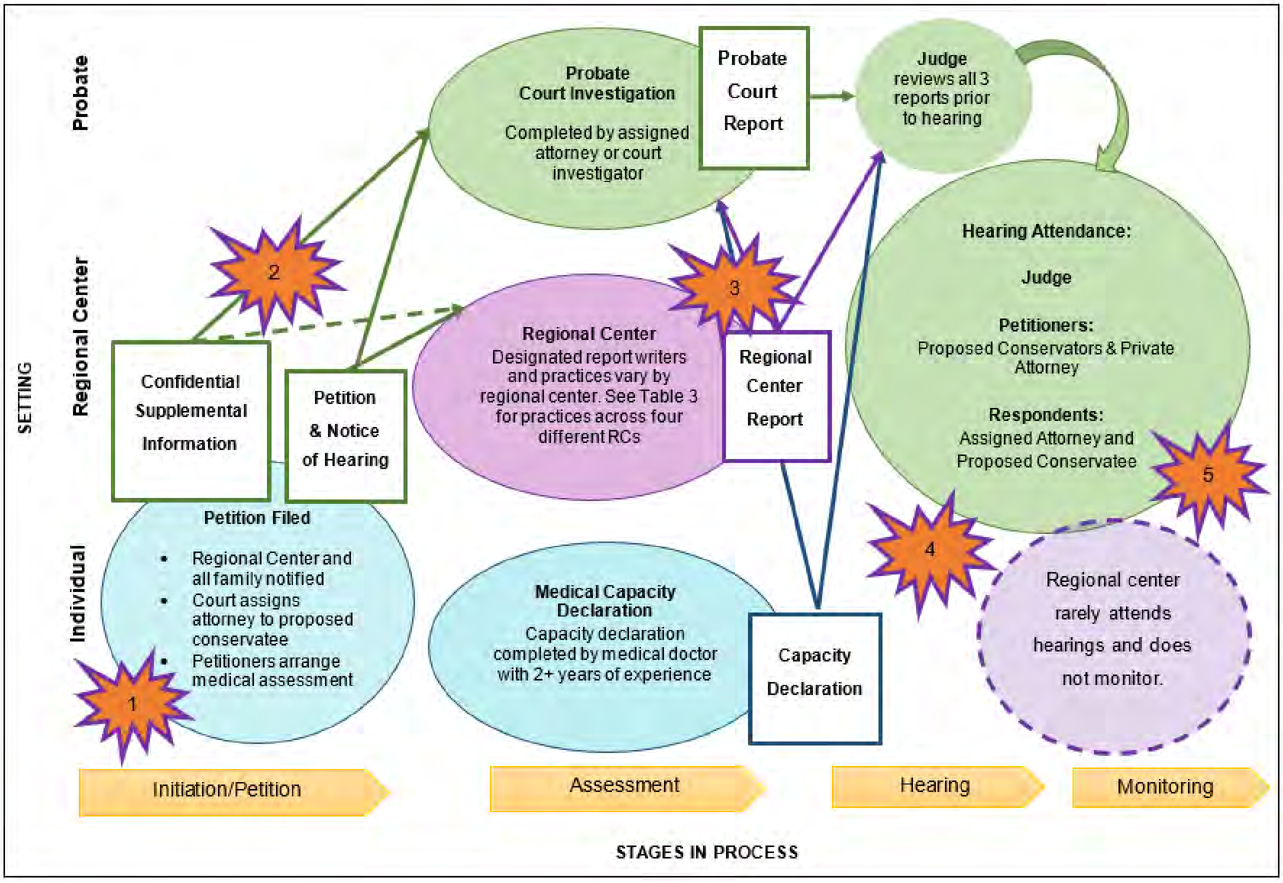


Figure 9: Sites for Intervention

The first moment when regional centers have an opportunity to intervene is leading up to and during the initiation/petition stage. This research found there is a critical need to increase public education about the importance of IDD rights, the disadvantages of limited conservatorships, and what LRAs offer that may be preferable. Most petitioner-informants admitted their lack of knowledge about LRAs as an option they could have considered. They said LRAs were never mentioned when they sought advice from trusted sources such as school officials or attorneys. Additionally, this research has shown how inadequately relevant organizations (like regional centers) communicate about LRAs through their media available to the public.

The second and third moments occur in the assessment stage. Both seek to correct missed opportunities for interpersonal collaboration and meetings between regional centers and probate court in lieu of letting documents dominate the process. The third and fourth moments take place during the hearing stage. I have added a fourth stage that specifically targets the lack of monitoring after a limited conservatorship has been established by the courts. Specific recommendations on how regional centers can intervene during these critical moments are discussed in Chapter 8. The tensions that contribute to the dysfunction and implications of such are discussed in the next in chapter.

CHAPTER 7: SOURCES OF TENSION (DISCUSSION)

When looking at issues that arise throughout the overall process, with focus on the regional center's participation, they can be organized around three main sources of tension: work conditions, professional IDD service delivery culture, and practices that prioritize institutional needs over the needs of the clients they serve. In short, this research has uncovered how work conditions alongside professional IDD culture ideology and discourse allow room for practices to emerge that depart from original mission and values. This inevitably harms clients, who are already marginalized and are being excluded from the process.

Overburdened System

Combined, the regional centers serve over 300,000 adults, all of whom receive individual service coordination, and 75% of whom receive services paid for through the regional center. Vogel et al (2019) warned that the system is growing at unsustainable levels. There are too many clients and not enough service coordinators. ARCA (2019) reports that the average service coordinator has a caseload of more than 90 clients. This view was echoed by many regional center informants. They cited challenges of working with such high caseloads, one of whom reported having 96 clients. This same report discussed service coordinator pay scales at regional centers:

> Nearly every regional center position pays less than the equivalent position in state government. From 2013–14, for example, the core staffing formula set regional center service coordinator salaries at $34,032, and the actual median salary for the position was $46,121. Had the core staffing formula kept pace with increases to the average state

> salary, the regional center service coordinator salary would be about $50,340.

Excessive caseloads only add to the problems. Not only are service coordinators underpaid, but they are overworked. The same study found:

> As of 2017, 20 of 21 regional centers failed to comply with at least one statutorily-mandated service coordinator caseload ratio. Meanwhile, California's average caseload ratio of 1:73 places it far above the 2005 nationwide median of 1:30-39.

The study went on to report that achieving compliance with state-mandated service coordinator ratios would require hiring an additional 1,000 service coordinators. A service coordinator with more than 20 years' experience said:

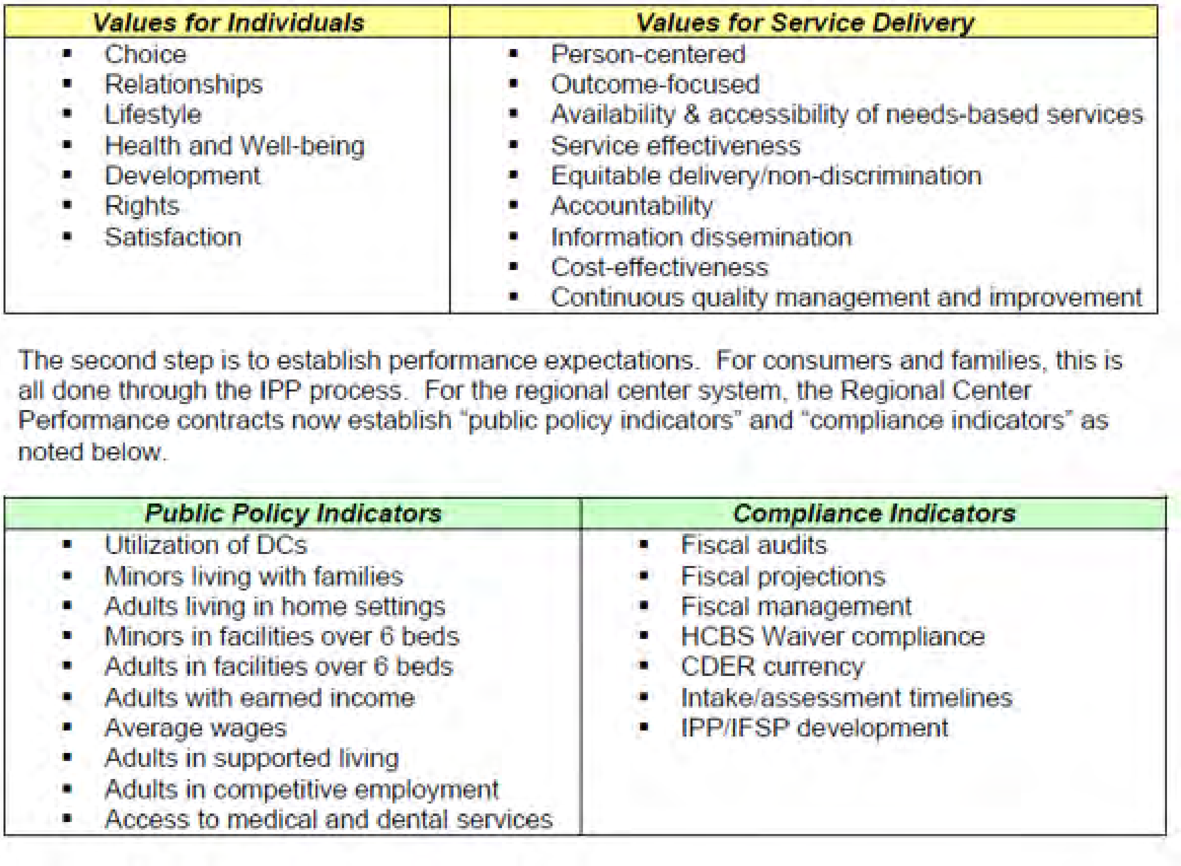
> No, they [regional centers] don't seem to push back against or challenge DDS. At least not in a significant way. I have not had a caseload under 85 since '03 or '04. Management either doesn't care or have no clue about being in the field. If they were the ones in the trenches trying to reattach limbs with government-issued Band-Aids… [extended pause and chuckle] I'd bet that if they [management] had to answer our phones for just one day, man, things would be different.

Without being given the resources and support needed, many regional center workers find the only way to stay afloat is to comply with demands of the institution—even if they disagree or know it would not be in the best interest of the clients they serve. It is critical to understand that informants across all sites find they have little say or control over the focus of their time and work efforts.

Institutionally Centered Process

When the gaze is shifted from work conditions, it is possible to see how the professional culture within the agencies shapes the process. Texts are used as a tool to operationalize institutional ideology, such as accountability and cost-efficiency. Tracing practices to dominant institutional values allows us to observe what forces are at work. They shape what workers' pay attention to and how they prioritize their work. In this way, agencies created to empower people with IDD can unknowingly contribute to their marginalization.

How regional center work is prioritized can be traced back to how service systems measure their own "success" at delivering those services. Figure 10 displays the values DDS lists in their 2008 HCBS Waiver Primer and Policy Manual that are central to California's service delivery system. On the top part are values central to individuals the regional center system is designed to serve. On the bottom, "Indicators" measure regional center's performance. Then, the DDS metrics can be traced through to regional center worker performance evaluations. The performance evaluation reviewed in this analysis was obtained from an informant who works in case management. It lists "Key Accountability Statistics" for measuring the quality of a service coordinator's work. The top five measures carry the most weight in these evaluations, making up 70 out of a maximum of total of 80 points. Measures include: compliance with Title 19 quality and productivity requirements (documenting at least 400 units/month), and compliance with federal and state requirements for SIRs, CDER, IPP submission. The focus here is clearly on institutional priorities and not on individual client values.



Values for Individuals	Values for Service Delivery
▪ Choice ▪ Relationships ▪ Lifestyle ▪ Health and Well-being ▪ Development ▪ Rights ▪ Satisfaction	▪ Person-centered ▪ Outcome-focused ▪ Availability & accessibility of needs-based services ▪ Service effectiveness ▪ Equitable delivery/non-discrimination ▪ Accountability ▪ Information dissemination ▪ Cost-effectiveness ▪ Continuous quality management and improvement

The second step is to establish performance expectations. For consumers and families, this is all done through the IPP process. For the regional center system, the Regional Center Performance contracts now establish "public policy indicators" and "compliance indicators" as noted below.

Public Policy Indicators	Compliance Indicators
▪ Utilization of DCs ▪ Minors living with families ▪ Adults living in home settings ▪ Minors in facilities over 6 beds ▪ Adults in facilities over 6 beds ▪ Adults with earned income ▪ Average wages ▪ Adults in supported living ▪ Adults in competitive employment ▪ Access to medical and dental services	▪ Fiscal audits ▪ Fiscal projections ▪ Fiscal management ▪ HCBS Waiver compliance ▪ CDER currency ▪ Intake/assessment timelines ▪ IPP/IFSP development

Figure 10: Measuring performance in the California IDD Service Delivery System
**Obtained from DDS (2008) HCBS Waiver Primer and Policy Manual*

To qualify for continued funding, the performance contract system hinges on a compliance hierarchy going from regional center/local level to the state and then federal levels. The system reveals its internal priorities by looking at how some compliance goals are almost always met while others are largely unattained. Most regional centers maintain close to 100% compliance with CDERs and IPP timelines. By contrast, in 2021, nearly all regional centers (20 out of 21) were out of compliance with laws and regulations that mandate maximum caseload ratios (Vogel 2019, ARCA 2020). WIC 4640.6 states that regional centers' staffing patterns must demonstrate that direct service coordination is the highest priority.

Governing agencies such as the regional centers appear to be less concerned about measuring “individual values.” For instance, there is no meaningful tracking or analysis of limited conservatorship petition outcomes or their clients’ rights lost in that process. These kinds of data have been used as a measure of accessing rights (NCI report 2017). An activist informant explained:

> Nobody at the state level keeps any data on any of these cases. There's nobody in charge. No one's paying attention, and we don't know how you can make good policy when you don't have data.

Values like independence, rights, and autonomy also appear to have fallen off the regional centers’ radar, while their attention has been redirected to accessing needed funds. This is reflected in the diminished attention given to protecting the fundamental civil rights of the people they serve. One peer advocate employed by a regional center noted, “There's very little education done at regional center on the disability rights movement.”

A service coordinator noted how attention to once-central values shifted over time:

> When I was trained [at regional center] in 2001, rights, choice, and autonomy were central in our basic service coordinator training. So was the history! My cohort had a whole day dedicated to the history of person-centered planning and client rights. It covered everything: institutionalization, forced sterilization, the people first, and IL [independent living] movement, crip camp. Man… [pause] It was powerful. I think about it all the time, and it makes me sad. These days they are taught just enough to get the paperwork done.

A training manual designed for service coordinators from 1999—more than 800 pages long—is available online. It was given to all new service coordinators in Southern California and included a 46-page chapter dedicated to teaching practices that emphasized values such as rights, choice, and autonomy. The manual also included exercises for service coordinators in training. One exercise dealt with practicing different ways of having challenging conversations with families. Another tested service coordinators on their knowledge of laws and regulations that require the use of LRAs. When comparing this 800+ page training guide from 1999 to a 106-page training manual from 2012, it becomes clear how the institutional messaging has shifted. The more recent manual did not include any information on the history and importance of the rights movements, limited conservatorships, or LRAs. Failure to include a significant topic like termination of rights sends the message, this individual value is not worth the effort or expense.

The above is evidence that the work has changed over the years, and that governing institutions are favoring their own needs over those of their clients—more so than in the past. A reform activist summed it up, saying, “You count what you care about.”

Disjuncture Between Ideology and Reality

The findings in this study reflect a disjuncture between the proclaimed values and ideology of governing service agencies and the lived realities of the people they are tasked with empowering. Table 6 illustrates a disjuncture between ideology in writing versus in practice. When looking at the way certain values are operationalized, it becomes clear that current practices are falling short. Dominant measures focus on what is important to the state (cost control, cost shifting, securing funds, compliance). If practices were aligned with values central to the Lanterman Act (e.g., independence, rights, autonomy), practices would be organized around them. Agencies would find a way to manage the culture of compliance while emphasizing Lanterman-Act values. For instance, a rights section would be standard on the IPP form. There would be templates that list LRAs for consideration. Publicly available information on limited conservatorships would be as comprehensive and accessible as all the information on generic (cost-shifting) resources. Further, regional center workers would be allowed to help with petitions, in the same way they are required to be trained and ready to assist families with accessing public benefits (e.g., HCBS waiver, IHSS).

The laws and regulations, as well as the mission and values of regional centers, are clear: the goal is to empower, advocate, and be person-centered. However, the findings in this study demonstrate that those values are not being practiced or experienced on the individual level. An example of this can be seen when exploring the potential of the IPP as a tool to secure services designed to increase self-advocacy and decision-making skills.

The IPP is more than a piece of paper. It is a legal agreement between the regional center and the client.

Table 6: Lanterman Act in Writing vs. Lanterman Act in Practice

Law in Writing	Law In Practice	Experience/Evidence
Person-centered, individualized service delivery	Standardized, institutionally centered	- Access to person-centered, individualized service delivery varies by RC
Client rights/self-determination/choice are top priority	These are low priority values	- Training on history of IDD rights movement is no longer a priority - Training on limited conservatorship not standard - These values are not included in IPP goals
Regional centers designated experts that advocate for client rights and are leading source of resources and information	Not proactive, failing to inform clients and public.	- Advocacy role is low priority compared to cost savings, efficiency, and compliance - Websites have minimal information - Not active in reform efforts - Don’t gather data
SCs are top priority	Cost efficiency is priority	- Salaries are lower than state average for similar jobs - Caseload ratios consistently exceed mandated limits

It lists all services the planning team agrees are needed to assist the client with meeting a time-limited, outcome-based, measurable goal that increases their independence or access to the community. One activist discussed the power behind the language used in IPP goals:

> We have to really be careful about how we label it [the goal to justify paying for service] for regional centers. It's all about the way that you word the goals. It needs to be clear that service is needed to help them [the regional center client] to be more self-determined.

For example, an IPP goal could be written as follows: “Jordon will become more self-determined by learning three new decision-making strategies by the next IPP meeting.”

This would then allow the regional center to purchase a service that would help Jordon meet that goal (e.g., by providing funding for them to attend a self-advocacy conference). Stating an official goal on the IPP allows the regional center to purchase a service that will help teach the skills needed to reach the goal. Unfortunately, goals addressing values central to the individuals served by regional center are rarely included in the IPP. A peer advocate employed by regional center explained, “We have goals in IPPs for ridiculous things. IPPs rarely include goals that address exercising rights and what does that look like and how to make informed choices.” Failing to include values like independence and decision-making as priority goals in the IPP hurts the client and perpetuates reliance. Such disempowering practices are failing to keep the promises of the Lanterman Act. Instead of empowering and promoting independence, regional center practices surrounding limited conservatorship foster the culture of compliance but fail to protect basic legal rights of the individuals they are mandated to serve.

The system is currently organized to prioritize institutional needs (efficiency) over their clients’ needs (individualized support). During an interview, a regional center parent shared the following when discussing their experience with the limited conservatorship process. Their comment describes the consequences of regional centers’ having lost sight of their original mission and purpose, and the damage done to what should be trust between the agency and family:

> Now you've got to wonder, are they really protecting and serving the client or are they protecting and serving themselves? Honestly, I still wonder. I still think it was just some bureaucratic inertia that had no individualized purpose other than automatic. The biggest, unfortunate, disappointing

> surprise was the difficulty created by the same organization that saved my child's life—the regional center.

Such testaments provide further evidence that the IDD service delivery system has lost sight of their mission and fundamental values of individualized service provision. Instead, the system focuses on measuring the costs and benefits of services provided.

In conclusion, the work conditions and professional culture within IDD service delivery create an environment that sets the stage for practices to deviate from values and mission of original intent. By explicating the process of establishing a limited conservatorship, I uncovered and traced how it came to be that the promise of the Lanterman Act has been overshadowed by streams of documents, evaluations, and service plans that regulate the time, focus, and actions of people participating in and experiencing the system. I show how governing agencies have organized well-intentioned people—frequently against their better judgment—to “serve as the State’s hand” when submitting objectified and institutionally-centered reports to the courts. These documents essentially remove the humanity and jeopardize the legal rights of the person they are trained to believe they are empowering. It is all done to maintain professionalism and preserve precious resources. The state is able to exercise invisible power over the experiences and realities of clients and service coordinators by using texts that are designed to objectify, categorize, and sort clients into boxes that serve budgetary and managerial needs of the governing institutions.

The findings in this study illustrate some of the tragic consequences of standardizing a process that was intended to be individualized. This is reflected by the finding that 100% of the 93 observed judgments for limited conservancy were granted. Findings also show how people working within the system (regional center workers, probate public defenders) also experience negative consequences from lack of time and resources. This same misdirection of resources means governing agencies fail to develop minimum standards and quality practices that protect the civil liberties of regional center clients. While clients are less adequately served, workers are increasingly disconnected from the original mission of their work. In summary, organization and practices operationalize structures of oppression and expose disjuncture between the intent and mission of regional centers (serve, empower, protect) and the way their services are experienced by those involved.

Overall, the findings indicate that most people with knowledge of, or involvement in, limited conservatorships are well aware of systemic failures. They agree the process needs attention, reorganization, and leadership. They want change too. While this study calls attention to substantial problems with current practices, its purpose is not to expose or blame a single person, agency, or organization. Instead, this study is a call to action. It maps out a path toward change. Chapter 8 presents recommendations and provides suggestions on how regional centers can make their practices related to limited conservatorship more person-centered and individualized, as the Lanterman Act intended.

CHAPTER 8: RECOMMENDATIONS AND CONCLUSIONS

In 1987, U. S. Representative Claude Pepper famously stated:

> The typical ward [conservatee] has fewer rights than the typical convicted felon. By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get

> and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception of the death penalty.

This quote crystallizes what is at stake when urging reform and intervention to help adults with IDD avoid a conservatorship, or what some refer to as a "civil death." This may seem dramatic, making it tempting to disregard this issue because we have laws, institutions, and systems in place that we assume will protect our civil liberties. However, as found in this study, the law in writing and law in practice are not the same thing. For example, California laws clearly mandate that conservatorships are only utilized when less restrictive alternatives are not available. Yet the literature overwhelmingly tells us that less restrictive options are routinely bypassed in favor of the most restrictive option—the assignment of a guardian/conservator (Jameson et al; 2015; Martinis, 2015; Millar, 2003; Millar & Renzaglia, 2002; NCD, 2018; U. S. Senate 2018; Payne-Christiansen & Sitlington, 2008; Salzman, 2010; Shogren et al 2018). Yet even with irrefutable evidence growing over the last 20 years, people can't believe—or don't care—that basic civil liberties are routinely removed with minimal or no due process. An activist offered insight on why reform efforts struggle to gain momentum:

> There's this assumption that the courts follow the law. You're asking people to believe that judges wearing robes sitting on the bench are not following the law. That's a really hard thing to accept. For those of us who have gone through the American school system, it was drilled into us that our laws guarantee and protect our freedom and personal rights. When you are unfortunate enough to land in probate court, and see a complete disregard for the law in court, your brain short circuits. You just can't even

> believe it for a while. It’s like a parody. If it wasn't real, if it wasn't someone's life being destroyed, it could be a comedy show.

A probate attorney offered their opinion on how the process came to be a patchwork of contradictions:

> Probate is a whole new world compared to criminal law. Not much thought is put into this area of law. I think it's because no one cares. To be frank, I had no idea what a conservatorship was and I'd never trained for it. I never had given any thought to it prior to my boss being like, ‘Hey, this opened up, we need you to take it over.’ I tell you this because it demonstrates a lack of care and that this is important. I think it explains why it's [guardianship/conservatorship policies] such a patchwork across the state, across different courtrooms, and across different judges. No one knows the best way to handle these, and no one’s talking about it because people either don’t care, or don’t know where to start.

Other informants described this confusingly complex process as a “mini-universe,” “Greek tragedy of epic proportions,” “circus,” “the Twilight Zone,” “nightmare,” “battlefield,” and “the Bermuda Triangle.”

While the process is fragmented across various laws, institutions, and agencies, this study uncovered a shared frustration and a consensus among informants that the current system is underfunded, overburdened, and lacks oversight. A probate attorney summarized the systemic nature of the barriers hindering the law from working as intended:

> I hate to be a cynic and I hate to be complicated and difficult, but there is no real solution. It’s a systemic problem with so many pieces that it’s impossible to address them all. There are things that can make it better.

> Mandating court-appointed counsel ensured they have representation, but didn’t guarantee the quality of representation. And what can you do, sanction everybody that doesn't do it perfectly? Laws can increase the training requirements, but how is it going to be accomplished without a budget? Legislation alone is not going to necessarily solve the problem.

An activist echoed similar concerns, explaining, “The problem is not so much with the law as it is with implementation. California needs to ensure that existing laws and regulations are not only funded, but are enforced.” With this in mind, my recommendations that aim to shift institutional priorities, practices, and culture.

Findings in this study make it clear that the recurring problem of insufficient budgets are a central issue impacting the ability of workers to carry out their duties in a person-centered way. Resolving budget-deficit issues is beyond my area of expertise and outside the scope of this paper. However, I feel obligated to at least address this major source of tension and include ideas informants offered on how regional centers could potentially secure at least some additional funds to assist with needed changes. The most common suggestion from informants was for regional centers to call on ARCA to pressure DDS, SCDD, and DRC to provide the regional centers with more support, guidance, and funding. Alternatively, a reform activist encouraged each regional center to apply pressure to DDS, by adding a line to their proposed budgets sent annually when renewing their individual contracts with the state. Other informants suggested the regional centers be proactive by applying for grants through rights advocacy organizations such as the American Civil Liberties Union (ACLU) and the National Council on Independent Living (NCIL).

This study reveals a dire lack of state-level guidance in California and leadership is a primary source of tension in the conservatorship process. In fact, many informants suggested that state-level agencies, such as DDS and SCDD, seem to actively avoid the topic of limited conservatorships. This contradicts the agencies' stated missions to advocate, empower, and protect. A regional center worker explained:

> I think there's this fear behind providing legal advice, and somehow filling out a form is the same as providing legal advice. I'm told to tell them what to do or what not to do in every other aspect of their life. But when it comes to conservatorships it's like, 'Whoa, no, no, no!' I can't even help you fill out a form where it says to put your name here. I'm told, 'No, we don't do that.'

Such claims are supported by the fact that between 2014-2021 Spectrum Institute, a nonprofit working toward probate reform sent multiple reports documenting serious flaws in the limited conservatorship process leading agencies, including: DDS, SCDD, DRC, CHSSA, California Judicial Committee, the Governor of California, and all 21 regional centers. These reports exposed that the number of limited conservatorships is steadily increasing (Coleman 2014, 2017, 2019; Coleman and Baladerian 2015) and that LRA are not being utilized (Coleman 2014, 2017, 2019). Further, Coleman (2021) points out despite the fact that as of 2019, DDS or the regional center, as designated local service agency, was conservator for over 435 regional center clients, the state continues to avoid taking any responsibility to protect the rights of their clients.

It was only after ABC10 Sacramento aired an investigative series in 2021 called "The Price of Care"—focusing public attention on the lack of state oversight in the limited conservatorship process—did DDS acknowledge a problem even existed. In a press release (DDS 2022), Nancy Bargmann, the Director of DDS declared:

> DDS is committed to working with our partners, including consumers and families, to effect positive change to DDS' conservatorship process. This includes building on our collective work in supporting individuals who have an intellectual or developmental disability through person-centered and culturally responsive approaches.

The also statement addressed the need to reform practices and evaluate the 413 conservatorships DDS/RC are currently conservator over. While I consider this a step in the right direction, it fails to acknowledge a comparable responsibility to better serve the estimated 57,000 regional center clients who are conserved by family members, law firms, public guardians, and other non-state entities. Excluding such a sizeable population of conserved individuals from their public statement does not instill confidence that DDS is willing or interested in leading potential reform efforts. Additionally, even if they were willing to exercise the needed leadership, there is little reason to expect prompt, forceful action, based on recent performance.

I believe, and this research supports my belief, that most people working within the IDD service delivery system are good people with the best intentions. They genuinely want to protect client rights and empower clients to be self-determined and as independent as possible. This is a common mission we are all working toward. I am hopeful this shared mission can unite our currently fragmented efforts. Further, I believe that most people in the field agree this mission is too important to wait. We can't afford to be complacent, passively waiting for DDS or SCDD—or any other government agency—to provide guidance and resources that bolster advocacy efforts. As such, the following recommendations, focused on regional centers throughout California, are designed to be implemented with or without state oversight or increased budgets.

"The Call is Coming from Inside the House": A Call to Action

I acknowledge that without support from leading state agencies (DDS, SCDD), without an increase in budgets, without a reduction in caseload ratios; implementing practices in an individualized way seems not only impossible, but undeniably places extra demands and burdens on already overworked and underpaid service coordinators. To account for this, I implore regional center management to consider ways in which they can help counter or absorb extra work burdens experienced by service coordinators. I have included a few suggestions on how this might be accomplished.

This paper, having focused on the role of regional centers as the IDD services experts, now explicitly calls on them as the most capable and practical agency to intervene and lead reform efforts. Most of my informants agreed that regional centers are the most appropriate agency to lead. A probate informant points out, "Regional centers are vital. I wish more [regional centers] would recognize their central and legal role. They are crucial to the process. That is why their [regional centers'] involvement is included in the law." Regional centers are the agencies that understand the complexity of IDD and are already designated by the state as advocates and local experts.

Recommended Actions for Regional Centers

The recommended actions below (see Figure 11) are based on a combination of data gathered for this study and knowledge gained during my nearly 20 years of experience working within the IDD service system. They are intended to make the processes and practices of establishing limited conservatorships more individualized and person-centered. All these recommendations could be implemented independently by regional centers, without guidance or mandates from DDS. The regional center already has many tools in place they can utilize to recenter their practices around the individual needs of their clients. Recommendations are organized around three actions that regional centers can take to spark change: (a) step up, (b) shape up, and (c) show up. These actions are illustrated in Figure 11.

Step Up

- Step up and lead collaboration efforts; e.g., designate a person or department as single point of contact for clients, families, court employees, etc.
- Increase education efforts with schools, courts, medical professionals, families, clients
- Create and share materials on shared decision-making and other LRAs
- Start gathering, evaluating conservatorship data needed to support reform efforts

Shape Up

- Shape up internal practices and procedures
- Develop internal practices that promote and support individualized and person-centered assessments; require training for all service coordinators
- Develop and enforce minimum standards, such as requiring an IPP meeting whenever a new petition is filed, or existing conservatorship is reviewed
- Regularly monitor existing conservatorships for appropriateness

Show Up

- Show up as an advocate for clients, and for service coordinators
- Show up at limited conservatorship hearings, school IEP meetings, and reform efforts
- Reconnect with and embrace role as advocate; e.g., utilize IPP and other exisiting tools to protect client rights and increase independence and self-determination
- Focus on changing internal institutional culture and organization to overcome current biases that perpetuate presumption of client incompetence and contribute to marginalization

Figure 11: Recommended Actions for Regional Centers

Step Up and lead collaboration efforts. "Step up" emphasizes the need for regional centers to lead collaboration efforts. This could be designating a point of contact (e.g., specially trained SC, manager or department) that SCs, clients, families, teachers, and probate workers could contact. In addition to easing the workload of service coordinators, this will likely consistently improve quality of reports. For one, if all regional center specialists knew about their right to request the petitioner's Confidential Supplemental Information document from the court, it would become a standard practice and strengthen the assessment report the regional center submits to the court.

Further, such practices benefit clients, families, and the courts as the go-to source for knowledge and support. A regional center manager discussed the benefit they derived from collaborating regularly with the public defender in their county:

> We were able to establish a practice where all cases the court wanted to hear from us [regional center] were scheduled on one day per month. So all necessary people were scheduled to be in the courtroom at the same time, on a regular basis. I think just in general it helped us to establish really good credibility with the court because we made it really clear to the judge we are here to assist on these cases. We really want the court to see us as a resource for them.

Regional centers could develop new, more useful public information that is not sufficiently available now—through already-available channels. For example, regional centers could revise the packets they already send to families during the client's age of transition (age 15-22), so it includes actionable advice on how parents can support and foster their child's decision-making skills. It could also present all the available options (limited conservatorships but also LRAs) that should be considered as their child with IDD reaches adulthood. All this material should also be on the regional center website, presented in a user-friendly, accessible manner. A regional center vendor pointed out how important it is that parents are well informed, and points out the lack of training:

> Parents are not always well prepared for the changes that happen when their child turns 18. Then all of a sudden, they have to deal with a whole set of laws and procedures that I think they don't fully understand. There's nobody who's there to say, 'Here's a brief class on conservatorship for you. This is what you should know at a basic level'

Stepping up includes dedicating time and resources to create materials and training regional center staff and other professionals like probate attorneys and special education teachers. One regional center manager shared some of the positive feedback received after performing a training session:

> I've met with a couple of probate attorneys who have said that they appreciated our trainings and discussions. It built up their level of familiarity with regional center and what we actually do. They seemed to find my talks on less restrictive options particularly beneficial because it helped them talk about different options with family members.

Training materials could explain the history of IDD rights, the disadvantages of limited conservatorships, LRAs, and how adults with IDD can be supported in a way that is empowering. The overall goal is to develop resources that increase general awareness of the risks that come along with conservatorships, as well as what LRAs offer. Additionally, developing a one-page guide in clear and simple language that explains limited conservatorship petitions—including how to avoid, contest, or terminate them—could help clients more successfully navigate their way through an intimidating, bureaucratic process.

Finally, gathering and analyzing data is another area of need that regional centers are well-equipped to manage. Currently, data on limited conservatorships (e.g., frequency, number of the seven powers requested/granted, terminations) are substantially missing: not captured, not evaluated, not used for process improvement. Clearly, this information is needed to make effective policy changes. Regional centers already have tools to capture these statistics, using CDER and IPP forms, which allow the agencies to gather and share data easily.

Shape up and improve internal practices. The shape-up action focuses on improving internal practices and working conditions. This includes strengthening training requirements and developing needed resources for internal use. Additionally, improved training and reference materials would emphasize IDD rights, limited conservatorship, and alternatives—and motivate employees with the Lanterman Act’s promise.

The call to shape up also addresses the need to make regional center assessment reports more accurate assessment of a client’s abilities and needs. For example, the report could be revised to make sure LRAs are reviewed and discussed in each one submitted to court. According to a probate attorney, addressing the LRA listed in the Confidential Supplemental Information attachment is a “good way to get the judge to pay attention because it could trigger a jury trial and clog up their calendar.”

Requiring an IPP meeting when petitions have been received has the potential to resolve many of the issues related to current processes: fragmentation, lack of inclusion, and insufficient individualization. An easy way to accomplish this would be to automatically call an IPP meeting with client, petitioner, assigned attorney, and others as needed when the petition is received. This would allow for the report writer to gauge the current circumstances, gather input from the client regarding their preferences, and offer an opportunity to introduce the idea of LRAs with the proposed conservators. Such a meeting could also help enable participants to try an LRA—such as a supported-decision-making agreement—before moving ahead in asking to terminate civil rights. This would benefit the client by providing them support and services that protect their rights. It would also help the client, service coordinator, and family/proposed conservators build trust, by providing the opportunity for dialogue on how to balance protecting their loved one while supporting and respecting their rights/autonomy. If participants found a workable alternative to moving ahead with a petition for a limited conservatorship, this would help ease probate court's crowded dockets.

Monitoring and tracking existing limited conservatorship for appropriateness is another relatively simple way regional centers can better support their clients. A regional center worker explained how a simple change increases the attention service coordinators give to limited conservatorship:

> If they could document it and treat a conservatorship in the same way they treat someone living in a licensed group home, where we know we have to see the clients at least four times a year. I don't understand why we couldn't do something similar with people in conservatorships. Adding this to the IPP would be so simple.

Finally, if regional center redesigned the template for its report to the court and made it a document that reflects values and concepts central to the Lanterman Act, this would be powerfully beneficial for all participants. Regional center reports need to present relevant information about the individual's unique circumstances, not just generalized institutional and medical concepts, such as being able to use transportation independently. Instead of approaching LRAs as an option that has failed or will fail, regional center documents and discussion could redirect the focus toward implementation of services that could be put in place to provide support in a way that does not involve terminating civil liberties.

Show Up and be an advocate. It is important for regional centers to advocate for both their clients and for their service coordinators. Currently, regional centers are placing institutional needs, over the needs of both. It wasn't always this way, as described by a regional center service coordinator with more than 25 years of experience:

> A while back we had more money to spend on resources that would benefit all of us [regional center clients and service coordinators]. We used to have a court liaison we could call anytime to get advice on anything court related. She [the liaison] led workshops for service coordinators and clients on conservatorships, restraining orders, bankruptcy, stuff like that. It was great. They [the liaison] were slashed back in '09 or '10 with all other nonessential positions when we had those crazy budget cuts. Yeah, after the Recession. That's when the culture shifted and [regional center] got super tight. I have a distinct memory of a staff meeting where we [service coordinators] were trained on determining the difference between need and want—we [regional center] only pay for what they [clients] need, not what they [clients] want. Yup. That's when we [service coordinators] had to start proving they [client] really needed something, like [a] life or death need in order to get anything paid for. If I asked them [management] to pay for door-to-door transportation [instead of the regular bus services] for a client going to and from work, I would have to have documentation, like an actual SIR or APS report to prove it was really needed. Like, if they [the client] hadn't already been robbed,

> then it’s not a need, it’s a want. We [service coordinators] went from proactive, to reactive.

This change in culture over the years was noted by other informants as well, and during my nearly 20 years in the field, is something I observed myself.

Before a regional center can effectively intervene in a meaningful and relevant manner, it is imperative for regional centers to examine and evaluate their own culture and priorities. They need to ensure that regional center’s efforts and actions genuinely align with original mission/values of the Lanterman Act. As the sociologist and educator Dr. Susan M. Turner said, “Things don’t just happen; people do things that are consequential.” In other words, actions matter.

An example of showing up “in action”— on the most fundamental human level—is being willing to pay for a regional center representative, such as a service coordinator or ‘court liaison’ to attend the hearing where a regional center client may have their rights terminated. Failing to require that a regional center representative attend these highly consequential hearings communicates that staff attendance is not worth the cost. A culture shift is needed to reframe the greater cost as the inappropriate removal of a client’s rights. This study provides evidence that regional center clients are at risk of having their rights removed with little to no due process. It should be crystal clear that regional centers cannot afford to be absent during such a critical moment. Establishing these actions as standard practices would demonstrate that regional centers not only care but they also take their mission and values seriously. They will stand up for their client and stand behind their recommendations to the court.

As part of a broader but necessary culture shift, I would urge regional centers to organize their practices in a way that stays focused on the promise of the Lanterman Act. This means prioritizing and delivering services that increase self-advocacy and decision-making skills instead of making them secondary because of institutional priorities. Table 7 (on following page) lists various codes and regs that can be used to implement services and supports that promote self-advocacy, decision-making skills, and even legal representation for limited conservatorship hearings.

Regional centers should show up by ensuring service coordinators have the time, knowledge, resources, and support needed to consistently provide person-centered services. This requires a cultural shift that places higher value on service coordination. Only through caring, competent service coordination will Californians with IDD be supported in a way that empowers them to be as self-determined as possible. Perhaps the importance of service coordination could become more highly-valued by management if some amount of case management duties were assigned to middle and upper tiers. If management could be convinced to try this idea—even on a small scale—it would no doubt help connect the entire organization to real human-centered experiences and the lived reality of regional center clients.

Last but not least, regional center can show up as an advocate by taking advantage of the IPP as a tool to access services and supports. An activist explained how they have used the IPP to secure supports for a regional center client:

> You need to have a goal that says, 'I want to end my conservatorship.' You need to put in writing, 'I want to end my conservatorship.' Ask for that goal. When you list it as a goal, regional center can then purchase the

> services and supports you would need to meet that goal. In this case, we helped her [the client] request job and transportation training, as well as independent living services. All of those things. And regional center paid for it.

In this example, the simple action of writing one goal on the right form can help put a client on the path to having their rights restored.

Table 7: California Laws and Regulations that Support Less Restrictive Alternatives

Probate Code:	
1860-1865	Allows the termination of conservatorship when the conservatee still meets grounds for conservatorship, but such intervention is deemed unnecessary.
1827	Jury trial can be requested if there is an objection to conservator being assigned.
1821 (a) (3)	LRA to be addressed by petitioner in Confidential Supplemental Information form. regional center can request a copy.
1800 (d) and 1851.1 (f)	Requires that least restrictive accommodations.
Welfare & Institutions Code:	
4433 and 4902 (a)	Authorizes DRC and OCRA to advocate for and represent clients
4502	Ensures same rights as every other Californian
4502.1	Right to choices and public/private agencies must provide opportunity for choices
4512 (b)	Authorizes regional center to pay for services which promote independence such as advocacy training or sociolegal services
4648 (b)(1)	States that in order to achieve IPP goals, regional center shall advocate for and protect the civil, legal, and service rights of people with IDD
4540 (a) and 4648 (b)(2)	Authorizes SCDD to serve as advocate
4541(a)	Authorizes SCDD to appoint representative
Other:	
T17 CCR 50510	Authorizes RC to secure services that increase self-determination and help clients access rights

The recommendations provided here describe specific changes that can be implemented with or without state-level support. The intent is to map out clear and concise steps regional centers can take to make their practices more person-centered, individualized, and organized in a way that values and prioritizes the input, needs, and reality of the client first. In the next section, I provide a conclusion, including a discussion of the significance, contributions, and limitations of this research. I also offer suggestions for future research.

Limitations and Looking Forward

This research uncovers how, in an attempt to get things done within a dysfunctional system where work quality suffers from lack of time and money, many actors in the limited-conservatorship process have turned to practices that fail to pay attention to the specific needs of the individual with IDD, as California law requires. As a result, the process has become institutionally centered and textually mediated.

My findings illustrate how a series of institutional documents designed to categorize and sort individuals into predetermined, "objective" boxes shape a judge's final ruling on granting a limited conservatorship. The stakes are high for the conservatee, whose rights can be terminated, retained, or restored through this process. Nonetheless, the outcome of this legal proceeding is reliably predictable. In this study of the process in two California counties' probate courts, the outcome was the same 100% of the time: petition granted. Institutional patterns and practices—not the unique needs or circumstances of the individual with IDD—are dominant forces in these critical legal proceedings.

The findings also show how people working within the system (e.g., regional center workers, probate public defenders) also experience negative consequences of a lack of time and resources, coupled with misplaced priorities. Governing agencies fail to adequately develop minimum standards and quality practices related to protecting the civil liberties of regional center clients, as they are increasingly disconnected from the original mission of their work. Looking specifically at the regional center service delivery system in California, these same findings hold true. In summary, organization and practices operationalize structures of oppression and expose a disjuncture between the intent and mission of regional centers (serve, empower, protect) and the way their services are experienced by those involved.

This study makes several contributions. Not only is it the first of its kind to use observations of limited conservatorship hearings in California, but also the findings align with the literature. This study adds to the evidence that the relentless stereotype of presumed incompetence, marginalization, and overall adverse circumstances of people with IDD have not changed that much despite extensive laws and protection measures (NCD 2018, U. S. Senate Report 2018). Additionally, this research adds to the growing body of literature documenting how urgently adult guardianship policies and procedures need reform (NCD 2018, Senate Report 2018).

My observations provide evidence that limited conservatorships are overly utilized, overly restrictive, and that assessment practices fail to consider and implement less restrictive alternatives, as required by law. Further, as originally intended, this research also contributes to both the field of sociology and IE as a transformative approach to applied research. Finally, this dissertation provides descriptive data, in addition to policy recommendations, to assist with reform efforts and inform state and local policymakers when making practical/effective changes.

This research does have limitations that need to be addressed. To start, this study was not designed to be generalizable. However, the data are transferable to other regional centers in California and to other states that have similar service delivery systems. Interview data were reviewed and confirmed with informants. The data derived from multiple public texts that dictate the process and organize practices can be confirmed through these public sources. Overall, the transferability and confirmability of the data make this research trustworthy.

This study leads to many paths for further research. For example, this study did not include as many or as diverse a group of informants as I had hoped. My 18 informants—representing a cross-section of actors in the process—were adequate for reaching saturation, allowing me to piece together a picture of how the system functions from multiple perspectives. However, future research would benefit from including a larger number of informants, who could represent a wider variety of perspectives. For example, future studies could seek out the participation of people with IDD, to contribute to research design and resource development. This would help ensure a future study's work addressed their needs and priorities.

My research, and most of the prior research on conservatorships and guardianships, focuses on outcomes but doesn't ask a key question: was this particular judgment the right outcome for this particular individual? My findings, as well as those of others, can support the conclusion that a dysfunctional system is failing the individual in the aggregate, but there is rich opportunity to take a deeper look, matching the outcome to the individual. Going even deeper on an individual basis, it would be powerful to identify how often a limited conservatorship was “done right,” (i.e., individualized, person-centered and granted as intended by the law) and then follow those conserved individuals for some period of time, to see if they were well served after all.

My observations provide an idea of trends and patterns, but this research was limited to two pseudonymous counties. I intentionally omitted demographics or other identifying data. A statewide study would be highly valuable. It could examine court sessions across all 58 counties of California, gathering a range of demographic information. Examining the impact of race, economic status, and gender would aid in exploring trends and patterns on a deeper level. A study exploring access to and use of ADA accommodations at hearings would also be beneficial, as this is a resource that already exists. Finally, future researchers could undertake a study to understand why individuals with IDD are still having their voting rights taken from them in limited conservancy proceedings, given that state laws have tightened protections in this area. Developing knowledge in all these areas would help us develop effective policies that prioritize and value client rights and make the process more person-centered.

To conclude, this research found that the complex process of establishing a limited conservatorship in California is textually-mediated and is centered around the needs of governing agencies and systems, as opposed to the needs of the individuals who rely on them. This is reflected by the lack of care, time, and resources governing agencies dedicate to developing minimum standards and quality practices that protect the civil liberties of regional center clients. Evidence presented here shows how current practices not only marginalize an already marginalized group but also have created a disjuncture between the intent and mission of regional centers (serve, empower, protect) and the way their services are experienced by those they serve. Additionally, this research has provided a roadmap that regional centers could use to improve their role in the limited conservatorship process, and benefit both their clients and their staff. My recommendations for regional centers are practical and actionable now. They can be implemented with or without the assistance or approval of California’s Department of Developmental Services. For the many dedicated, caring professionals of California’s regional center system, this is an opportunity to be leaders for change.

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APPENDIX A: SAMPLE INTERVIEW QUESTIONS

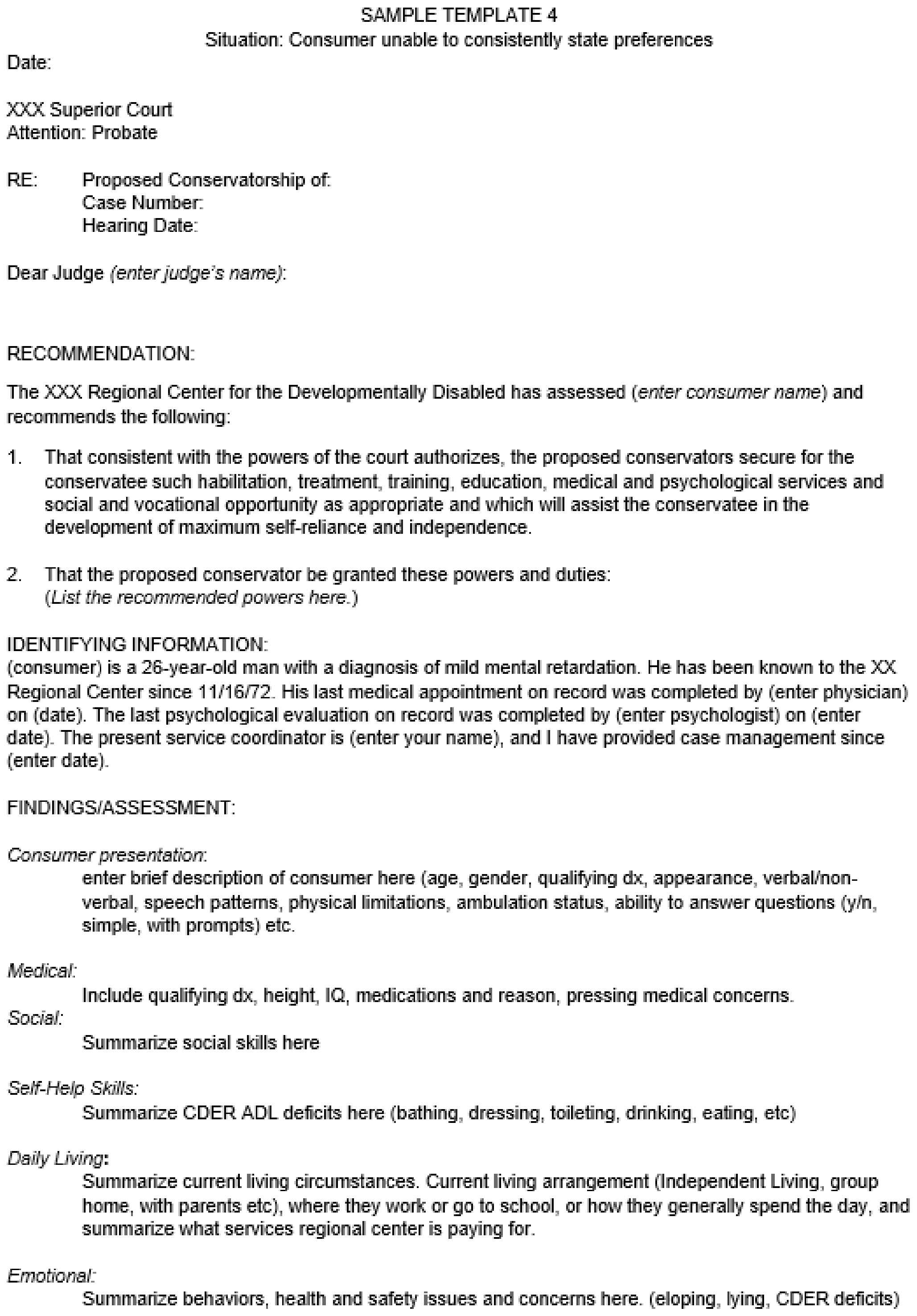
- Tell me about your experience(s) with limited conservatorships. How did things unfold?
- Explain what you do when you receive a new request. What is your process? What do you and why?
- How is their work connected with the work of other people?
- What skills/knowledge are needed to do this work? Training/experience requirements?
- What are troubles/successes that arise from doing this work?
- What resources are available and involved in this work? What resources are not available?
- What are the main documents used in this work? How are they used specifically? What do they include? Where do they go? What do they focus on?
- What is the mission/goal of your work, what are the guiding principles and values?
- What kind of alternatives to guardianship are considered by the regional centers? How do regional centers explore less restrictive alternatives?
- What kind of consequences can limited conservatorships have on people with IDD?
- What could improve the process?

APPENDIX B: OBSERVATION DATA COLLECTION TOOL

# of min	Powers requested	RC attend	RC report	LRA reviewed?	Outcome	Conservatee involvement	Notes

Memos:

APPENDIX C: SAMPLE OF REGIONAL CENTER ASSESSMENT REPORT



SAMPLE TEMPLATE 4
Situation: Consumer unable to consistently state preferences

Date:

XXX Superior Court
Attention: Probate

RE: Proposed Conservatorship of:
Case Number:
Hearing Date:

Dear Judge *(enter judge's name)*:

RECOMMENDATION:

The XXX Regional Center for the Developmentally Disabled has assessed (*enter consumer name*) and recommends the following:

1. That consistent with the powers of the court authorizes, the proposed conservators secure for the conservatee such habilitation, treatment, training, education, medical and psychological services and social and vocational opportunity as appropriate and which will assist the conservatee in the development of maximum self-reliance and independence.

2. That the proposed conservator be granted these powers and duties:
(*List the recommended powers here.*)

IDENTIFYING INFORMATION:
(consumer) is a 26-year-old man with a diagnosis of mild mental retardation. He has been known to the XX Regional Center since 11/16/72. His last medical appointment on record was completed by (enter physician) on (date). The last psychological evaluation on record was completed by (enter psychologist) on (enter date). The present service coordinator is (enter your name), and I have provided case management since (enter date).

FINDINGS/ASSESSMENT:

Consumer presentation:
enter brief description of consumer here (age, gender, qualifying dx, appearance, verbal/non-verbal, speech patterns, physical limitations, ambulation status, ability to answer questions (y/n, simple, with prompts) etc.

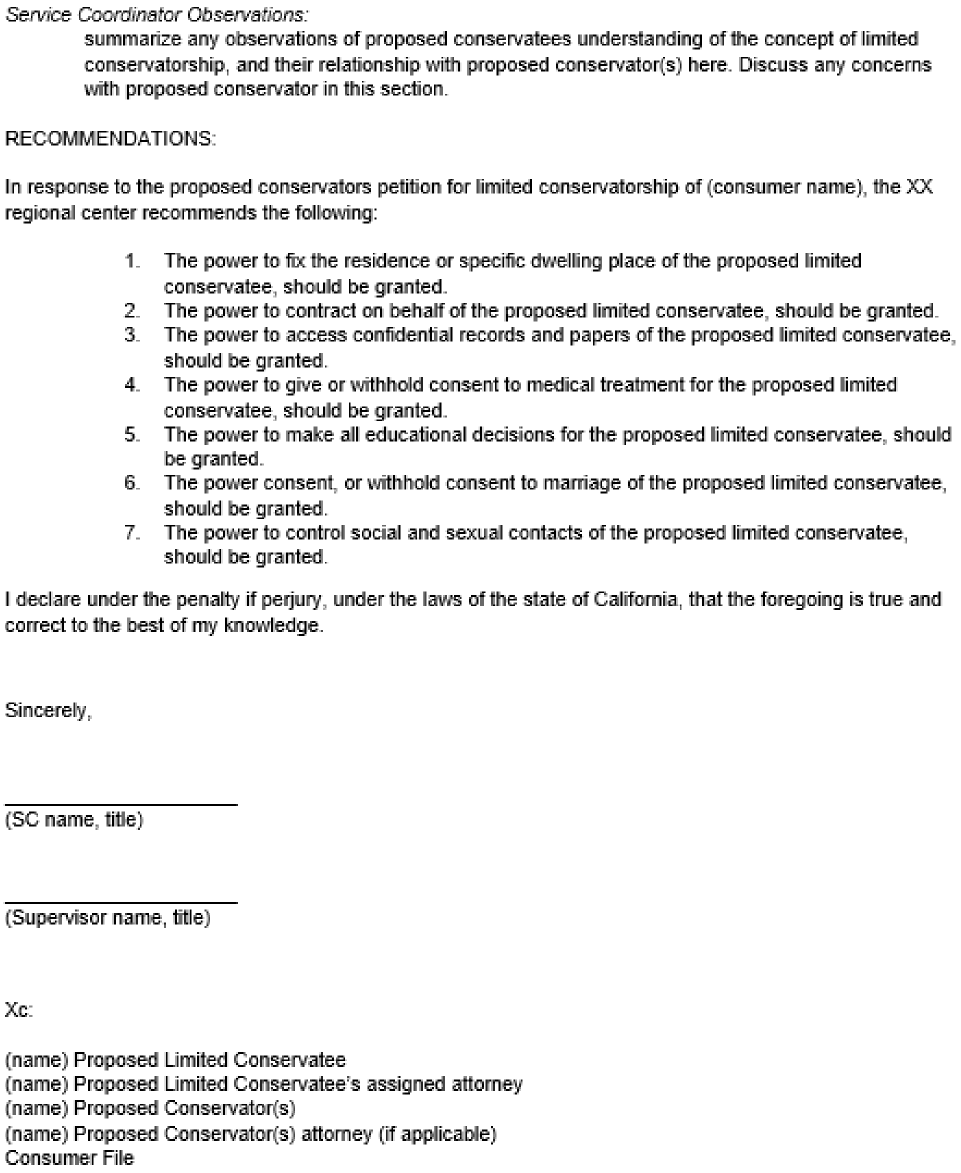
Medical:
Include qualifying dx, height, IQ, medications and reason, pressing medical concerns.

Social:
Summarize social skills here

Self-Help Skills:
Summarize CDER ADL deficits here (bathing, dressing, toileting, drinking, eating, etc)

Daily Living:
Summarize current living circumstances. Current living arrangement (Independent Living, group home, with parents etc), where they work or go to school, or how they generally spend the day, and summarize what services regional center is paying for.

Emotional:
Summarize behaviors, health and safety issues and concerns here. (eloping, lying, CDER deficits)



Service Coordinator Observations:

summarize any observations of proposed conservatees understanding of the concept of limited conservatorship, and their relationship with proposed conservator(s) here. Discuss any concerns with proposed conservator in this section.

RECOMMENDATIONS:

In response to the proposed conservators petition for limited conservatorship of (consumer name), the XX regional center recommends the following:

1. The power to fix the residence or specific dwelling place of the proposed limited conservatee, should be granted.
2. The power to contract on behalf of the proposed limited conservatee, should be granted.
3. The power to access confidential records and papers of the proposed limited conservatee, should be granted.
4. The power to give or withhold consent to medical treatment for the proposed limited conservatee, should be granted.
5. The power to make all educational decisions for the proposed limited conservatee, should be granted.
6. The power consent, or withhold consent to marriage of the proposed limited conservatee, should be granted.
7. The power to control social and sexual contacts of the proposed limited conservatee, should be granted.

I declare under the penalty if perjury, under the laws of the state of California, that the foregoing is true and correct to the best of my knowledge.

Sincerely,

____
(SC name, title)

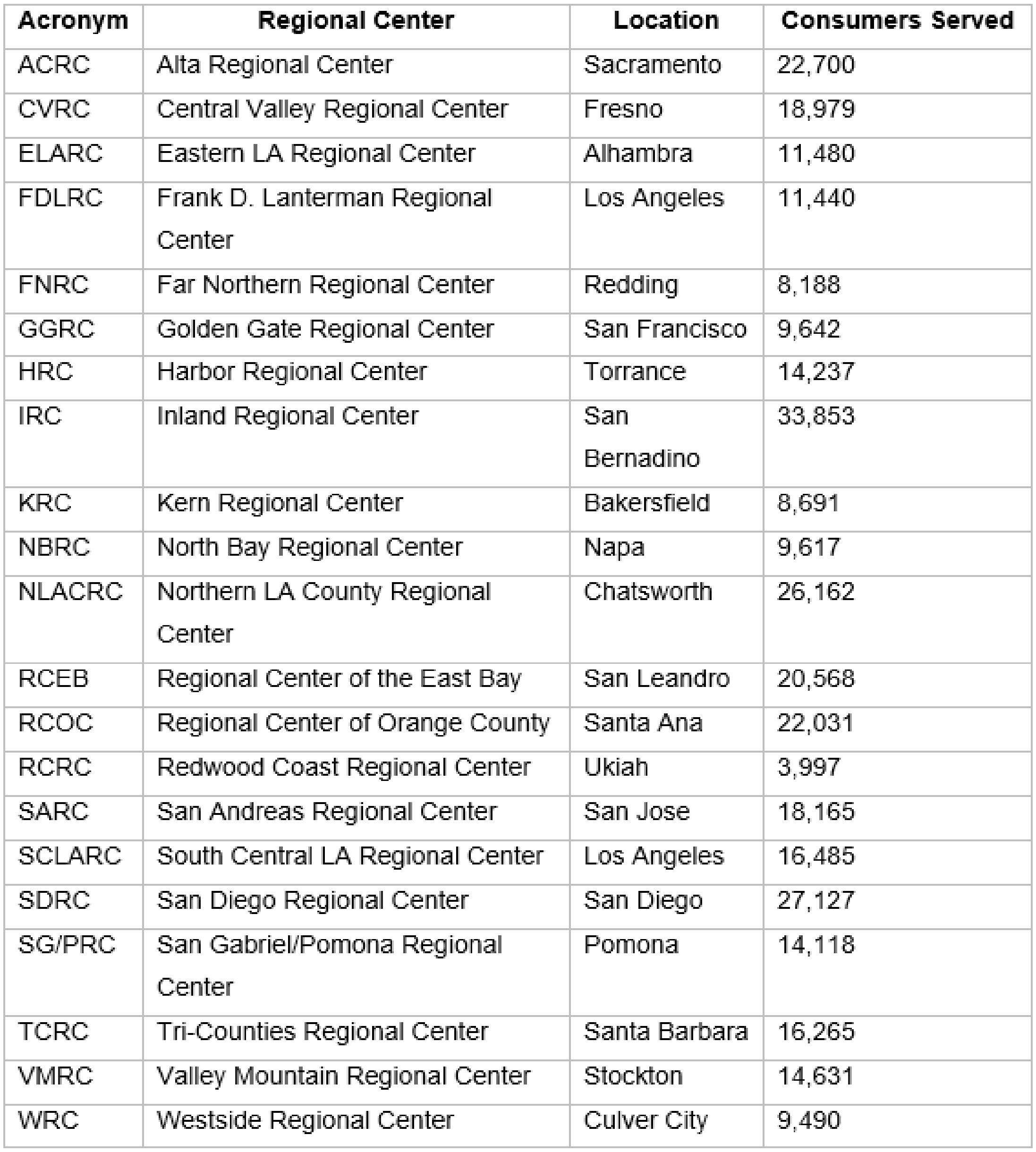
____
(Supervisor name, title)

Xc:

(name) Proposed Limited Conservatee
(name) Proposed Limited Conservatee's assigned attorney
(name) Proposed Conservator(s)
(name) Proposed Conservator(s) attorney (if applicable)
Consumer File

APPENDIX D: LIST OF REGIONAL CENTERS AND LOCATIONS

*Obtained from Vogel et al (2019).



Acronym	Regional Center	Location	Consumers Served
ACRC	Alta Regional Center	Sacramento	22,700
CVRC	Central Valley Regional Center	Fresno	18,979
ELARC	Eastern LA Regional Center	Alhambra	11,480
FDLRC	Frank D. Lanterman Regional Center	Los Angeles	11,440
FNRC	Far Northern Regional Center	Redding	8,188
GGRC	Golden Gate Regional Center	San Francisco	9,642
HRC	Harbor Regional Center	Torrance	14,237
IRC	Inland Regional Center	San Bernadino	33,853
KRC	Kern Regional Center	Bakersfield	8,691
NBRC	North Bay Regional Center	Napa	9,617
NLACRC	Northern LA County Regional Center	Chatsworth	26,162
RCEB	Regional Center of the East Bay	San Leandro	20,568
RCOC	Regional Center of Orange County	Santa Ana	22,031
RCRC	Redwood Coast Regional Center	Ukiah	3,997
SARC	San Andreas Regional Center	San Jose	18,165
SCLARC	South Central LA Regional Center	Los Angeles	16,485
SDRC	San Diego Regional Center	San Diego	27,127
SG/PRC	San Gabriel/Pomona Regional Center	Pomona	14,118
TCRC	Tri-Counties Regional Center	Santa Barbara	16,265
VMRC	Valley Mountain Regional Center	Stockton	14,631
WRC	Westside Regional Center	Culver City	9,490

APPENDIX E: LINKS TO REGIONAL CENTER WEBSITES

Alta California Regional Center

Central Valley Regional Center

Eastern Los Angeles Regional Center

Far Northern Regional Center

Frank D. Lanterman Regional Center

Golden Gate Regional Center

Harbor Regional Center

Inland Regional Center

Kern Regional Center

North Bay Regional Center

North Los Angeles County Regional Center

Redwood Coast Regional Center

Regional Center of the East Bay

Regional Center of Orange County

San Andreas Regional Center

San Diego Regional Center

San Gabriel/Pomona Regional Center

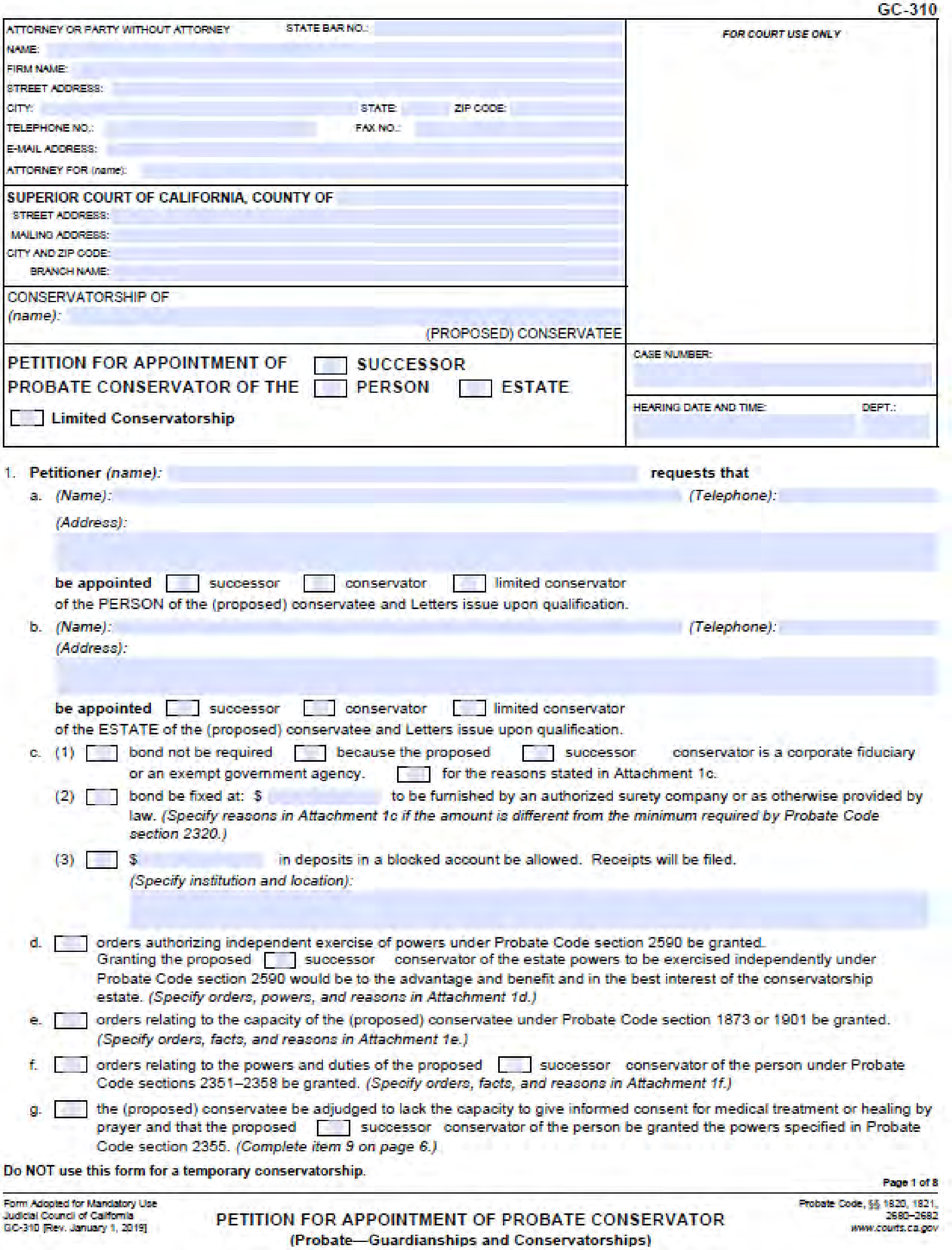
South Central Los Angeles Regional Center

Tri Counties Regional Center

Valley Mountain Regional Center

Westside Regional Center

APPENDIX F: PETITION FOR LIMITED CONSERVATORSHIP (PROBATE)



GC-310

ATTORNEY OR PARTY WITHOUT ATTORNEY STATE BAR NO.: NAME: FIRM NAME: STREET ADDRESS: CITY: STATE: ZIP CODE: TELEPHONE NO.: FAX NO.: E-MAIL ADDRESS: ATTORNEY FOR *(name)*:	*FOR COURT USE ONLY*
SUPERIOR COURT OF CALIFORNIA, COUNTY OF STREET ADDRESS: MAILING ADDRESS: CITY AND ZIP CODE: BRANCH NAME:	
CONSERVATORSHIP OF *(name)*: (PROPOSED) CONSERVATEE	
PETITION FOR APPOINTMENT OF ☐ SUCCESSOR **PROBATE CONSERVATOR OF THE ☐ PERSON ☐ ESTATE** ☐ **Limited Conservatorship**	CASE NUMBER: HEARING DATE AND TIME: DEPT.:

1. **Petitioner** *(name)*: **requests that**
   a. *(Name)*: *(Telephone)*:
   (Address):
   be appointed ☐ successor ☐ conservator ☐ limited conservator
   of the PERSON of the (proposed) conservatee and Letters issue upon qualification.
   b. *(Name)*: *(Telephone)*:
   (Address):
   be appointed ☐ successor ☐ conservator ☐ limited conservator
   of the ESTATE of the (proposed) conservatee and Letters issue upon qualification.
   c. (1) ☐ bond not be required ☐ because the proposed ☐ successor conservator is a corporate fiduciary or an exempt government agency. ☐ for the reasons stated in Attachment 1c.
   (2) ☐ bond be fixed at: $ to be furnished by an authorized surety company or as otherwise provided by law. *(Specify reasons in Attachment 1c if the amount is different from the minimum required by Probate Code section 2320.)*
   (3) ☐ $ in deposits in a blocked account be allowed. Receipts will be filed.
   (Specify institution and location):
   d. ☐ orders authorizing independent exercise of powers under Probate Code section 2590 be granted. Granting the proposed ☐ successor conservator of the estate powers to be exercised independently under Probate Code section 2590 would be to the advantage and benefit and in the best interest of the conservatorship estate. *(Specify orders, powers, and reasons in Attachment 1d.)*
   e. ☐ orders relating to the capacity of the (proposed) conservatee under Probate Code section 1873 or 1901 be granted. *(Specify orders, facts, and reasons in Attachment 1e.)*
   f. ☐ orders relating to the powers and duties of the proposed ☐ successor conservator of the person under Probate Code sections 2351–2358 be granted. *(Specify orders, facts, and reasons in Attachment 1f.)*
   g. ☐ the (proposed) conservatee be adjudged to lack the capacity to give informed consent for medical treatment or healing by prayer and that the proposed ☐ successor conservator of the person be granted the powers specified in Probate Code section 2355. *(Complete item 9 on page 6.)*

Do NOT use this form for a temporary conservatorship.

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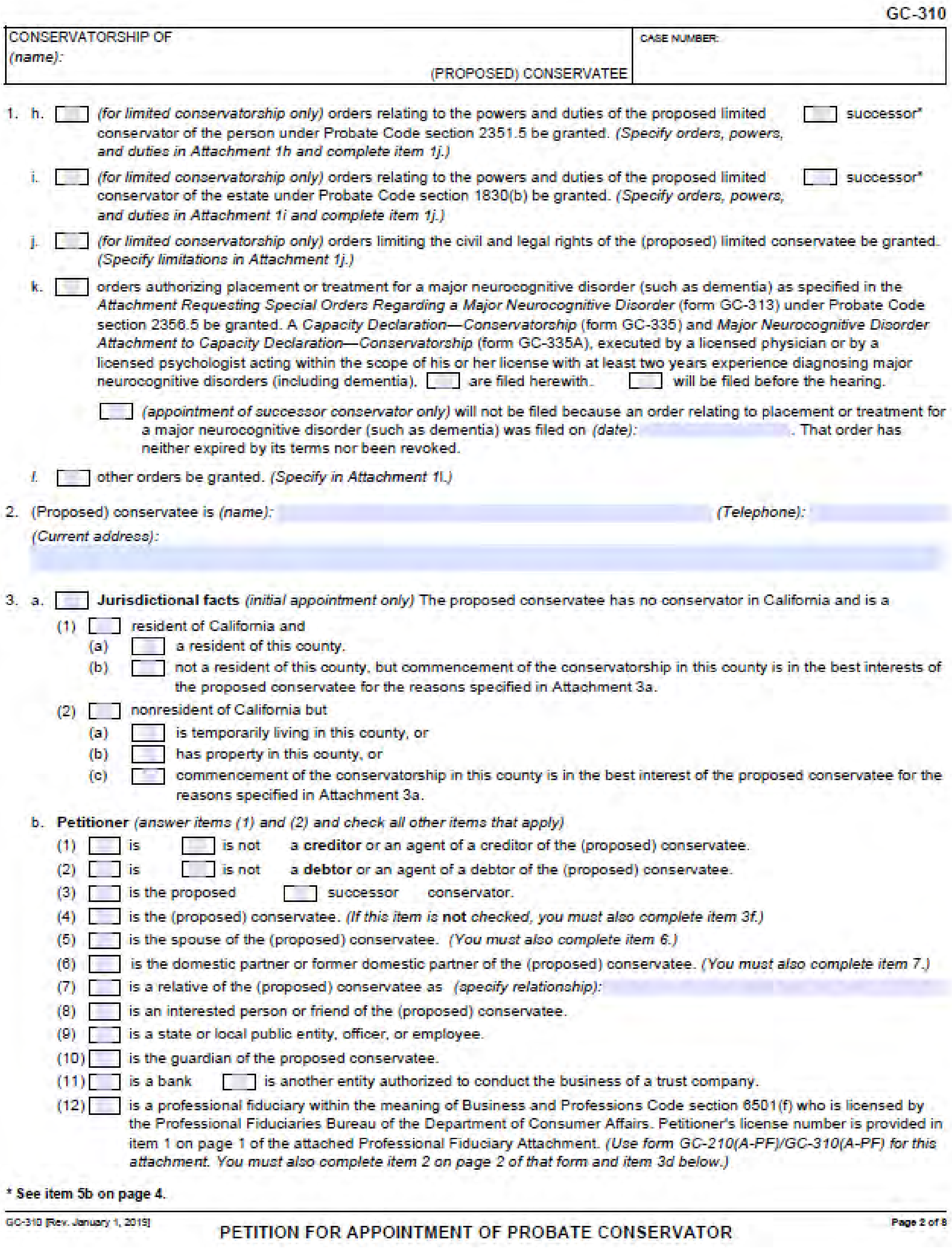
Form Adopted for Mandatory Use
Judicial Council of California
GC-310 [Rev. January 1, 2019]

PETITION FOR APPOINTMENT OF PROBATE CONSERVATOR
(Probate—Guardianships and Conservatorships)

Probate Code, §§ 1820, 1821, 2680–2682
www.courts.ca.gov



CONSERVATORSHIP OF
(name):
(PROPOSED) CONSERVATEE

CASE NUMBER:

1. h. ☐ *(for limited conservatorship only)* orders relating to the powers and duties of the proposed limited ☐ successor* conservator of the person under Probate Code section 2351.5 be granted. *(Specify orders, powers, and duties in Attachment 1h and complete item 1j.)*

   i. ☐ *(for limited conservatorship only)* orders relating to the powers and duties of the proposed limited ☐ successor* conservator of the estate under Probate Code section 1830(b) be granted. *(Specify orders, powers, and duties in Attachment 1i and complete item 1j.)*

   j. ☐ *(for limited conservatorship only)* orders limiting the civil and legal rights of the (proposed) limited conservatee be granted. *(Specify limitations in Attachment 1j.)*

   k. ☐ orders authorizing placement or treatment for a major neurocognitive disorder (such as dementia) as specified in the *Attachment Requesting Special Orders Regarding a Major Neurocognitive Disorder* (form GC-313) under Probate Code section 2356.5 be granted. A *Capacity Declaration—Conservatorship* (form GC-335) and *Major Neurocognitive Disorder Attachment to Capacity Declaration—Conservatorship* (form GC-335A), executed by a licensed physician or by a licensed psychologist acting within the scope of his or her license with at least two years experience diagnosing major neurocognitive disorders (including dementia). ☐ are filed herewith. ☐ will be filed before the hearing.

      ☐ *(appointment of successor conservator only)* will not be filed because an order relating to placement or treatment for a major neurocognitive disorder (such as dementia) was filed on *(date):* . That order has neither expired by its terms nor been revoked.

   l. ☐ other orders be granted. *(Specify in Attachment 1l.)*

2. (Proposed) conservatee is *(name):* *(Telephone):*
   (Current address):

3. a. ☐ **Jurisdictional facts** *(initial appointment only)* The proposed conservatee has no conservator in California and is a
      (1) ☐ resident of California and
         (a) ☐ a resident of this county.
         (b) ☐ not a resident of this county, but commencement of the conservatorship in this county is in the best interests of the proposed conservatee for the reasons specified in Attachment 3a.
      (2) ☐ nonresident of California but
         (a) ☐ is temporarily living in this county, or
         (b) ☐ has property in this county, or
         (c) ☐ commencement of the conservatorship in this county is in the best interest of the proposed conservatee for the reasons specified in Attachment 3a.

   b. **Petitioner** *(answer items (1) and (2) and check all other items that apply)*
      (1) ☐ is ☐ is not a **creditor** or an agent of a creditor of the (proposed) conservatee.
      (2) ☐ is ☐ is not a **debtor** or an agent of a debtor of the (proposed) conservatee.
      (3) ☐ is the proposed ☐ successor conservator.
      (4) ☐ is the (proposed) conservatee. *(If this item is* **not** *checked, you must also complete item 3f.)*
      (5) ☐ is the spouse of the (proposed) conservatee. *(You must also complete item 6.)*
      (6) ☐ is the domestic partner or former domestic partner of the (proposed) conservatee. *(You must also complete item 7.)*
      (7) ☐ is a relative of the (proposed) conservatee as *(specify relationship):*
      (8) ☐ is an interested person or friend of the (proposed) conservatee.
      (9) ☐ is a state or local public entity, officer, or employee.
      (10) ☐ is the guardian of the proposed conservatee.
      (11) ☐ is a bank ☐ is another entity authorized to conduct the business of a trust company.
      (12) ☐ is a professional fiduciary within the meaning of Business and Professions Code section 6501(f) who is licensed by the Professional Fiduciaries Bureau of the Department of Consumer Affairs. Petitioner's license number is provided in item 1 on page 1 of the attached Professional Fiduciary Attachment. *(Use form GC-210(A-PF)/GC-310(A-PF) for this attachment. You must also complete item 2 on page 2 of that form and item 3d below.)*

*** See item 5b on page 4.**

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CONSERVATORSHIP OF *(name):* (PROPOSED) CONSERVATEE	CASE NUMBER:

3\. c. **Proposed** ☐ **successor** **conservator** is *(check all that apply)*

(1) ☐ a nominee. *(Affix nomination as Attachment 3c(1).)*
(2) ☐ the spouse of the (proposed) conservatee. *(You must also complete item 6.)*
(3) ☐ the domestic partner or former domestic partner of the (proposed) conservatee. *(You must also complete item 7.)*
(4) ☐ a relative of the (proposed) conservatee as *(specify relationship):*
(5) ☐ a bank. ☐ another entity authorized to conduct the business of a trust company.
(6) ☐ a nonprofit charitable corporation that meets the requirements of Probate Code section 2104.
(7) ☐ a professional fiduciary, as defined in Business and Professions Code section 6501(f). His or her statement concerning licensure or exemption is provided in item 1 on page 1 of the attached *Professional Fiduciary Attachment. (Use form GC-210(A-PF)/GC-310(A-PF) for this attachment.)*
(8) ☐ other *(specify):*

d. ☐ Engagement and prior relationship with petitioning professional fiduciary *(complete this item if petitioner is licensed by the Professional Fiduciaries Bureau.)*

(1) ☐ Statements of who engaged petitioner, or how petitioner was engaged to file this petition, and a description of any prior relationship petitioner had with the (proposed) conservatee or his or her family or friends, are provided in item 2 on page 2 of the attached *Professional Fiduciary Attachment. (Use form GC-210(A-PF)/GC-310(A-PF) for this attachment.)*

(2) ☐ A petition for appointment of a temporary conservator is filed with this petition. That petition contains statements of who engaged petitioner, how petitioner was engaged to file this petition, and a description of any prior relationship petitioner had with the (proposed) conservatee or his or her family and friends.

e. **Character and estimated value of the property of the estate** *(complete items (1) or (2) and (3), (4), and (5)):*

(1) ☐ *(For appointment of successor conservator only, if complete Inventory and Appraisal filed by predecessor):*
Personal property: $, per Inventory and Appraisal filed in this proceeding on *(specify dates of filing of all inventories and appraisals):*

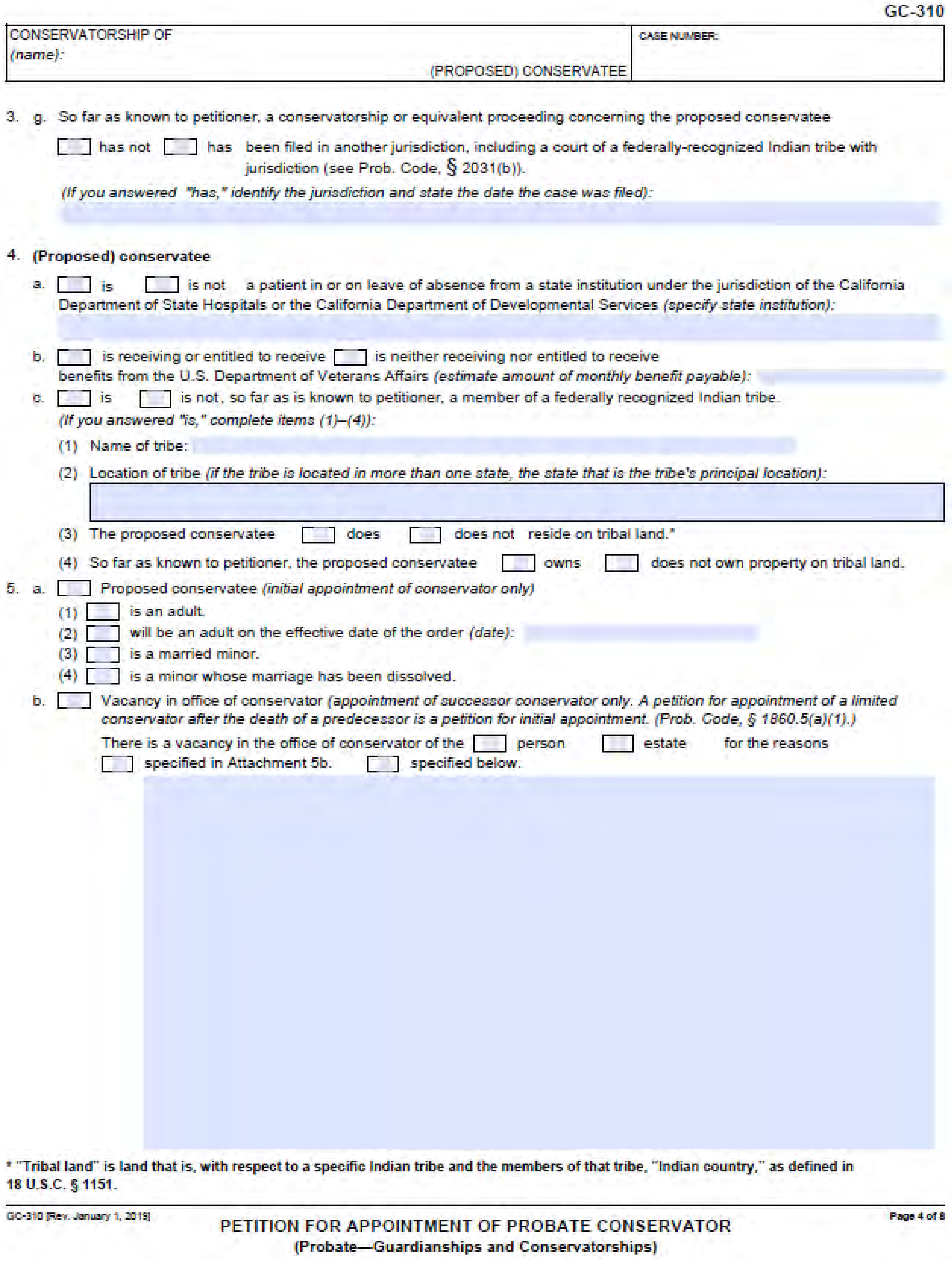
(2) ☐ Estimated value of personal property:	$
(3) Annual gross income from	
(a) real property:	$
(b) personal property:	$
(c) pensions:	$
(d) wages:	$
(e) public assistance benefits:	$
(f) other:	$
(4) **Total** of (1) or (2) and (3):	$
(5) Real property:	$

(a) ☐ per Inventory and Appraisal identified in item (1).
(b) ☐ estimated value.

f. ☐ Due diligence *(complete this item if the (proposed) conservatee is not a petitioner):*

(1) Efforts to find the (proposed) conservatee's relatives or reasons why it is not feasible to contact any of them are described on Attachment 3f(1).

(2) Statements of the (proposed) conservatee's preferences concerning the appointment of any (successor) conservator and the appointment of the proposed (successor) conservator or reasons why it is not feasible to ascertain those preferences are contained on Attachment 3f(2).



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CONSERVATORSHIP OF *(name):* (PROPOSED) CONSERVATEE	CASE NUMBER:

3\. g. So far as known to petitioner, a conservatorship or equivalent proceeding concerning the proposed conservatee

☐ has not ☐ has been filed in another jurisdiction, including a court of a federally-recognized Indian tribe with jurisdiction (see Prob. Code, § 2031(b)).

(If you answered "has," identify the jurisdiction and state the date the case was filed):

4\. **(Proposed) conservatee**

a. ☐ is ☐ is not a patient in or on leave of absence from a state institution under the jurisdiction of the California Department of State Hospitals or the California Department of Developmental Services *(specify state institution):*

b. ☐ is receiving or entitled to receive ☐ is neither receiving nor entitled to receive benefits from the U.S. Department of Veterans Affairs *(estimate amount of monthly benefit payable):*

c. ☐ is ☐ is not, so far as is known to petitioner, a member of a federally recognized Indian tribe.

(If you answered "is," complete items (1)–(4)):

(1) Name of tribe:

(2) Location of tribe *(if the tribe is located in more than one state, the state that is the tribe's principal location):*

(3) The proposed conservatee ☐ does ☐ does not reside on tribal land.*

(4) So far as known to petitioner, the proposed conservatee ☐ owns ☐ does not own property on tribal land.

5\. a. ☐ Proposed conservatee *(initial appointment of conservator only)*

(1) ☐ is an adult.

(2) ☐ will be an adult on the effective date of the order *(date):*

(3) ☐ is a married minor.

(4) ☐ is a minor whose marriage has been dissolved.

b. ☐ Vacancy in office of conservator *(appointment of successor conservator only. A petition for appointment of a limited conservator after the death of a predecessor is a petition for initial appointment. (Prob. Code, § 1860.5(a)(1).)*

There is a vacancy in the office of conservator of the ☐ person ☐ estate for the reasons

☐ specified in Attachment 5b. ☐ specified below.

*** "Tribal land" is land that is, with respect to a specific Indian tribe and the members of that tribe, "Indian country," as defined in 18 U.S.C. § 1151.**

GC-310 [Rev. January 1, 2019]

PETITION FOR APPOINTMENT OF PROBATE CONSERVATOR

(Probate—Guardianships and Conservatorships)

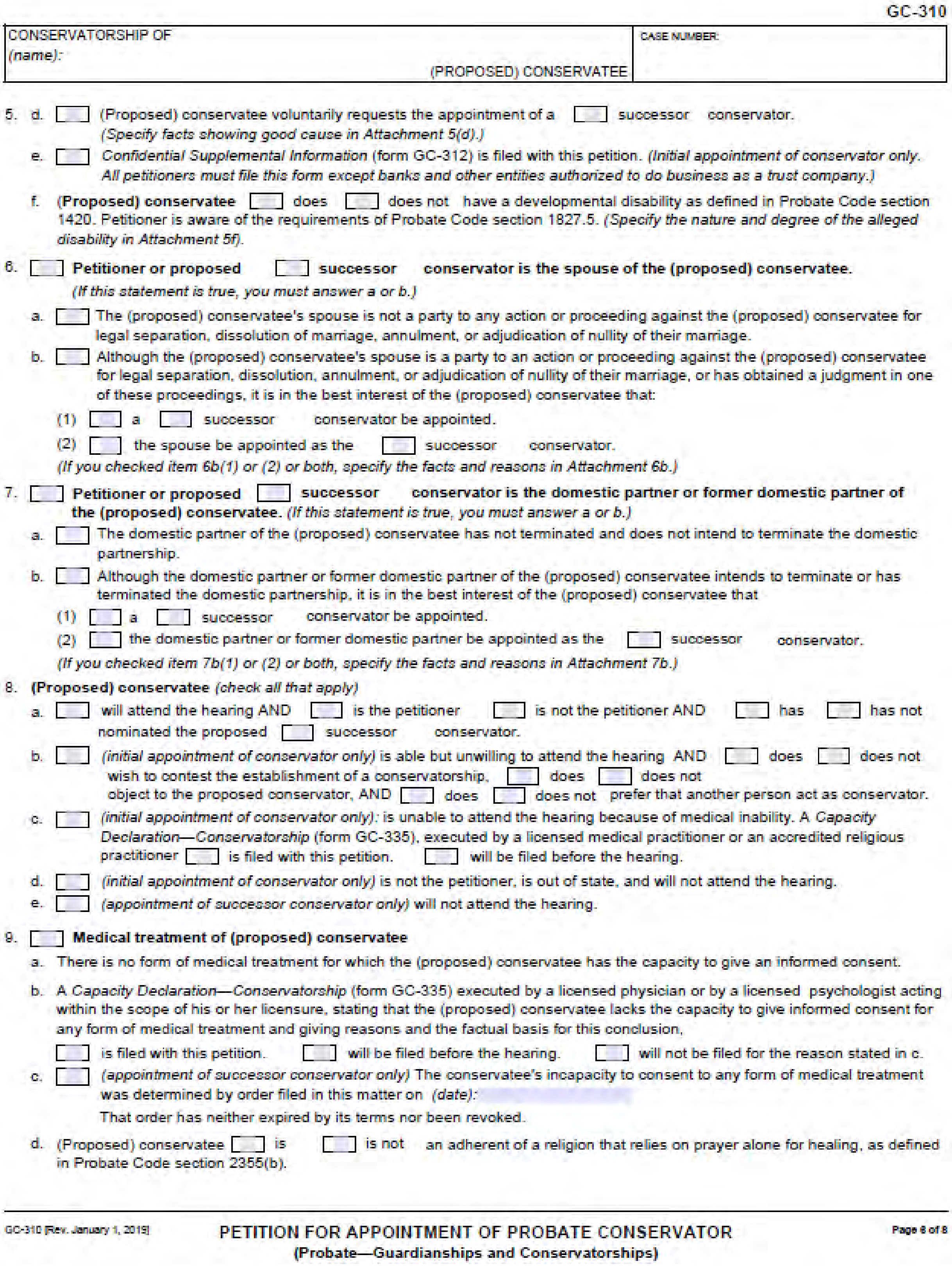
Page 4 of 8

CONSERVATORSHIP OF *(name):* (PROPOSED) CONSERVATEE	CASE NUMBER:

5. c. **(Proposed) conservatee** requires a conservator and is

(1) ☐ unable to properly provide for his or her personal needs for physical health, food, clothing, or shelter.
Supporting facts are ☐ specified in Attachment 5c(1) ☐ as follows:

(2) ☐ substantially unable to manage his or her financial resources or to resist fraud or undue influence.
Supporting facts are ☐ specified in Attachment 5c(2) ☐ as follows:



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CONSERVATORSHIP OF *(name):* (PROPOSED) CONSERVATEE	CASE NUMBER:

5\. d. ☐ (Proposed) conservatee voluntarily requests the appointment of a ☐ successor conservator. *(Specify facts showing good cause in Attachment 5(d).)*

e. ☐ *Confidential Supplemental Information* (form GC-312) is filed with this petition. *(Initial appointment of conservator only. All petitioners must file this form except banks and other entities authorized to do business as a trust company.)*

f. **(Proposed) conservatee** ☐ does ☐ does not have a developmental disability as defined in Probate Code section 1420. Petitioner is aware of the requirements of Probate Code section 1827.5. *(Specify the nature and degree of the alleged disability in Attachment 5f).*

6\. ☐ **Petitioner or proposed** ☐ **successor conservator is the spouse of the (proposed) conservatee.** *(If this statement is true, you must answer a or b.)*

a. ☐ The (proposed) conservatee's spouse is not a party to any action or proceeding against the (proposed) conservatee for legal separation, dissolution of marriage, annulment, or adjudication of nullity of their marriage.

b. ☐ Although the (proposed) conservatee's spouse is a party to an action or proceeding against the (proposed) conservatee for legal separation, dissolution, annulment, or adjudication of nullity of their marriage, or has obtained a judgment in one of these proceedings, it is in the best interest of the (proposed) conservatee that:

(1) ☐ a ☐ successor conservator be appointed.

(2) ☐ the spouse be appointed as the ☐ successor conservator.

(If you checked item 6b(1) or (2) or both, specify the facts and reasons in Attachment 6b.)

7\. ☐ **Petitioner or proposed** ☐ **successor conservator is the domestic partner or former domestic partner of the (proposed) conservatee.** *(If this statement is true, you must answer a or b.)*

a. ☐ The domestic partner of the (proposed) conservatee has not terminated and does not intend to terminate the domestic partnership.

b. ☐ Although the domestic partner or former domestic partner of the (proposed) conservatee intends to terminate or has terminated the domestic partnership, it is in the best interest of the (proposed) conservatee that

(1) ☐ a ☐ successor conservator be appointed.

(2) ☐ the domestic partner or former domestic partner be appointed as the ☐ successor conservator.

(If you checked item 7b(1) or (2) or both, specify the facts and reasons in Attachment 7b.)

8\. **(Proposed) conservatee** *(check all that apply)*

a. ☐ will attend the hearing AND ☐ is the petitioner ☐ is not the petitioner AND ☐ has ☐ has not nominated the proposed ☐ successor conservator.

b. ☐ *(initial appointment of conservator only)* is able but unwilling to attend the hearing AND ☐ does ☐ does not wish to contest the establishment of a conservatorship, ☐ does ☐ does not object to the proposed conservator, AND ☐ does ☐ does not prefer that another person act as conservator.

c. ☐ *(initial appointment of conservator only):* is unable to attend the hearing because of medical inability. A *Capacity Declaration—Conservatorship* (form GC-335), executed by a licensed medical practitioner or an accredited religious practitioner ☐ is filed with this petition. ☐ will be filed before the hearing.

d. ☐ *(initial appointment of conservator only)* is not the petitioner, is out of state, and will not attend the hearing.

e. ☐ *(appointment of successor conservator only)* will not attend the hearing.

9\. ☐ **Medical treatment of (proposed) conservatee**

a. There is no form of medical treatment for which the (proposed) conservatee has the capacity to give an informed consent.

b. A *Capacity Declaration—Conservatorship* (form GC-335) executed by a licensed physician or by a licensed psychologist acting within the scope of his or her licensure, stating that the (proposed) conservatee lacks the capacity to give informed consent for any form of medical treatment and giving reasons and the factual basis for this conclusion,

☐ is filed with this petition. ☐ will be filed before the hearing. ☐ will not be filed for the reason stated in c.

c. ☐ *(appointment of successor conservator only)* The conservatee's incapacity to consent to any form of medical treatment was determined by order filed in this matter on *(date):*

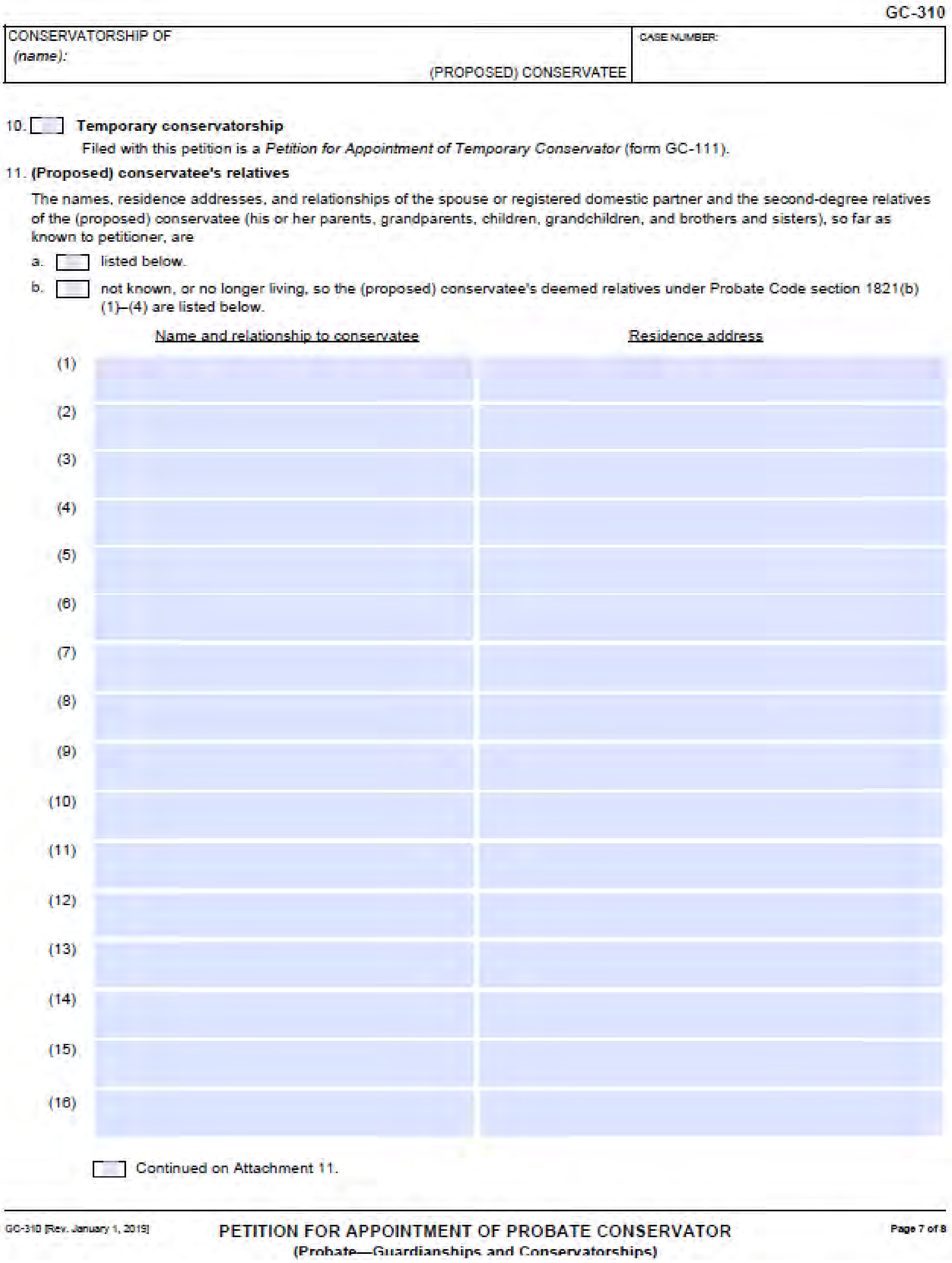
That order has neither expired by its terms nor been revoked.

d. (Proposed) conservatee ☐ is ☐ is not an adherent of a religion that relies on prayer alone for healing, as defined in Probate Code section 2355(b).

GC-310 [Rev. January 1, 2019]

PETITION FOR APPOINTMENT OF PROBATE CONSERVATOR
(Probate—Guardianships and Conservatorships)

Page 6 of 8



GC-310

CONSERVATORSHIP OF *(name)*: (PROPOSED) CONSERVATEE	CASE NUMBER:

10. ☐ **Temporary conservatorship**

Filed with this petition is a *Petition for Appointment of Temporary Conservator* (form GC-111).

11. **(Proposed) conservatee's relatives**

The names, residence addresses, and relationships of the spouse or registered domestic partner and the second-degree relatives of the (proposed) conservatee (his or her parents, grandparents, children, grandchildren, and brothers and sisters), so far as known to petitioner, are

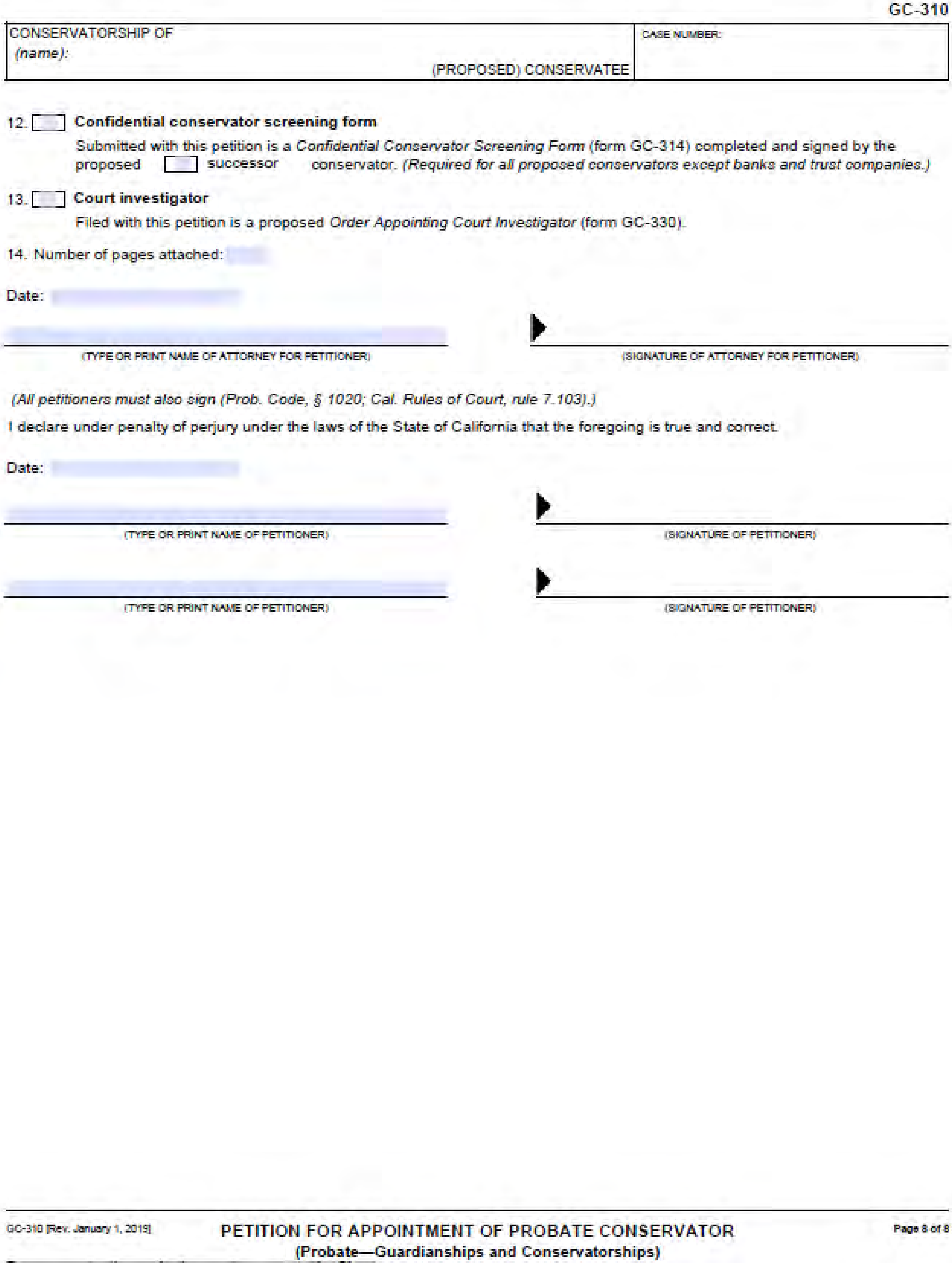
a. ☐ listed below.

b. ☐ not known, or no longer living, so the (proposed) conservatee's deemed relatives under Probate Code section 1821(b)(1)–(4) are listed below.

	Name and relationship to conservatee	Residence address
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
(11)		
(12)		
(13)		
(14)		
(15)		
(16)		

☐ Continued on Attachment 11.

GC-310 [Rev. January 1, 2015] PETITION FOR APPOINTMENT OF PROBATE CONSERVATOR (Probate—Guardianships and Conservatorships) Page 7 of 8



GC-310

CONSERVATORSHIP OF *(name):* (PROPOSED) CONSERVATEE	CASE NUMBER:

12. ☐ **Confidential conservator screening form**

Submitted with this petition is a *Confidential Conservator Screening Form* (form GC-314) completed and signed by the proposed ☐ successor conservator. *(Required for all proposed conservators except banks and trust companies.)*

13. ☐ **Court investigator**

Filed with this petition is a proposed *Order Appointing Court Investigator* (form GC-330).

14. Number of pages attached:

Date:

(TYPE OR PRINT NAME OF ATTORNEY FOR PETITIONER) ▶ (SIGNATURE OF ATTORNEY FOR PETITIONER)

(All petitioners must also sign (Prob. Code, § 1020; Cal. Rules of Court, rule 7.103).)

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date:

(TYPE OR PRINT NAME OF PETITIONER) ▶ (SIGNATURE OF PETITIONER)

(TYPE OR PRINT NAME OF PETITIONER) ▶ (SIGNATURE OF PETITIONER)

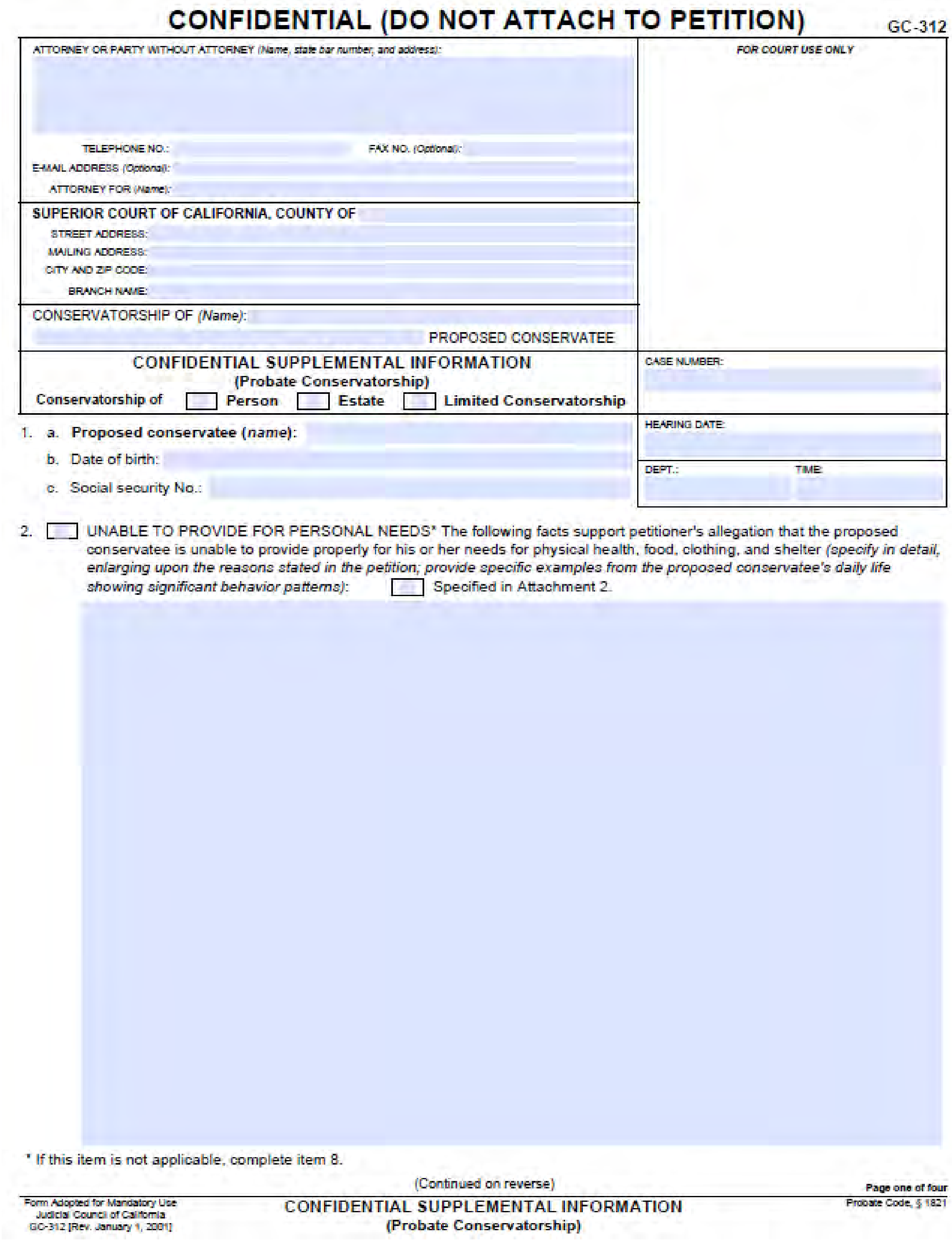
GC-310 [Rev. January 1, 2019]

PETITION FOR APPOINTMENT OF PROBATE CONSERVATOR

(Probate—Guardianships and Conservatorships)

Page 8 of 8

APPENDIX G: CONFIDENTIAL SUPPLEMENTAL INFORMATION (PROBATE)



CONFIDENTIAL (DO NOT ATTACH TO PETITION)

GC-312

ATTORNEY OR PARTY WITHOUT ATTORNEY *(Name, state bar number, and address)*:

TELEPHONE NO.: FAX NO. *(Optional)*:

E-MAIL ADDRESS *(Optional)*:

ATTORNEY FOR *(Name)*:

FOR COURT USE ONLY

SUPERIOR COURT OF CALIFORNIA, COUNTY OF

STREET ADDRESS:

MAILING ADDRESS:

CITY AND ZIP CODE:

BRANCH NAME:

CONSERVATORSHIP OF *(Name)*:

PROPOSED CONSERVATEE

CONFIDENTIAL SUPPLEMENTAL INFORMATION

(Probate Conservatorship)

Conservatorship of ☐ **Person** ☐ **Estate** ☐ **Limited Conservatorship**

CASE NUMBER:

HEARING DATE:

DEPT.: TIME:

1. a. **Proposed conservatee (*name*):**
   b. Date of birth:
   c. Social security No.:

2. ☐ UNABLE TO PROVIDE FOR PERSONAL NEEDS* The following facts support petitioner's allegation that the proposed conservatee is unable to provide properly for his or her needs for physical health, food, clothing, and shelter *(specify in detail, enlarging upon the reasons stated in the petition; provide specific examples from the proposed conservatee's daily life showing significant behavior patterns)*: ☐ Specified in Attachment 2.

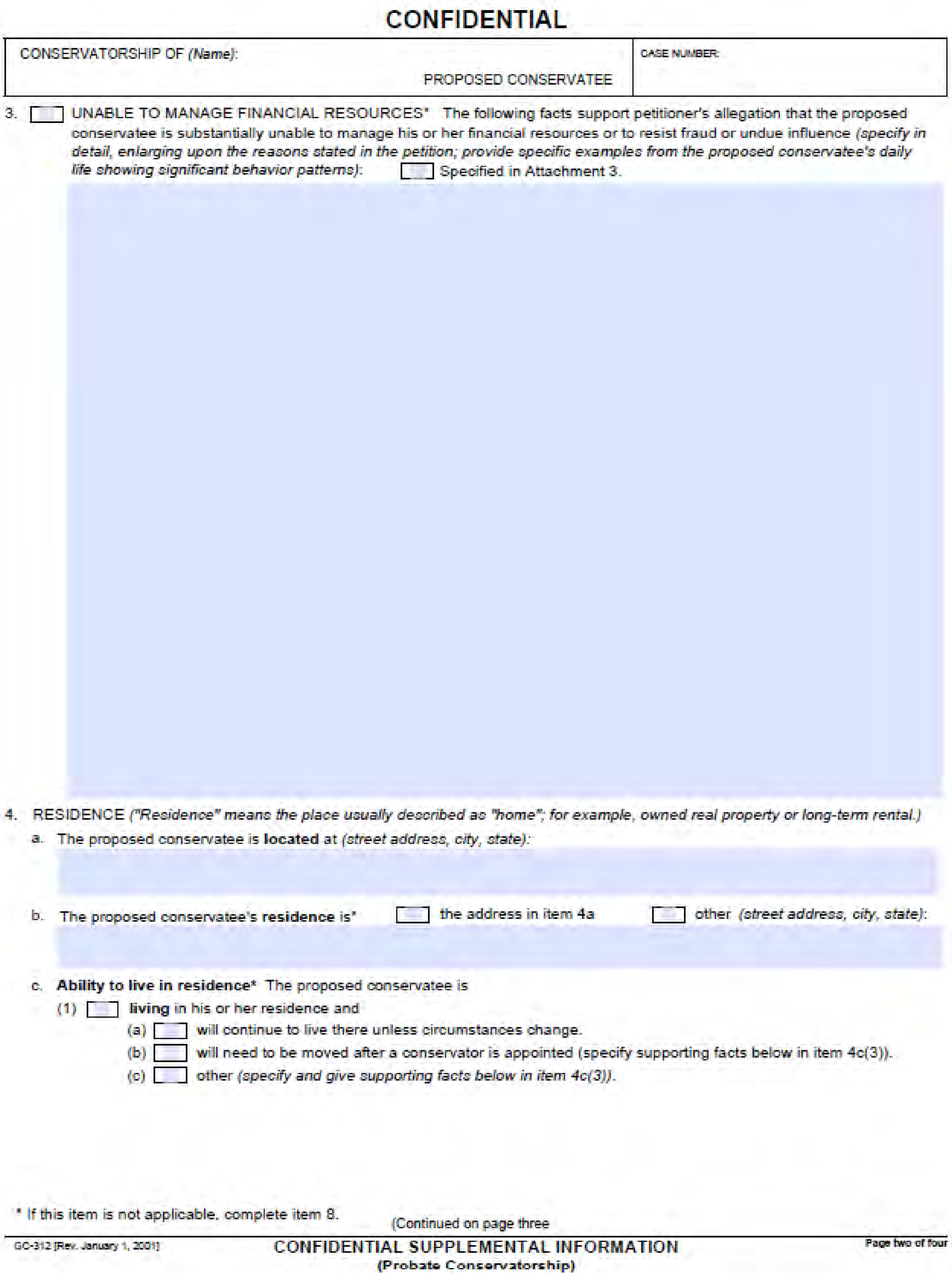
* If this item is not applicable, complete item 8.

(Continued on reverse)

Form Adopted for Mandatory Use
Judicial Council of California
GC-312 [Rev. January 1, 2001]

CONFIDENTIAL SUPPLEMENTAL INFORMATION
(Probate Conservatorship)

Page one of four
Probate Code, § 1821



CONFIDENTIAL

CONSERVATORSHIP OF *(Name)*: PROPOSED CONSERVATEE	CASE NUMBER:

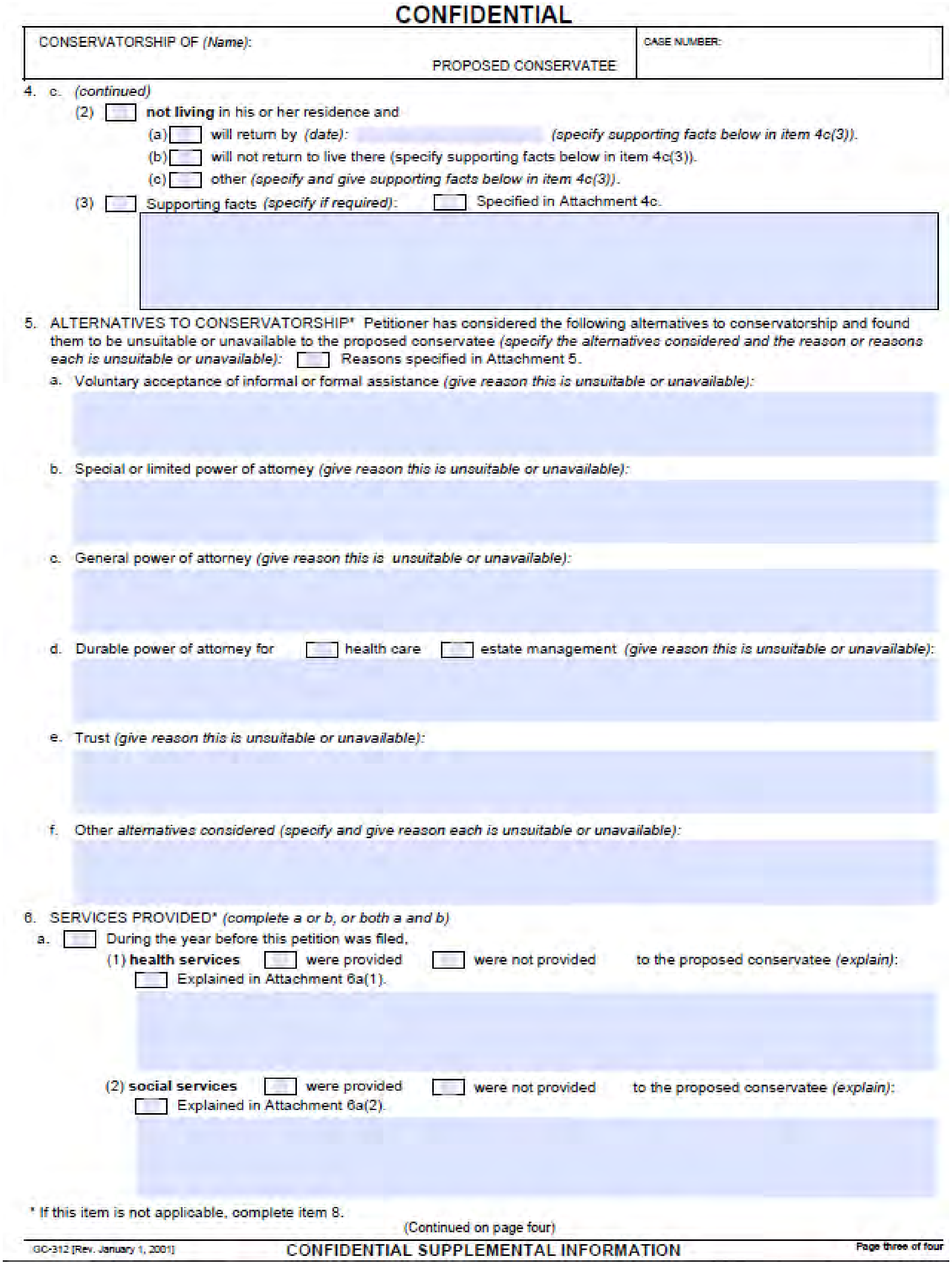
3. ☐ UNABLE TO MANAGE FINANCIAL RESOURCES* The following facts support petitioner's allegation that the proposed conservatee is substantially unable to manage his or her financial resources or to resist fraud or undue influence *(specify in detail, enlarging upon the reasons stated in the petition; provide specific examples from the proposed conservatee's daily life showing significant behavior patterns)*: ☐ Specified in Attachment 3.

4. RESIDENCE *("Residence" means the place usually described as "home"; for example, owned real property or long-term rental.)*
   a. The proposed conservatee is **located** at *(street address, city, state)*:
   b. The proposed conservatee's **residence** is* ☐ the address in item 4a ☐ other *(street address, city, state)*:
   c. **Ability to live in residence*** The proposed conservatee is
      (1) ☐ **living** in his or her residence and
         (a) ☐ will continue to live there unless circumstances change.
         (b) ☐ will need to be moved after a conservator is appointed (specify supporting facts below in item 4c(3)).
         (c) ☐ other *(specify and give supporting facts below in item 4c(3))*.

* If this item is not applicable, complete item 8.

(Continued on page three

CONFIDENTIAL SUPPLEMENTAL INFORMATION
(Probate Conservatorship)



CONFIDENTIAL

CONSERVATORSHIP OF *(Name)*: PROPOSED CONSERVATEE	CASE NUMBER:

4\. c. *(continued)*

(2) ☐ **not living** in his or her residence and

(a) ☐ will return by *(date)*: *(specify supporting facts below in item 4c(3)).*

(b) ☐ will not return to live there (specify supporting facts below in item 4c(3)).

(c) ☐ other *(specify and give supporting facts below in item 4c(3)).*

(3) ☐ Supporting facts *(specify if required)*: ☐ Specified in Attachment 4c.

5\. ALTERNATIVES TO CONSERVATORSHIP* Petitioner has considered the following alternatives to conservatorship and found them to be unsuitable or unavailable to the proposed conservatee *(specify the alternatives considered and the reason or reasons each is unsuitable or unavailable)*: ☐ Reasons specified in Attachment 5.

a. Voluntary acceptance of informal or formal assistance *(give reason this is unsuitable or unavailable)*:

b. Special or limited power of attorney *(give reason this is unsuitable or unavailable)*:

c. General power of attorney *(give reason this is unsuitable or unavailable)*:

d. Durable power of attorney for ☐ health care ☐ estate management *(give reason this is unsuitable or unavailable)*:

e. Trust *(give reason this is unsuitable or unavailable)*:

f. Other *alternatives considered (specify and give reason each is unsuitable or unavailable)*:

6\. SERVICES PROVIDED* *(complete a or b, or both a and b)*

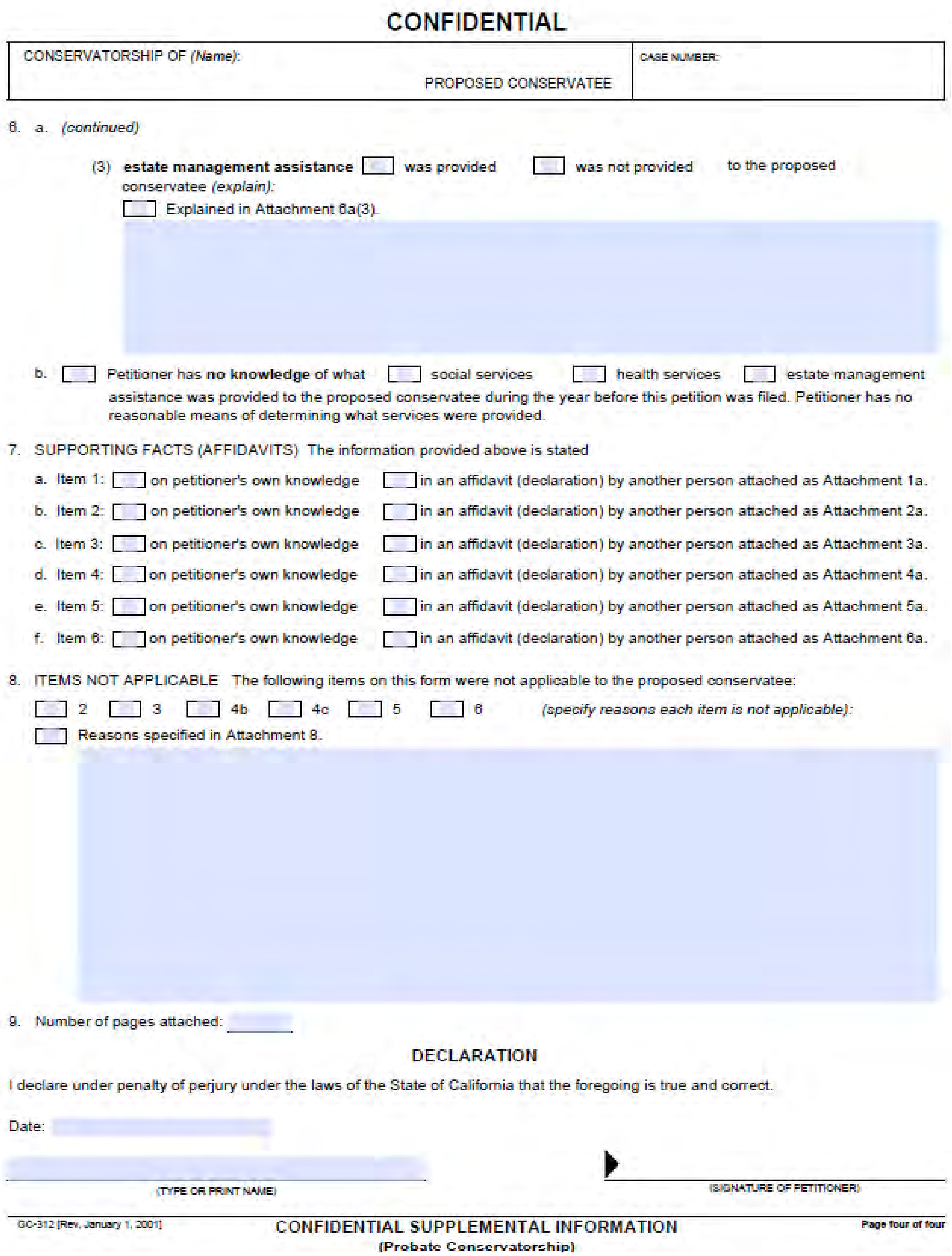
a. ☐ During the year before this petition was filed,

(1) **health services** ☐ were provided ☐ were not provided to the proposed conservatee *(explain)*:
☐ Explained in Attachment 6a(1).

(2) **social services** ☐ were provided ☐ were not provided to the proposed conservatee *(explain)*:
☐ Explained in Attachment 6a(2).

* If this item is not applicable, complete item 8.

(Continued on page four)



CONFIDENTIAL

CONSERVATORSHIP OF *(Name)*: PROPOSED CONSERVATEE	CASE NUMBER:

6\. a. *(continued)*

(3) **estate management assistance** ☐ was provided ☐ was not provided to the proposed conservatee *(explain)*:
☐ Explained in Attachment 6a(3).

b. ☐ Petitioner has **no knowledge** of what ☐ social services ☐ health services ☐ estate management assistance was provided to the proposed conservatee during the year before this petition was filed. Petitioner has no reasonable means of determining what services were provided.

7\. SUPPORTING FACTS (AFFIDAVITS) The information provided above is stated

a. Item 1: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 1a.
b. Item 2: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 2a.
c. Item 3: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 3a.
d. Item 4: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 4a.
e. Item 5: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 5a.
f. Item 6: ☐ on petitioner's own knowledge ☐ in an affidavit (declaration) by another person attached as Attachment 6a.

8\. ITEMS NOT APPLICABLE The following items on this form were not applicable to the proposed conservatee:
☐ 2 ☐ 3 ☐ 4b ☐ 4c ☐ 5 ☐ 6 *(specify reasons each item is not applicable)*:
☐ Reasons specified in Attachment 8.

9\. Number of pages attached: ______

DECLARATION

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

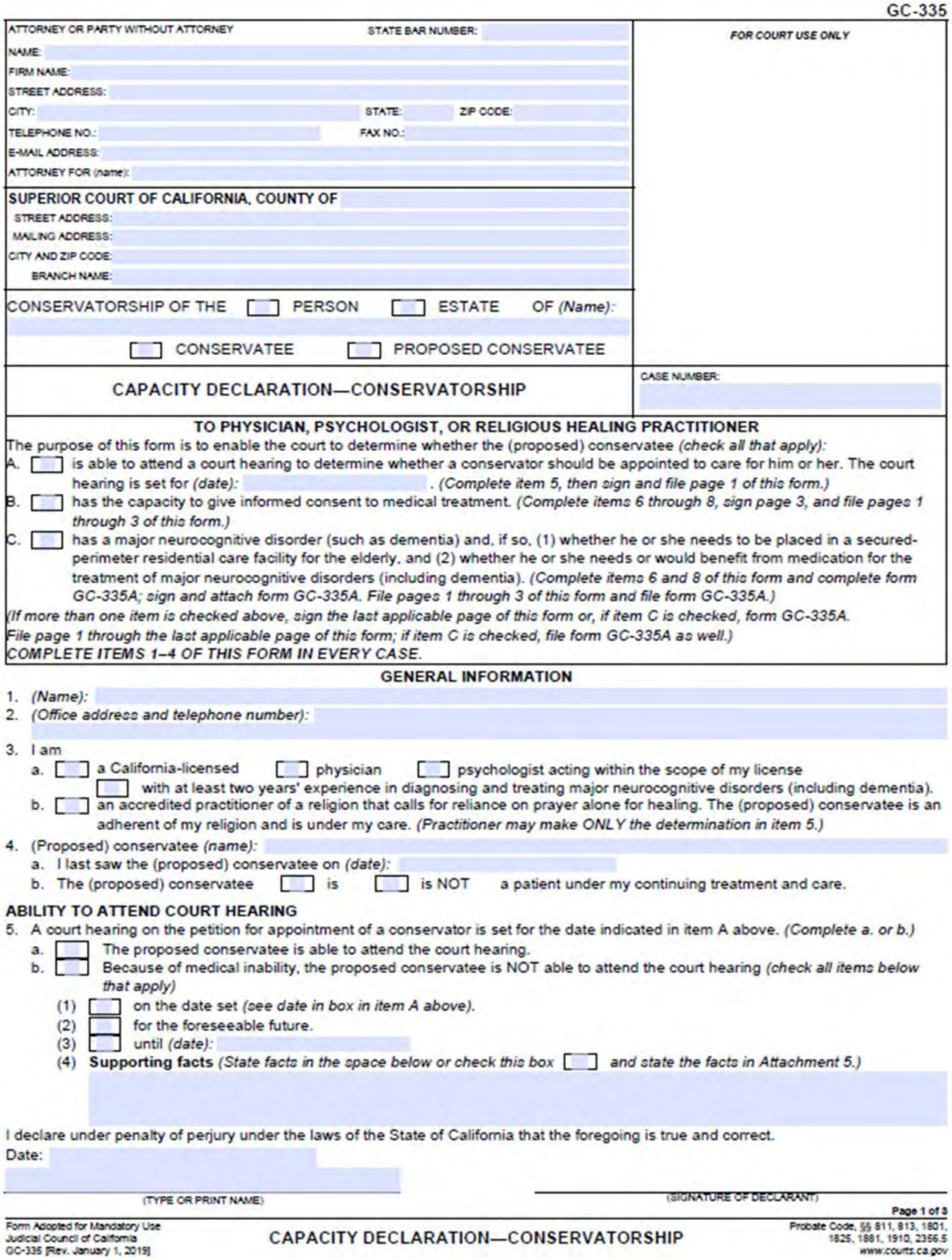
Date:

(TYPE OR PRINT NAME)

▶ (SIGNATURE OF PETITIONER)

GC-312 [Rev. January 1, 2001] **CONFIDENTIAL SUPPLEMENTAL INFORMATION** **(Probate Conservatorship)** Page four of four

APPENDIX H: CAPACITY DECLARATION (PROBATE)



GC-335

ATTORNEY OR PARTY WITHOUT ATTORNEY STATE BAR NUMBER:
NAME:
FIRM NAME:
STREET ADDRESS:
CITY: STATE: ZIP CODE:
TELEPHONE NO.: FAX NO.:
E-MAIL ADDRESS:
ATTORNEY FOR *(name)*:

FOR COURT USE ONLY

SUPERIOR COURT OF CALIFORNIA, COUNTY OF
STREET ADDRESS:
MAILING ADDRESS:
CITY AND ZIP CODE:
BRANCH NAME:

CONSERVATORSHIP OF THE ☐ PERSON ☐ ESTATE OF *(Name)*:

☐ CONSERVATEE ☐ PROPOSED CONSERVATEE

CAPACITY DECLARATION—CONSERVATORSHIP

CASE NUMBER:

TO PHYSICIAN, PSYCHOLOGIST, OR RELIGIOUS HEALING PRACTITIONER

The purpose of this form is to enable the court to determine whether the (proposed) conservatee *(check all that apply)*:

A. ☐ is able to attend a court hearing to determine whether a conservator should be appointed to care for him or her. The court hearing is set for *(date)*: . *(Complete item 5, then sign and file page 1 of this form.)*

B. ☐ has the capacity to give informed consent to medical treatment. *(Complete items 6 through 8, sign page 3, and file pages 1 through 3 of this form.)*

C. ☐ has a major neurocognitive disorder (such as dementia) and, if so, (1) whether he or she needs to be placed in a secured-perimeter residential care facility for the elderly, and (2) whether he or she needs or would benefit from medication for the treatment of major neurocognitive disorders (including dementia). *(Complete items 6 and 8 of this form and complete form GC-335A; sign and attach form GC-335A. File pages 1 through 3 of this form and file form GC-335A.)*

(If more than one item is checked above, sign the last applicable page of this form or, if item C is checked, form GC-335A. File page 1 through the last applicable page of this form; if item C is checked, file form GC-335A as well.)

COMPLETE ITEMS 1–4 OF THIS FORM IN EVERY CASE.

GENERAL INFORMATION

1. *(Name)*:
2. *(Office address and telephone number)*:
3. I am
   a. ☐ a California-licensed ☐ physician ☐ psychologist acting within the scope of my license
      ☐ with at least two years' experience in diagnosing and treating major neurocognitive disorders (including dementia).
   b. ☐ an accredited practitioner of a religion that calls for reliance on prayer alone for healing. The (proposed) conservatee is an adherent of my religion and is under my care. *(Practitioner may make ONLY the determination in item 5.)*
4. (Proposed) conservatee *(name)*:
   a. I last saw the (proposed) conservatee on *(date)*:
   b. The (proposed) conservatee ☐ is ☐ is NOT a patient under my continuing treatment and care.

ABILITY TO ATTEND COURT HEARING

5. A court hearing on the petition for appointment of a conservator is set for the date indicated in item A above. *(Complete a. or b.)*
   a. ☐ The proposed conservatee is able to attend the court hearing.
   b. ☐ Because of medical inability, the proposed conservatee is NOT able to attend the court hearing *(check all items below that apply)*
      (1) ☐ on the date set *(see date in box in item A above)*.
      (2) ☐ for the foreseeable future.
      (3) ☐ until *(date)*:
      (4) **Supporting facts** *(State facts in the space below or check this box* ☐ *and state the facts in Attachment 5.)*

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date:

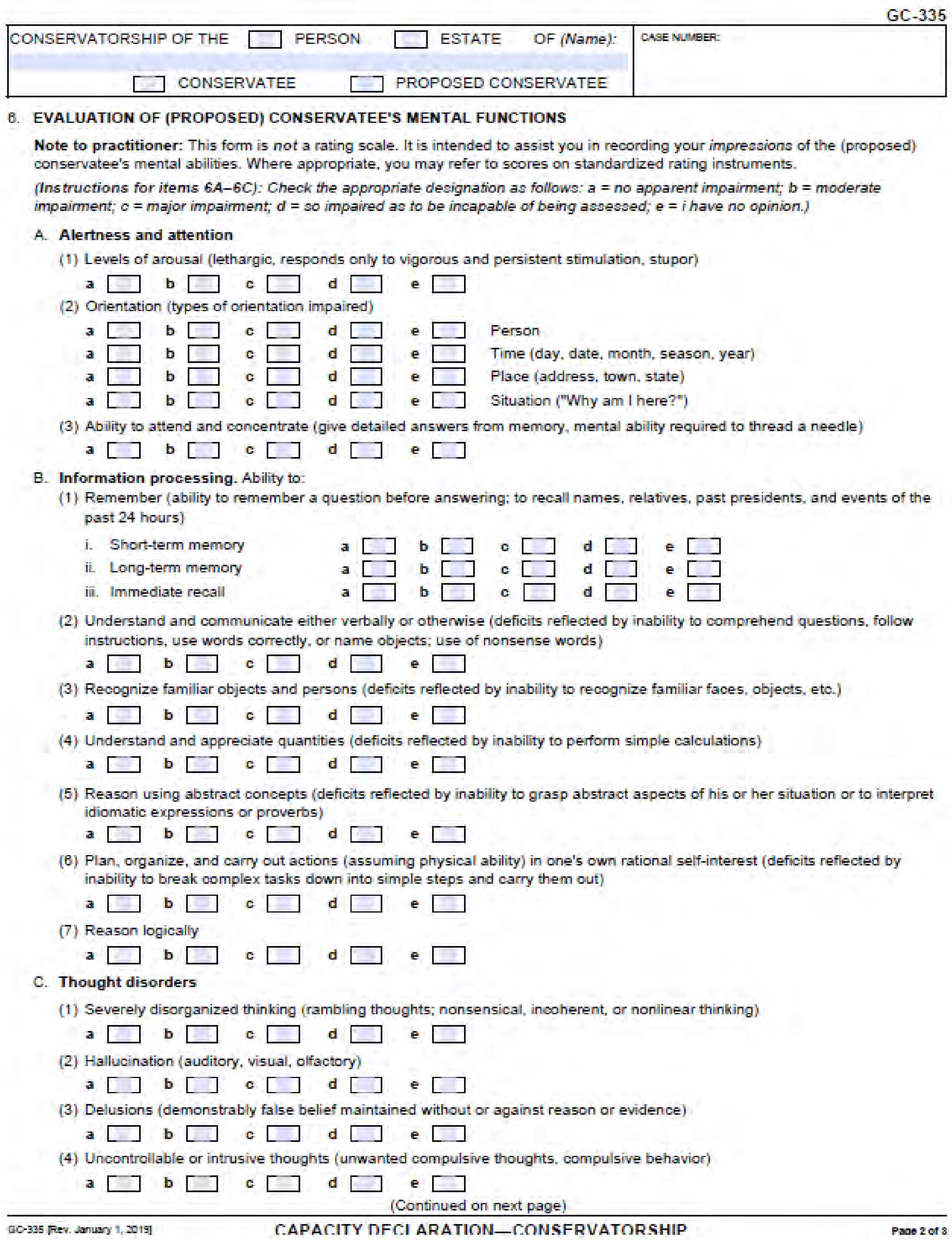
(TYPE OR PRINT NAME) (SIGNATURE OF DECLARANT)

Page 1 of 3

Form Adopted for Mandatory Use
Judicial Council of California
GC-335 [Rev. January 1, 2019]

CAPACITY DECLARATION—CONSERVATORSHIP

Probate Code, §§ 811, 813, 1801, 1825, 1881, 1910, 2356.5
www.courts.ca.gov



CONSERVATORSHIP OF THE ☐ PERSON ☐ ESTATE OF *(Name)*: ☐ CONSERVATEE ☐ PROPOSED CONSERVATEE	CASE NUMBER:

6. **EVALUATION OF (PROPOSED) CONSERVATEE'S MENTAL FUNCTIONS**

Note to practitioner: This form is *not* a rating scale. It is intended to assist you in recording your *impressions* of the (proposed) conservatee's mental abilities. Where appropriate, you may refer to scores on standardized rating instruments.

(Instructions for items 6A–6C): Check the appropriate designation as follows: a = no apparent impairment; b = moderate impairment; c = major impairment; d = so impaired as to be incapable of being assessed; e = i have no opinion.)

A. **Alertness and attention**

(1) Levels of arousal (lethargic, responds only to vigorous and persistent stimulation, stupor)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(2) Orientation (types of orientation impaired)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐ Person
a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐ Time (day, date, month, season, year)
a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐ Place (address, town, state)
a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐ Situation ("Why am I here?")

(3) Ability to attend and concentrate (give detailed answers from memory, mental ability required to thread a needle)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

B. **Information processing.** Ability to:

(1) Remember (ability to remember a question before answering; to recall names, relatives, past presidents, and events of the past 24 hours)

i. Short-term memory **a** ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐
ii. Long-term memory **a** ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐
iii. Immediate recall **a** ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(2) Understand and communicate either verbally or otherwise (deficits reflected by inability to comprehend questions, follow instructions, use words correctly, or name objects; use of nonsense words)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(3) Recognize familiar objects and persons (deficits reflected by inability to recognize familiar faces, objects, etc.)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(4) Understand and appreciate quantities (deficits reflected by inability to perform simple calculations)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(5) Reason using abstract concepts (deficits reflected by inability to grasp abstract aspects of his or her situation or to interpret idiomatic expressions or proverbs)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(6) Plan, organize, and carry out actions (assuming physical ability) in one's own rational self-interest (deficits reflected by inability to break complex tasks down into simple steps and carry them out)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(7) Reason logically

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

C. **Thought disorders**

(1) Severely disorganized thinking (rambling thoughts; nonsensical, incoherent, or nonlinear thinking)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(2) Hallucination (auditory, visual, olfactory)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(3) Delusions (demonstrably false belief maintained without or against reason or evidence)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

(4) Uncontrollable or intrusive thoughts (unwanted compulsive thoughts, compulsive behavior)

a ☐ **b** ☐ **c** ☐ **d** ☐ **e** ☐

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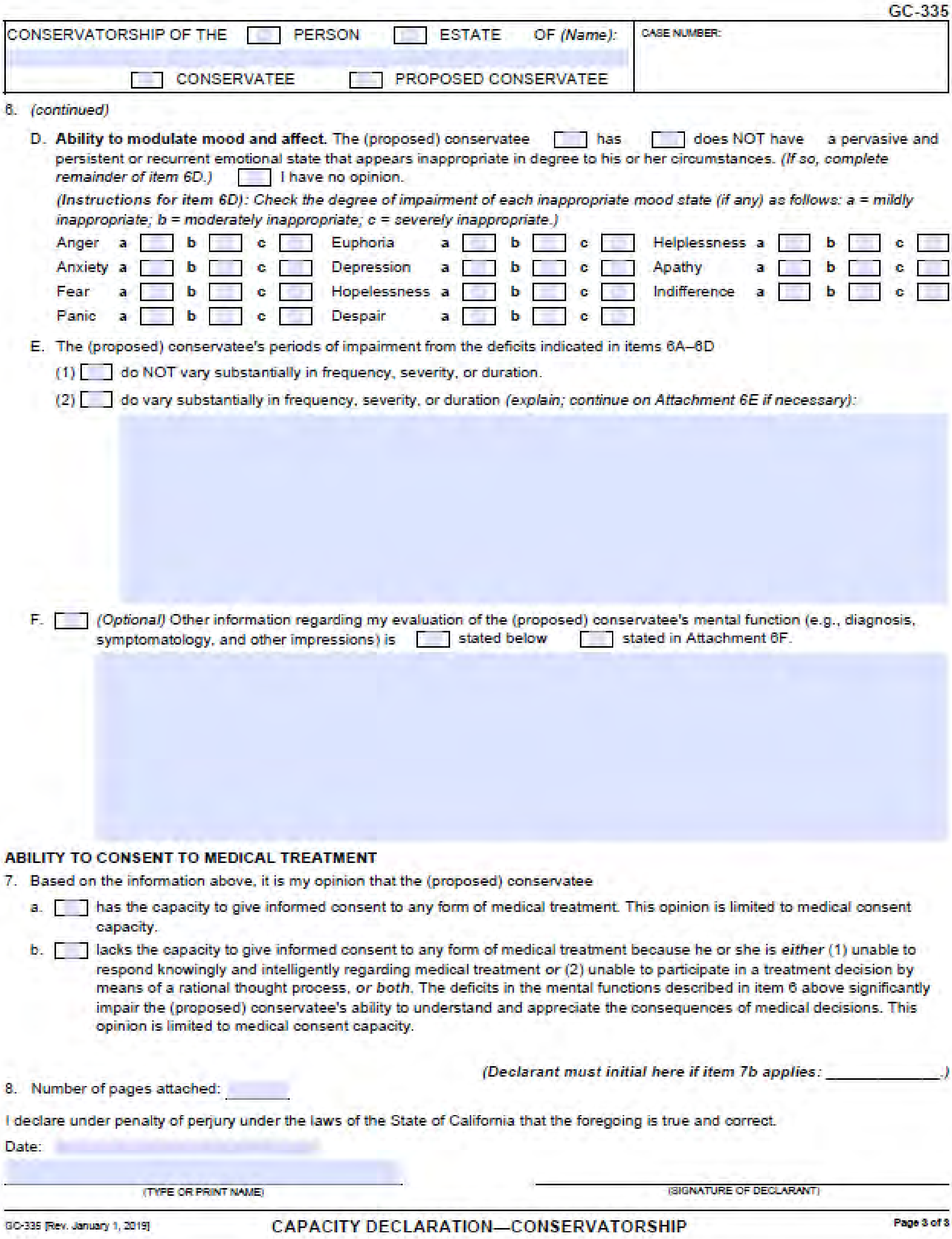

GC-335

CONSERVATORSHIP OF THE ☐ PERSON ☐ ESTATE OF *(Name):* ☐ CONSERVATEE ☐ PROPOSED CONSERVATEE	CASE NUMBER:

6. *(continued)*

D. **Ability to modulate mood and affect.** The (proposed) conservatee ☐ has ☐ does NOT have a pervasive and persistent or recurrent emotional state that appears inappropriate in degree to his or her circumstances. *(If so, complete remainder of item 6D.)* ☐ I have no opinion.

***(Instructions for item 6D):** Check the degree of impairment of each inappropriate mood state (if any) as follows: a = mildly inappropriate; b = moderately inappropriate; c = severely inappropriate.)*

Anger a ☐ b ☐ c ☐	Euphoria a ☐ b ☐ c ☐	Helplessness a ☐ b ☐ c ☐
Anxiety a ☐ b ☐ c ☐	Depression a ☐ b ☐ c ☐	Apathy a ☐ b ☐ c ☐
Fear a ☐ b ☐ c ☐	Hopelessness a ☐ b ☐ c ☐	Indifference a ☐ b ☐ c ☐
Panic a ☐ b ☐ c ☐	Despair a ☐ b ☐ c ☐	

E. The (proposed) conservatee's periods of impairment from the deficits indicated in items 6A–6D

(1) ☐ do NOT vary substantially in frequency, severity, or duration.

(2) ☐ do vary substantially in frequency, severity, or duration *(explain; continue on Attachment 6E if necessary):*

F. ☐ *(Optional)* Other information regarding my evaluation of the (proposed) conservatee's mental function (e.g., diagnosis, symptomatology, and other impressions) is ☐ stated below ☐ stated in Attachment 6F.

ABILITY TO CONSENT TO MEDICAL TREATMENT

7. Based on the information above, it is my opinion that the (proposed) conservatee

a. ☐ has the capacity to give informed consent to any form of medical treatment. This opinion is limited to medical consent capacity.

b. ☐ lacks the capacity to give informed consent to any form of medical treatment because he or she is *either* (1) unable to respond knowingly and intelligently regarding medical treatment *or* (2) unable to participate in a treatment decision by means of a rational thought process, *or both*. The deficits in the mental functions described in item 6 above significantly impair the (proposed) conservatee's ability to understand and appreciate the consequences of medical decisions. This opinion is limited to medical consent capacity.

***(Declarant must initial here if item 7b applies:** _____________.)*

8. Number of pages attached: ______

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.

Date:

____
(TYPE OR PRINT NAME)

____
(SIGNATURE OF DECLARANT)

GC-335 [Rev. January 1, 2019] CAPACITY DECLARATION—CONSERVATORSHIP Page 3 of 3