Additional Public Comments

Comments Submitted by
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January 8, 2021

Certified Professional Guardian Board
Administrative Office of the Courts
PO Box 41170
Olympia WA 98504

Sent by email only

Re: CPG Certification

Dear Certified Professional Guardian Board:

I read the letter from Miriam Doyle, the Program Manager for the UW Continuum College. I appreciate her concerns about ensuring new CPGs are qualified since they will be interacting with vulnerable adults. No one wants unqualified guardians. I disagree with Ms. Doyle that CPGs certified during the hiatus should be granted only a provisional certification and required to take further UW training at a later date. My reasons are:

The Center for Guardianship Certification testing process is rigorous and a person without some guardianship experience is not allowed to take the test.

The Center for Guardianship Certification test is, by accounts of professional guardians who have taken it, not easy. A person is not eligible to take the test without being able to describe experience in a minimum of <u>three</u> different NCG core competencies and without relevant education experience. The core competencies are:

a. Knowledge and application of guardianship principles as they relate to the professional role of the guardian.

b. Knowledge of the personal aspects for a person subject to guardianship and the ability to address those special situations or circumstances affecting the person.

c. Knowledge of the theory and application of decision-making principles and limitations in making surrogate decisions.

d. Knowledge of laws, courts, and legal processes, including the guardian's responsibility to modify, terminate or limit a guardianship.

e. Knowledge and application of the responsibilities of the guardian of the person including planning for and overseeing supports and services.
f. Knowledge and application of the responsibilities for financial management of a person's estate.

g. Knowledge and application of the principles and responsibilities surrounding surrogate medical decisions, including the ability to identify issues that have legal and ethical consequences for both the guardian and the person under guardianship.

In addition, the prospective test taker must have a combination of education and CGC approved coursework. For example, a person with a two-year degree in a field related to guardianship (nursing, social work, accounting, criminal justice) must submit proof of 10 hours of approved coursework.

The applicants who wish to become CPGs pursuant to the 2020 guidelines issued by the Board will have to have a degree related to guardianship, show proof of at least 10 hours of additional coursework, and have experience related to three core competencies. All of that is in addition to the Board's review of the applicant's experience and education and the 12 hour course developed for Washington. Then, of course, the applicant must pass the CGC test.

There are many professionals who are available to assist the AOC with the March and April Washington-specific training for new CPGs.

There have been concerns raised that the AOC will have difficulty putting together the coursework for the March and April 2021 Washington-specific training because of the change to the law. This concern is a red herring. All guardians (and guardian attorneys) are in the same situation of having to learn the new law and determining what practices might need to change.

Trainings have been happening for a year. WAPG has put on two all day trainings with a focus on existing law and the changes under the UGA. Most Bar associations have held similar trainings. Mark Vohr has been a regular presenter and is well-qualified to teach. Sage Graves is another attorney who is very familiar with the other protective arrangements section of the law. I have spoken about emergency and temporary guardianships. David Lord spoke about supported decision-making at an early WINGS conference, years ago.

Washington is lucky to have many qualified attorneys, guardians, and other professionals who can be called on to assist the AOC with the March and April trainings.

This year has given professional organizations the opportunity to reassess their requirements and the Board should do the same.

The pandemic and lockdowns caused the Washington State Bar Association to allow students to become licensed without taking the Bar exam as long as they had graduated from accredited law schools. The decision opened the door to other discussions about whether the Bar exam and the education process for lawyers is structured to support diversity.

The CPG Board has discussed in the past the requirements for becoming a professional

guardian, including education, relevant experience, and training. Washington has a robust program and should continue to question whether all of the components are serving the goal of having sufficient, well-qualified guardians who are fully aware of their role and responsibility.

I think the only way to really learn what a guardian does is to be a guardian. I speak as someone who has been involved in guardianship for 20 years as a Guardian ad Litem, guardian investigator for the Board, attorney for lay and professional guardians. Yet, I still am constantly learning about the day-to-day experience of person who is the actual guardian.

I appreciate the chance to comment on Ms. Doyle's letter. I encourage the Board to not change the requirements it has promulgated for CPG certification this year.

Very truly yours,

Deborah Jameson

DEBORAH JAMESON

Comments submitted by

Christina Baldwin

January 7, 2021

January 11, 2021

Good morning, Honorable Judge Anderson and esteemed Board Members,

My name is Tina Baldwin and I appreciate the opportunity to speak to you.

I am a lay co-guardian of the estate, the chairperson of the board of trustees of Spectrum Institute, the project director of Spectrum's Mental Health Project, and the mother of a daughter who has Down syndrome.

My remarks pertain to materials that were sent to the court's WINGS listserv in preparation for the January 11 meeting.

In mid-December, the CDC added people with Down syndrome to list of those most at risk of severe COVID.

I also sent a pdf of an article by Meredith Widman titled "COVID-19 is 10 times deadlier for people with Down syndrome, raising calls for early vaccination."

She reports on a study that in which " findings from a large international survey found that people with DS hospitalized with COVID-19 who are 40 and older bear most of the increased risk, with a mortality of 51% versus 7% for those under 40. “At about the age of 40, things are getting really bad ... [with] a mortality rate comparable with those older than 80 in the general population.”

Many guardians are responsible for the care of people with Down syndrome and they should be monitoring closely that residential staff are providing the same level of precaution as they do for seniors. I

know this isn't happening and I want to ask the CPG Board to notify all guardians about this risk of COVID for people with Down syndrome and need to follow CDC guidelines for high-risk populations including the limitation "of interactions with other people as much as possible." This proactive step could save the life of many people with Down syndrome.

Lastly, I sent a pdf of a transcript of a talk given last November by Juan Fortea, Ph.D. in a zoom presentation for *LuMInd IDSC*. In this presentation, Dr. Fortea said "Down syndrome is now considered a genetically determined form of Alzheimer's disease." He also said that blood tests are available for diagnosis and cost about $50.

I am aware that many CPG are not aware of this, but it absolutely reinforces a guardian's duty to provide mental health services as mandated under the Americans with Disabilities Act (ADA) and Washington State law (RCW 49.60.030).

The State of Mississippi was sued by the US Dept. of Justice and lost. So, they are being forced by a court order to comply with the ADA in the delivery of mental health service. I sent a pdf of this federal court order FYI for today's meeting. The delivery of mental health service in compliance with federal ADA law should be of major concern to the CPG Board.

I would like to suggest today that both the OAC and the CPG Board begin to educate both lay and certified professional guardians that failure to provide mental health service is disability discrimination and that there is a potential of criminal liability if:
* they ignore a vulnerable person under their guardianship obvious need for psychological therapy,
*if they choose to focus on behavior modification rather than mental health evaluation and treatment that addresses the underlying causes of those symptoms or,

* if they approve requests for more restrictive services from residential and employment providers based claims of challenging behaviors without recommendations from professional mental health experts with professional expertise working with people with developmental and intellectual disabilities.

RCW 74.34 makes abuse of a dependent adult a crime. People under guardianship are dependent adults. It therefore would be a criminal offense for either a lay or professional guardian to willfully permit the health of a person under their care to be injured. Failing to secure treatment from a qualified mental health professional to address the underlying causes of troubling behaviors is clearly permitting the health of a vulnerable adult under their protection to be injured.

I appreciate the opportunity to speak to you this morning. Thank you.

Comments Submitted by
Tina Baldwin
January 6, 2021

No. 3:16-CV-622-CWR-FKB

UNITED STATES OF AMERICA,

Plaintiff,

v.

STATE OF MISSISSIPPI,

Defendant.

MEMORANDUM OPINION AND ORDER

Before CARLTON W. REEVES, *District Judge*.

Melody Worsham has a unique perspective on Mississippi's mental health system. She knows the system as a patient because she has struggled with serious mental illness (SMI) throughout her life. But she also knows it as a professional, in her job as a certified peer support specialist. That means Ms. Worsham is trained to help other persons with SMI "overcome the obstacles that might be getting in their way of living the life they want to live. And also navigating the system,

helping to find resources, and then just being moral support, you know, just being there for somebody." Trial Tr. 323.

Ms. Worsham was one of dozens of witnesses who testified in this case about whether Mississippi unnecessarily institutionalizes persons with SMI. The trial record spans four weeks of testimony, thousands of pages of exhibits, and voluminous legal briefs by both sides, and still does not begin to reflect the enormity of Mississippi's mental health system. One would be forgiven for throwing their hands up in exasperation at the complexity of the situation.

Yet we reached a moment of lucidity when Ms. Worsham was cross-examined by one of the State's attorneys. Ms. Worsham readily testified that the State was acting in good faith. "I think the people that I have worked with at the Department of Mental Health really want to see this change. I really do." Trial Tr. 344. But Ms. Worsham could not agree that the State was making a "major effort" to expand community-based services throughout Mississippi:

> It's like they stop right at that point to do the very thing that actually would make a difference. They stop. So there is a lot of talk, there is a lot of planning, but there is also a lot of people being hurt in the process.

Trial Tr. 348.

The Court fully agrees with Ms. Worsham. On paper, Mississippi has a mental health system with an array of appropriate community-based services. In practice, however, the mental health system is hospital-centered and has major gaps in its community care. The result is a system that excludes adults with SMI from full integration into the communities in which

they live and work, in violation of the Americans with Disabilities Act (ADA).

At its heart, this case is about how Mississippi can best help the thousands of Melody Worshams who call our State home. The State generally understands the urgency of these needs, and it understands its obligations under federal law. It is moving toward fulfilling those obligations. The main question at trial was, has it moved fast enough to find itself in compliance with the ADA?

The United States Department of Justice has presented compelling evidence that the answer to that question is "no." Mississippi's current mental health system—the system in effect, not the system Mississippi might create by 2029—falls short of the requirements established by law. The below discussion explains why.

I.

The Americans with Disabilities Act

In 1990, Congress passed the ADA, "the last major civil rights bill to be signed into law,"[1] to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101

[1] David M. Perry, *How George H.W. Bush Proved Himself to the Disability Right Community*, Pacific Standard (Dec. 6, 2018). The ADA is regarded as one of President George H.W. Bush's greatest legislative achievements. *See, e.g.*, Rachel Withers, *George H.W. Bush was a Champion for People with Disabilities*, Vox.com (Dec. 2, 2018) (quoting Lex Frieden, a professor at the University of Texas Health Science Center at Houston, as saying that President H.W. Bush "considered [the ADA] among some of his greatest accomplishments. From time to time, he told me he felt like it was the best thing that he did.").

(b)(1).[2] Congress explained in the statute exactly what it wanted to rectify. Some of those explanations have direct bearing on our situation nearly 30 years later.

Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." *Id.* § 12101(a)(2). It specifically acknowledged that such discrimination "persists in such critical areas as . . . institutionalization" and "health services." *Id.* § 12101 (a)(3). Congress then wrote that "individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, . . . failure to make modifications to existing facilities and practices, . . . segregation, and relegation to lesser services." *Id.* § 12101(a)(5).

To establish a violation of the ADA, "plaintiffs must demonstrate that (1) they are 'qualified individuals' with a disability; (2) that the defendants are subject to the ADA; and (3) that plaintiffs were denied the opportunity to participate in or benefit from defendants' services, programs, or activities, or were otherwise discriminated against by defendants, by

[2] At the signing of the historic legislation, President Bush declared that "every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom." He continued, "[t]his historic act is the world's first comprehensive declaration of equality for people with disabilities – the first. Its passage has made the United States the international leader on this human rights issue." President George H.W. Bush, Statement upon Signing the Americans with Disabilities Act (July 26, 1990).

reason of plaintiffs' disabilities." *Henrietta D. v. Bloomberg*, 331 F.3d 261, 272 (2d Cir. 2003) (citation omitted).

Title II of the ADA prohibits discrimination by public entities. It establishes that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. "Title II does not only benefit individuals with disabilities. . . . Congress specifically found that disability discrimination 'costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.'" *Frame v. City of Arlington*, 657 F.3d 215, 230 (5th Cir. 2011) (en banc) (citations omitted).

Congress instructed the Attorney General to promulgate regulations implementing Title II. Those regulations require public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). Such a setting "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. Pt. 35, App. B. Public entities "shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130 (b)(7)(i).[3]

[3] This affirmative obligation distinguishes the ADA. Unlike other anti-discrimination laws, the ADA "was considered innovative in that it went

The Supreme Court interpreted Title II in the landmark case *Olmstead v. L.C ex rel. Zimring*, 527 U.S. 581 (1999). It first noted that "Congress explicitly identified unjustified 'segregation' of persons with disabilities as a 'form of discrimination.'" 527 U.S. at 600 (citation and brackets omitted). The Court then reasoned that "unjustified institutional isolation of persons with disabilities is a form of discrimination [that] reflects two evident judgments."

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.
>
> Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

'beyond a mere nondiscrimination rule to demand the alteration of societal structures that, however unintentionally, stand in the way of opportunities for people with disabilities' through its reasonable accommodation requirement." Ariana Cernius, *Enforcing the Americans with Disabilities Act for the "Invisibly Disabled": Not a Handout, Just a Hand*, 25 Geo. J. Poverty L. & Pol'y 35, 50 (2017) (citations omitted). Not only are persons with disabilities "entitled to reasonable accommodations to a public entity's services, programs, and activities, . . . it is discriminatory when an entity fails to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services." *Id*. (quotation marks and citations omitted).

Id. at 600–01 (citations and brackets omitted).

Because discrimination on the basis of disability might not be obvious, the Court tried to explain the "dissimilar treatment" in simpler terms. It came up with this: "In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice." *Id.* at 601 (citation omitted).

Olmstead's final holding reads as follows:

> States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Id. at 607.[4] This is often referred to as the "integration mandate." *Disability Advocates, Inc. v. Paterson (DAI I)*, 653 F. Supp.

[4] Thus, "*Olmstead* is noteworthy for its broad recognition of the rights of people institutionalized in congregate facilities to live and receive needed services and supports in the community. Critically, *Olmstead* endorsed the congressional finding in the ADA that institutionalization constituted discrimination." Robert D. Dinerstein & Shira Wakschlag, *Using the ADA's "Integration Mandate" to Disrupt Mass Incarceration*, 96 Denv. L. Rev. 917, 926 (2019) (citing 42 U.S.C. § 12101(a)(3)). The decision "has come to stand

2d 184, 190–91 (E.D.N.Y. 2009), *vacated on other grounds sub nom. Disability Advocates, Inc. v. New York Coal. for Quality Assisted Living, Inc. (DAI II)*, 675 F.3d 149 (2d Cir. 2012). "[F]ollowing *Olmstead,* courts have looked to the language of the Attorney General's regulations interpreting Title II, as well as the holding in *Olmstead,* as the standard by which to determine a violation of the ADA's integration mandate." *Id*. (citations omitted).

Though *Olmstead* spoke of "the State's treatment professionals," courts recognize that any treatment professional, whether employed by the state or not, may be used to show that community placement is appropriate. *See Fisher v. Okla. Health Care Auth.,* 335 F.3d 1175, 1181 (10th Cir. 2003). If establishing a case required reliance on the government's own treatment professionals, states could circumscribe the requirements of Title II. *See Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 290–91 (E.D.N.Y. 2008); *Long v. Benson*, No. 4:08-CV-26, 2008 WL 4571904, at *2 (N.D. Fla. Oct. 14, 2008); *see also Martin v. Taft*, 222 F. Supp. 2d 940, 972 n.25 (S.D. Ohio 2002).

II.

Procedural Background and Preliminary Arguments

In 2011, the United States Department of Justice issued a findings letter summarizing the results of its long investigation into the State of Mississippi's mental health system. It concluded that Mississippi was "unnecessarily institutionalizing persons with mental illness" in violation of the ADA's integration mandate. Docket No. 150-24 at 2. After years of

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for a ringing endorsement of community integration of people with mental disabilities in multiple aspects of daily life." *Id*. at 929.

negotiations failed, the United States filed this suit in 2016. It named the State as the sole defendant. *See* Docket No. 1.

The parties have stipulated that the State is a public entity that must comply with the ADA and its implementing regulations. Trial Stipulations ¶ 1.[5] The State controls and operates the mental health system through the Mississippi Department of Mental Health (DMH), which provides services, and the Mississippi Division of Medicaid, which pays for services for Medicaid-enrolled persons. *Id.* ¶ 2. Persons with SMI are "almost always" eligible for Medicaid. Trial Tr. 1402.

The United States alleges that Mississippi over-relies on state psychiatric hospitals in violation of *Olmstead*. Adults with SMI are forced into segregated hospital settings instead of being able to stay in their communities with the help and support of their families and local services. The United States claims that as a result, all Mississippians with SMI are denied the most integrated setting in which to receive services, and are at serious risk of institutionalization.[6]

The case culminated in a four-week bench trial in June and July of 2019.[7] The parties have now submitted their post-trial

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[5] The Trial Stipulations were filed at Docket No. 231-1. In this opinion, the plaintiff's exhibits are cited as "PX," the defendant's exhibits are cited as "DX," and joint exhibits are cited as "JX."

[6] The United States' allegations echo President Bush's lament that "tragically . . . the blessings of liberty have been limited or even denied" to many persons with disabilities. President Bush, *supra* note 2.

[7] The attorneys for both sides provided admirable representation to their clients. The Court appreciates how all involved worked together in good faith for the most efficient management of this case, and treated the subject of this matter with the seriousness and respect it deserves. The

proposed findings of facts and conclusions of law. *See* Docket Nos. 232–33.

Motion practice established that the United States filed this action pursuant to its authority to enforce Title II of the ADA, 42 U.S.C. § 12133, and under the Civil Rights of Institutionalized Persons Act, 42 U.S.C. § 1997a. *See United States v. Mississippi*, No. 3:16-CV-622-CWR-FKB, 2019 WL 2092569, at *2–3 (S.D. Miss. May 13, 2019); *see also DAI II*, 675 F.3d at 162 (finding that the United States had standing to bring suit on behalf of thousands of individuals with SMI living in segregated settings). The United States has complied with the necessary statutory prerequisites. The State has not challenged that these prerequisites have been met at or since trial.

The State, however, has raised several arguments that all suggest the same conclusion: despite the statutory authority to bring such a suit, the United States cannot prevail in this case because it is the sole plaintiff. Without other named plaintiffs or a certified class of individuals, the State says, there is no violation of the ADA. These arguments must be addressed first, because while not expressly articulated as such, they invoke the basic principle of Article III standing that a plaintiff must suffer an "injury-in-fact." *Lujan v. Defs. of Wildlife*, 504 U.S. 555, 560 (1992).

First, the State argues that the United States has not proven that anyone was unnecessarily hospitalized. Second, the State argues that the United States has not proven that anyone was denied the benefits of, or excluded from participation in, any

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professionalism they exhibited during the trial is one which the Court wishes it experienced in each of its cases.

community-based program. Third, the State contends that because the United States does not have named plaintiffs who are currently institutionalized, this case is "only" an at-risk of institutionalization case. Docket No. 232 at 15.

The first two arguments were refuted at trial. The United States' experts provided dozens of examples of individuals who were unnecessarily hospitalized or hospitalized too long because they were excluded from community-based services. Some of the persons the United States' experts analyzed for this suit were still hospitalized when the experts interviewed them. All of that evidence will be discussed below. In this section, though, the Court will discuss the third argument: whether this case is somehow deficient for emphasizing that Mississippians remain at risk of institutionalization and re-institutionalization.

Most of the cases brought pursuant to Title II's integration mandate are brought by individual plaintiffs or classes of persons. *E.g.*, *Olmstead*, 527 U.S. at 593 (reciting that plaintiffs L.C. and E.W. were persons with disabilities who challenged their institutionalization). This case is different. Here, the United States alleges, *inter alia*, that Mississippi's system pushes thousands of people into segregated hospital settings that could have been avoided with community-based services. When persons with SMI are eventually discharged, it claims, Mississippi's ongoing lack of community-based services means they are at serious risk of re-institutionalization.

The Fifth Circuit has not reviewed a similar case, so decisions from around the country guide this Court's determination. *Cf. Shumpert v. City of Tupelo*, 905 F.3d 310, 320 (5th Cir. 2018), *as revised* (Sept. 25, 2018) ("If there is no directly controlling

authority, this court may rely on decisions from other circuits to the extent that they constitute a robust consensus of cases of persuasive authority.").

The cases show that Title II protects not only those persons currently institutionalized, but also those at serious risk of institutionalization. *See Steimel v. Wernert*, 823 F.3d 902, 911–13 (7th Cir. 2016); *Davis v. Shah*, 821 F.3d 231, 263 (2d Cir. 2016); *Pashby v. Delia*, 709 F.3d 307, 321–22 (4th Cir. 2013); *M.R. v. Dreyfus*, 663 F.3d 1100, 1116 (9th Cir. 2011), *amended by* 697 F.3d 706 (9th Cir. 2012); *Fisher*, 335 F.3d at 1181; *Steward v. Abbott*, 189 F. Supp. 3d 620, 633 (W.D. Tex. 2016); *Pitts v. Greenstein*, No. 10-635-JJB-SR, 2011 WL 1897552, at *3 (M.D. La. May 18, 2011); *DAI I*, 653 F. Supp. 2d at 187–88 (finding violation of ADA and Rehabilitation Act where approximately 4,300 individuals with SMI were "residing in, or at risk of entry into" segregated settings), *vacated sub nom. DAI II*, 675 F.3d at 162 (finding that original plaintiff lacked organizational standing but the United States could bring such a suit). In other words, the prospective approach taken by the United States is supported by the weight of authorities from around the country.

The State argues that these cases have differing fact patterns. The argument is unpersuasive because these cases all evaluated the key premise at issue here—whether at risk of institutionalization claims are valid.

In *Pashby*, for example, the Fourth Circuit rejected the idea that an *Olmstead* claim is limited to instances of "actual institutionalization." 709 F.3d at 321. It instead agreed with the plaintiffs that *Olmstead* protects those facing "risk of institutionalization." *Id.* at 322. The Tenth Circuit added that a contrary conclusion makes little sense, as the ADA's "protections

would be meaningless if plaintiffs were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation." *Fisher*, 335 F.3d at 1181; *see also Steimel*, 823 F.3d at 912. "Unsurprisingly, . . . courts of appeals applying the disability discrimination claim recognized in *Olmstead* have consistently held that the risk of institutionalization can support a valid claim under the integration mandate." *Davis*, 821 F.3d at 263 (collecting cases).

Unsatisfied with this principle, Mississippi pivots, and says those cases are distinguishable because those defendants were making "policy changes" to take away services, whereas here, Mississippi is simply moving slowly on deinstitutionalization. But that is not a complete statement of the facts or the law. The evidence showed that Mississippi is making policy changes that both decrease *and increase* institutionalization. For example, the State is increasing hospital beds at some of its facilities. The law, meanwhile, indicates that the ADA and *Olmstead* protect persons trapped in a snail's-pace deinstitutionalization.

The ADA is unique among civil rights laws. It is "a 'broad mandate' of 'comprehensive character' and 'sweeping purpose' intended 'to eliminate discrimination against disabled individuals, and to integrate them into the economic and social mainstream of American life.'" *Frame*, 657 F.3d at 223 (citations omitted). Somewhat unusually, the ADA "impose[s] upon public entities *an affirmative obligation* to make reasonable accommodations for disabled individuals. Where a defendant fails to meet this affirmative obligation, the cause of that failure is *irrelevant*." *Bennett-Nelson v. Louisiana Bd. of*

Regents, 431 F.3d 448, 454–55 (5th Cir. 2005) (emphasis added and citations omitted).

This affirmative obligation extends to deinstitutionalization cases. *Olmstead* explicitly holds that "States are *required* to provide community-based treatment" if three elements are met. 527 U.S. at 607 (emphasis added).[8] None of those elements turn on whether the State is eliminating services or failing to provide services. The rate-of-change question is instead folded into element three of the standard; whether community placement "can be reasonably accommodated." *Id.*

Case law also indicates that states dragging their feet on deinstitutionalization can be held accountable under *Olmstead*.

In *Frederick L.*, the Third Circuit was faced with a situation with similarities to our own. Both parties sought deinstitutionalization and citizens' "integration into community-based healthcare programs." *Frederick L. v. Dep't of Pub. Welfare of Pa. (Frederick L. II)*, 422 F.3d 151, 154 (3d Cir. 2005). They disputed only the timeline of implementation (or lack thereof). The appellate court found that although the Commonwealth of Pennsylvania "proffers general assurances and good faith

[8] Similarly, the ADA's implementing regulations provide that public entities "*shall* make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7)(i) (emphasis added). Nothing in this regulation provides an exception for states that characterize segregation on the basis of disability as a mere failure to act. Such an exception might well swallow the rule.

intentions to effectuate deinstitutionalization," that was not enough to satisfy the ADA.

> General assurances and good-faith intentions neither meet the federal laws nor a patient's expectations. Their implementation may change with each administration . . . , regardless of how genuine; they are simply insufficient guarantors in light of the hardship daily inflicted upon patients through unnecessary and indefinite institutionalization.

Id. at 158–59. The Third Circuit concluded that under *Olmstead*, states must provide more than "a vague assurance" of "future deinstitutionalization"; that "verifiable benchmarks or timelines" are "necessary elements of an acceptable plan"; and that any plan must "demonstrate a commitment to community placement in a manner for which [the state government] can be held accountable by the courts." *Id.* at 155–56. This Court agrees, and will therefore consider the State's arguments regarding the timing of deinstitutionalization later in the *Olmstead* analysis, rather than as a bar to the entire action.

Given all of these authorities, the Court cannot sustain the State's preliminary legal arguments. The Court will now turn to the evidence.

III.

Mississippi's Mental Health System

Mississippi's mental health system looks like a broad continuum of care—with community services on one end and the state hospitals on the other. On one end, the State is divided

into regions, each covered by a community mental health center that provides a range of services. On the other end, a handful of state hospitals are used to institutionalize patients when necessary.

Dr. Robert Drake, one of the United States' experts, testified that the community-based system described in Mississippi's manuals "is well written." Trial Tr. 105. In practice, however, the continuum of care morphs from a line into a circle. Mississippians with SMI are faced with a recurring cycle of hospitalizations, without adequate community-based services to stop the next commitment. This process of "cycling admissions" is "the hallmark of a failed system." Trial Tr. 119.

A. Community-Based Services

"The State offers community-based mental health services primarily through fourteen regional community mental health centers (CMHCs). DMH is responsible for certifying, monitoring, and assisting the CMHCs." Trial Stipulations ¶ 5. DMH promulgates standards for the CMHCs and provides them with grant funding, but the management of each CMHC is left to a board appointed by the county supervisors within the catchment area covered by the CMHC. *Id.* ¶ 7; Trial Tr. 1579.

"Community-based services" refers to a bundle of evidence-based practices. If these services are provided in a county, they are provided through the regional CMHC. Each kind of service is described in more detail below.

- *Programs of Assertive Community Treatment (PACT)*: PACT is the most intensive community-based service available in Mississippi. It is for individuals "who have the most severe and persistent mental illnesses, have

severe symptoms and impairments, and have not benefited from traditional outpatient programs." JX 60 at 215; *see* Trial Stipulations ¶¶ 189–90. PACT teams include some combination of psychiatric nurse practitioners, psychiatrists, registered nurses, community support specialists, peer support specialists, employment and housing specialists, therapists, and program coordinators. *See* Trial Tr. 529 and 2194. Currently, PACT services are offered in Mississippi through eight PACT teams, which together cover 14 of Mississippi's 82 counties. *See* PX 413; Trial Stipulations ¶ 195.

- *Mobile Crisis Response Services*: "All fourteen CMHC regions established Mobile Crisis Response Teams in 2014. Mobile crisis response services are required by DMH regulation to be available 24 hours a day, 7 days a week, 365 days a year." Trial Stipulations ¶¶ 208–09.
- *Crisis Stabilization Units (CSUs)*: "CSUs provide psychiatric supervision, nursing, therapy, and psychotherapy to individuals experiencing psychiatric crises, and are designed to prevent civil commitment and/or longer-term inpatient hospitalization by addressing acute symptoms, distress, and further decompensation." *Id*. ¶ 212. There are nine CSUs in Mississippi. They are located in Batesville, Brookhaven, Cleveland, Corinth, Grenada, Gulfport, Laurel, Newton, and Jackson. *Id*. ¶ 222.[9]

[9] The ninth CSU was added in Hinds County, the State's most populous county, in the spring of 2019, past the fact cut-off date agreed to by the parties. *See* Trial Tr. 2202. Nevertheless, this is relevant for understanding the complete range of services currently provided by DMH.

- *Community Support Services*: Community support services are similar to PACT services, but are less intensive. They allow healthcare professionals to provide in-home services like medication management and referrals to other service providers. Medicaid will reimburse up to 100 hours of community support services per person per year. *See* Trial Tr. 40 and 1345.
- *Peer Support Services*: "Peer Supports are provided in Mississippi by Certified Peer Support Specialists (CPSS), individuals or family members of individuals who have received mental health services and have received training and certification from the State. CPSS may work in State Hospitals, as part of PACT or Mobile Crisis Response Teams, for CMHCs, or for other providers and serve as a resource for individuals with mental illness. Peer specialists engage in person-centered activities with a rehabilitation and resiliency/recovery focus. These activities allow consumers of mental health services and their family members the opportunity to build skills for coping with and managing psychiatric symptoms and challenges associated with various disabilities while directing their own recovery." Trial Stipulations ¶¶ 251–52.
- *Supported Employment*: "Supported Employment for SMI assists individuals with severe and persistent mental illness in obtaining and maintaining competitive employment." *Id*. ¶ 227. "In FY17 116 individuals with SMI received supported employment." *Id*. ¶ 232.

- *Permanent Supported Housing*: "According to SAMHSA,[10] Permanent Supported Housing is an evidence-based practice that provides an integrated, community-based alternative to hospitals, nursing facilities, and other segregated settings. It includes housing where tenants have a private and secure place to make their home, just like other members of the community, and the mental health support services necessary to maintain the housing." *Id*. ¶ 235. In Mississippi, supported housing services are delivered through a program known as CHOICE. "CHOICE recipients receive mental health services from the local CMHC or other providers and are eligible for a rental subsidy administ[ered] through MHC." *Id*. ¶ 237. "In FY17 205 individuals were served through CHOICE." *Id*. ¶ 249.

The evidence established that the descriptions of the services provided by CMHCs is adequate. The problem is that the descriptions do not match the reality of service delivery, in terms of what is actually provided and where it is provided. Some of those realities are presented below.

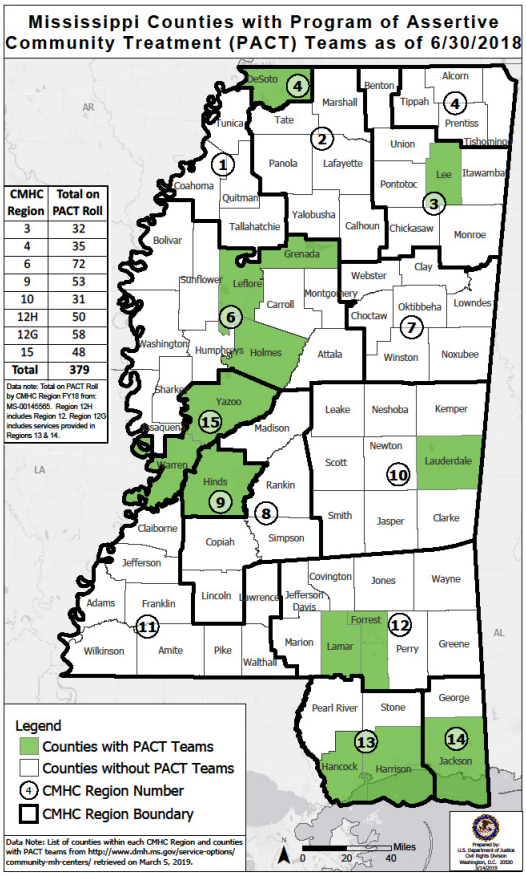
1. PACT is unavailable and under-enrolled.

The following map provides an understanding of the regional catchment areas that each CMHC covers. It shows that PACT services do not exist in 68 of Mississippi's 82 counties.

[10] The Substance Abuse and Mental Health Services Administration (SAMHSA) is an agency within the U.S. Department of Health and Human Services.

Figure 1

Mississippi Counties with PACT Teams as of June 2018[11]



PACT is the most intensive community-based service. It targets individuals who need the most assistance staying out of the hospital. The prime candidate for PACT is someone who has had multiple hospitalizations, such as the 743

[11] PX 413.

Mississippians hospitalized more than once between 2015 and 2017. *See* PX 405 at 28.[12] The United States refers to this group as the "heavy utilizers" of the mental health system. Trial Tr. 2468.

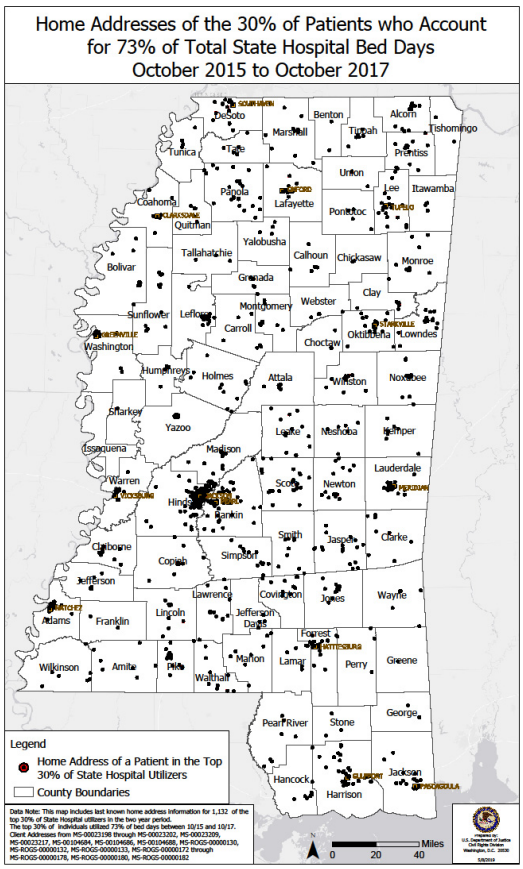
As of September 2018, however, only 384 people in the state were receiving PACT services. *See* JX 50 at 8. The problem is obvious. If there are more than 700 heavy utilizers who have been hospitalized multiple times, but fewer than 400 persons receive PACT services, the penetration rate of PACT services is low.

Again, one obvious reason for the under-enrollment of heavy utilizers is geographical. The below map shows that many of Mississippi's most-hospitalized persons live in areas where PACT services are not available.

[12] Dr. Todd MacKenzie, one of the United States' experts, compiled state hospital admission records from October 2015 through October 2017. He found that during that time frame, 514 patients were admitted twice, 147 patients were admitted three times, and 82 patients had four or more admissions. Trial Tr. 278. Over that period, just 30% of state hospital patients accounted for 73% of the total state hospital bed days. *See* PX 419.

Figure 2

Home Addresses of the top 30% of Hospital Utilizers[13]



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Even in those 14 counties where PACT exists, there is another problem. Testimony revealed that existing PACT teams are not operating at full capacity. A DMH Bureau Director attributed the shortfall to "staff issues" and the fact that some

[13] PX 419.

patients "choose not to have that level of intervention in their life." Trial Tr. 1587–88.

The first explanation is understandable. The second is less persuasive. Other states' experiences show that patients do in fact choose to have intensive community-based services in their lives. We know this because other states have significantly higher PACT penetration rates. One of the State's experts testified that if Mississippi's PACT services had the nation's average penetration rate, a total of 1,329 Mississippians with SMI would be receiving PACT services. Trial Tr. 1539. That is nearly 1,000 persons more than are being served today.

2. Mobile Crisis Services are illusory.

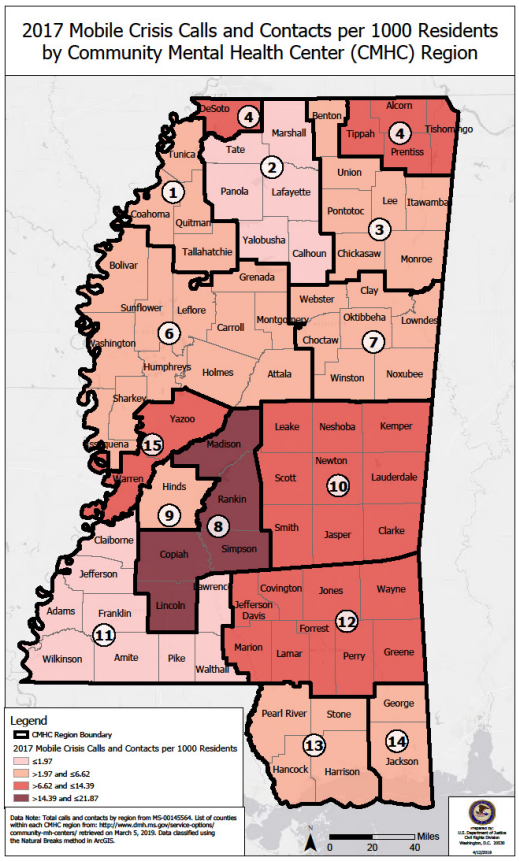
Geographic availability does not always translate into true accessibility. The Court heard from Sheriff Travis Patten, the top law enforcement official in Adams County, Mississippi. He testified that although his county is covered by the CMHC for Region 11, when people call the mobile crisis line, the Adams County Sheriff's Department is dispatched to respond to the call. That is in large part because the mobile crisis team is based in McComb, over an hour away. His department never sees the mobile crisis team. *See* Trial Tr. 914–15.

Ms. Worsham, the certified peer support specialist, has called the mobile crisis line in Gulfport "dozens of times." Trial Tr. 335. They came only once. Trial Tr. 336. Every other time, they told her to take herself or her client to the hospital or call the police. Trial Tr. 336–37.

It is no surprise then that the mobile crisis lines covering Adams County and Gulfport are utilized less often than others in the state. The below map shows the utilization of this service by region:

Figure 3

2017 Mobile Crisis Calls and Contacts per 1000 Residents[14]



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3. Crisis Stabilization Units are not available.

Not all of the CMHCs have crisis stabilization units. Sheriff Patten does not have a CSU in Adams County or in the larger Region 11 catchment area. That is a missed opportunity, as

[14] PX 415.

the State does not dispute that CSUs are an effective diversion from hospitalization. DMH data show that CSUs successfully divert a patient from a state hospital 91.85% of the time. *See* PX 354 at 9.

4. Peer Support Services are not billed.

Peer support services are included in the Mississippi Medicaid State Plan, but there is no indication that the service is being utilized across the State. Shockingly, in the three most populous regions of the State, CMHCs billed Medicaid for a *total* of 17 persons who received peer support services in 2017. *See* PX 407 at 22; PX 423 at 2; Trial Tr. 1356–57.

Meanwhile, Mississippi has only two peer-run drop-in centers—places that allow anyone suffering from SMI to come in at any time and connect with peers. Those are located in Gulfport and Jackson. *See* Trial Tr. 328–30 and 2206.

5. Supported Employment is miniscule.

In 2018, 257 Mississippians received supported employment services. *See* DX 302 at 21; Trial Tr. 1515 and 1558. Not surprisingly, despite working as a peer support specialist within the community, Melody Worsham is not aware of anyone with SMI who has received supported employment services. *See* Trial Tr. 341.

One of the State's experts, Ted Lutterman, testified that Mississippi's penetration rate on supported employment is "quite low." Trial Tr. 1515. If it were increased to the national average, he said, a total of 1,266 people would benefit from the service. Trial Tr. 1558. That is (once again) 1,000 more people a year than the State is currently serving.

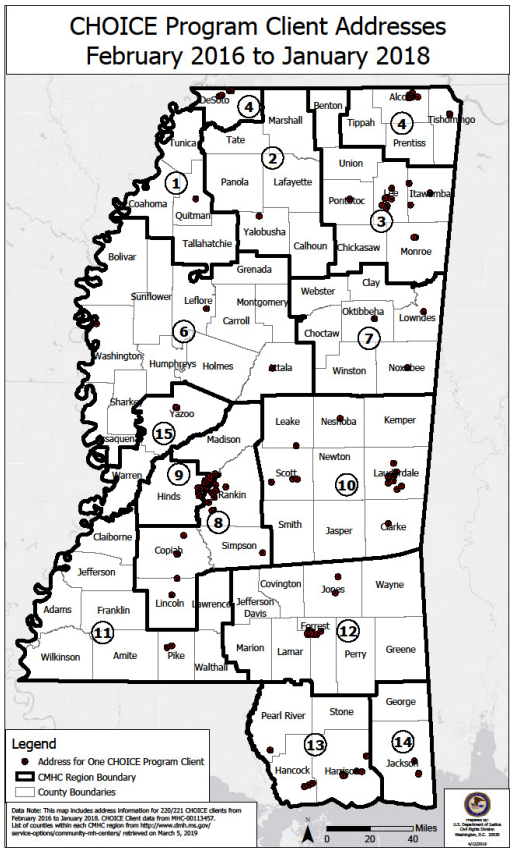
In 2019, DMH attempted to increase supported employment services by giving new $40,000 grants to seven CMHCs. *See* DX 12 at 2; Trial Tr. 1631–32. Each grant would pay for one additional supported employment specialist, who in turn could assist another 20 to 25 clients per region. Trial Tr. 1632. While that is a step in the right direction, it represents one fewer supported employment specialist than DMH recommended *per region in 2011*, and will help a maximum of 175 Mississippians with SMI. *See* Trial Tr. 1632. A DMH official explained this at trial by saying, "You just have to go with the funding you have." Trial Tr. 1632.

6. CHOICE is far too small.

The CHOICE housing program is grossly underutilized. Overall, about 400 Mississippians have benefited from CHOICE. *See* Trial Tr. 742. The map below shows seven CMHC regions with fewer than five individuals enrolled in CHOICE, despite an estimate by the program administrator that over 2,500 beds statewide are needed. *See* JX 5 at 3.

Figure 4

CHOICE Program Utilization 2016-2018[15]



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7. Other management concerns.

One reason many community services are underutilized is the lack of data-driven management. *See* PX 407 at 31; Trial Tr. 1396. DMH executives admitted that they do not regularly

[15] PX 416.

review data on community-services utilization, much less use that data to drive programmatic changes. *See* Trial Tr. 1639–40; Allen Dep. 10–11; Holloway Dep. 34–35; Hurley Dep. 48–49; Toten Dep. 21–22, 109, 133–34, 140, 194, and 208–09. As an example, the clinical director at South Mississippi State Hospital testified that the committee established to monitor hospital readmission rates stopped meeting regularly. Reeves Dep. 24–25. "I think we addressed whatever we were capable of addressing," he said. *Id.* at 25.

A different kind of management problem concerns DMH's relationship with community health providers. DMH views CMHCs as independent, autonomous organizations, *see* Allen Dep. 14–15 and 45, but DMH sets the standards for the CMHCs and gives them grants for programs, *see id.* at 14–15 and Trial Stipulations ¶¶ 5–7. It is ultimately DMH's responsibility to manage the expansion of community-based services at CMHCs.

B. State Hospitals

On the other end of the continuum of care are the state hospitals. "DMH funds and operates four State Hospitals: Mississippi State Hospital in Whitfield, MS (MSH), East Mississippi State Hospital, in Meridian, MS (EMSH), North Mississippi State Hospital, in Tupelo (NMSH), MS, and South Mississippi State Hospital, in Purvis, MS (SMSH)."[16] Trial Stipulations ¶ 9.

[16] DMH also runs the Central Mississippi Residential Center in Newton, a step-down facility that helps transition individuals from the state hospitals to the community. *See* Trial Stipulations ¶ 186.

In 2018, a total of 2,784 Mississippians were institutionalized across the four hospitals. *See* PX 412 at 3. That year, the State had 438 state hospital beds.[17] *See* Trial Tr. 2453; PX 412A at 1. These beds cost the State between $360 and $474 per person per day. *See* PX 452 at 38; PX 453 at 30; PX 454 at 20; PX 455 at 20.

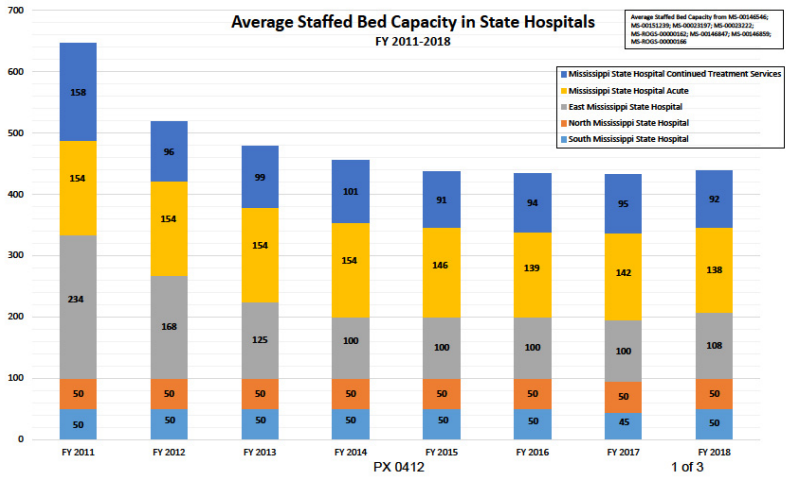
Mississippi has relatively more hospital beds and a higher hospital bed utilization rate than most states. *See* PX 393 at 39; PX 394 at 20 and 27. The State concedes that its "hospital utilization rate is higher than the national and regional rates," but emphasizes that since 2008 it has fallen faster than the regional and national averages. Docket No. 232 at 44.

While the number of hospital beds in Mississippi fell from 2011 to 2014, it has remained relatively stable since then. *See* PX 412 at 1. The graphic below demonstrates such:

[17] This total does not include "forensic" beds, which are used for pretrial mental health evaluations or for persons found not guilty by reason of insanity. *See* Trial Tr. 1363 and 2321. Forensic beds have largely been excluded from this suit because they serve a need in the criminal justice field. That, however, does not mean that the State does not face challenges with the availability of those beds. *See* Adam Northam, *Bed shortage leaves mentally ill in jail*, The Daily Leader, Sept. 8, 2018 ("He's not a criminal, he's a sick man, and his confinement to the jail instead of the hospital is shameful, said Lincoln County Sheriff Steve Rushing.").

Figure 5

Average Staffed Bed Capacity in State Hospitals[18]



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Bo Chastain, the Director of Mississippi State Hospital, testified that he intends to operate the same number of beds each year. Trial Tr. 2272. One of the United States' experts testified that "East Mississippi [State] Hospital actually added beds as did South Mississippi State Hospital in 2018." Trial Tr. 1362.

When compared to other states, Mississippi allocates significantly more of its budget to institutional settings and correspondingly less of its budget to community-based services. *See* PX 407 at 29. Mississippi's funding allocation is about a decade behind other states. In 2015, for example, Mississippi's proportional spending on community-based services was less than the 2006 national average. *See* Trial Tr. 1544.

The State admits that the share of its budget spent on institutional care remains above the national average. *See* Docket

[18] PX 412 at 1.

No. 232 at 44. If federal Medicaid dollars are excluded from the calculation, only 35.65% of Mississippi's mental health spending went to community-based services in 2017. *See* PX 319; PX 407 at 29; Trial Tr. 1419.

There is no dispute that the state hospitals are "institutional, segregated settings." Trial Stipulations ¶ 11. If you are in a state hospital, your "routine is determined by other people, and the food is determined by other people, and your privacy level is determined by []other people." Trial Tr. 511. Life there is best described by those who have experienced it.

According to Blair Duren, who has been admitted on three occasions, state hospitals are "very scary."

> It's anxiety and depression and paranoia all built up. There is a lot of sick people who are very sick and have worse issues than myself, and it was very hard to be in a hospital because you were told, you know, when to go to bed, when it's time to eat. There is no freedom. There is no independence at all, no privacy.

Trial Tr. 568–69. Another patient told one of the United States' experts that "it was the most humiliating experience she had ever had in her life." Trial Tr. 966. Others said it was "like a prison." Trial Tr. 966. "It's no life to be in a hospital," one of the United States' experts said. "It's being alive, but that's different than having a life." Trial Tr. 509–10.

Ms. Worsham told the Court that:

> I'm terrified of [state hospitals]. . . . They take all your rights away and there is no dignity. They pump people full of drugs. They make you use

> a community bathroom even though you have your own room. Women who are menstruating have to walk around the halls with a handful of tampons. If I want to rest or if a person wants to rest, they have to just lay in the hallway. They don't let people rest. Sometimes there is coercion. I would never want to be there, and I have made efforts in the past to stay out of them.

Trial Tr. 335. Individuals at East Mississippi State Hospital have to earn back the privilege of wearing their wedding ring. An expert said that was "unusual and extreme." Trial Tr. 1333.

T.M. is a man with SMI who has been admitted to state hospitals on six different occasions. Trial Tr. 778. While hospitalized in Meridian, on the other side of the state from his mother in the Delta, he once wrote her a letter saying, "I'm not sure when [or] if I'll ever see you again." PX 1102 at 2; Trial Tr. 782.

It particularly struck this Court that a single hospitalization can result in you losing custody of your children. That is what happened to Person 11, a 41-year-old woman with two daughters. When she was interviewed by one of the United States' experts, she still had not regained custody of her children. Trial Tr. 853–54.

Transition planning is another area of concern. While individuals being discharged are often given a date to report to the local CMHC, there is no follow-up or consistent connection to local services. *See* Trial Tr. 818. DMH documents show that in 2016, only 20% of patients met with a CMHC representative before being discharged from the hospital. *See* PX 151 at 9. The Social Services Director at MSH, who supervises 40 social

workers, testified that a social worker's involvement with the patient ends as soon as the patient leaves the hospital. Fleming Dep. 8 and 79.

It is common for state hospitals to use the same discharge plan even after an individual has returned for another commitment. Katherine Burson, one of the United States' experts, "found the discharge planning to be formulaic. People pretty much got the same discharge plan, and it -- I didn't see discharge plans change, even when in the past the discharge plan hadn't worked." Trial Tr. 1091. Person 3, for example, was admitted to state hospitals three times between 2014 and 2016, and his planning looked identical upon each discharge. *See* Trial Tr. 819–32. Some patients did not have access to medication upon discharge, which led to rehospitalization "relatively quickly." Trial Tr. 445.

IV.

Everyday Mississippians

The Court heard from several DMH executives who testified about the extent of community-based services currently provided by the State.[19] They uniformly agreed that the State prioritizes community-based care. *See* Trial Tr. 1613, 1672–73, 2050, 2293, and 2331. One of the challenges mentioned by these witnesses is the lack of a qualified workforce for mental

[19] These witnesses included Jake Hutchins, Bureau Director of Behavioral Health at DMH; Marc Lewis, Director of the Bureau of Certification and Quality Outcomes at DMH; Steven Allen, Deputy Executive Director of DMH; Director Chastain of MSH; and Diana Mikula, Executive Director of DMH.

healthcare employers across Mississippi.[20] *See* Trial Tr. 2258 and 2318–20.

The United States, in contrast, called several people who have used the State's mental health services or whose family members have used such services. They all testified that a lack of community-based services is devasting to individuals with SMI and their families.

The Court heard harrowing and tragic stories about what happens when people fall through the cracks. Through tears, H.B. shared one of those stories.

His daughter, S.B., is a 52-year-old woman who has relied on the State's mental health system for approximately three decades. S.B. has been in state hospitals 23 times in that span. H.B. has been forced to initiate commitment proceedings several times, because he has no other options and S.B. does not receive any services when she is not hospitalized.[21] *See* Trial Tr. 721–42. "I would have liked to have had other options that

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[20] One of the factors contributing to this problem is a lack of competitive pay. Director Chastain testified that a direct care worker in a state hospital has a starting salary of approximately $17,500, which is far from a living wage. *See* Trial Tr. 2258.

[21] In the winter of 2013-2014, H.B. was unable to locate his daughter. S.B. had been living in a care home called Creation Elite, where she alleged that a male staff attendant was sexually assaulting her. In response, the owner of the home moved S.B. into an apartment without any oversight, and she quickly stopped taking her medication. *See* Trial Tr. 726–31; DX 338. Personal care homes seem to be a particularly egregious problem. There is little oversight and nothing to ensure that "care" is actually provided.

were -- were better options, but they weren't there." Trial Tr. 738.[22]

C.R. told the Court about her cousin, T.M., who has been hospitalized six times. One time, a social worker at MSH called and asked C.R.—a layperson—"what is the discharge plan for T.M.?" At the time, C.R. did not even know that T.M. had been hospitalized. C.R. has never heard about crisis stabilization services that could help T.M. when he is in the community.[23] *See* Trial Tr. 773–86.

The witnesses also offered glimpses into what it is like when the State provides the services it promises. Dr. Kathy Crockett, Executive Director of Hinds Behavioral Health Services, testified for the State about the array of services provided in Hinds County, including (among other things) a PACT team, crisis stabilization unit, and drop-in center. *See* Trial Tr. 2192–94. She says they serve everyone they can, but would "love to" expand their community-based services because there are others out there who need assistance. Trial Tr. 2228 and 2235.

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[22] S.B.'s story gets even sadder. Eighteen years ago, her father took custody of her son at three days old, and later adopted him. That child was the product of what H.B., a former police officer, described as a felonious relationship—a married man had taken advantage of his daughter. *See* Trial Tr. 756–57. Years later, in large part because of the lack of services, S.B.'s mental health declined to a "bad state." One day she was walking in the street and was struck by a hit-and-run driver. She suffered two broken legs, a broken pelvis, and a concussion, resulting in two knee replacement surgeries. Her total hospital stay was five months, including rehabilitation so that she could learn to walk again. *See* Trial Tr. 731–32 and 764–66.

[23] Similar to S.B., T.M. also spent time in a personal care home that was shut down. T.M.'s personal care home was unlicensed. *See* Trial Tr. 793.

Kim Sistrunk is the PACT team leader in Tupelo. While she has funding only to provide services to persons living in Lee County, she described a committed, on-the-ground team that helps clients manage SMI and learn to live fulfilled lives. Trial Tr. 529 and 540. Her PACT team has a client who, with their support, has maintained a job at a local furniture manufacturer, increased her credit score, and recently bought her own car. Before connecting with PACT, the client was dependent on others to get around. *See* Trial Tr. 537–38. Mr. Duren, a client who was quoted earlier in this opinion, provided heartfelt testimony about the "dramatic[]" impact Ms. Sistrunk's team has had on his life—the therapy sessions they offer, their careful preparation of "med boxes," and even the fact that they have a washer and dryer on-site. Trial Tr. 570–72.

Ms. Sistrunk has seen firsthand how her team can divert clients from hospitalization. The team has a client in his fifties who does not have any family or friends to support him. They noticed that he had become suicidal, and they were able to get him into a crisis stabilization unit for a few days. The providers at the CSU "tweaked" his medications successfully. The PACT team was there to pick him up and take him home. Prior to his connection to PACT services, this gentleman had been committed for longer stays in state hospitals because of similar suicidal symptoms. *See* Trial Tr. 540–41.

Ms. Worsham shared Dr. Crockett and Ms. Sistrunk's sentiments about the impact community-based services can have.

> I have seen amazing progress in people's recovery. . . . I have seen people when I first started there that had kind of resolved the life that I thought I had for me back in the day, that I'm

> just going to never work, nobody wants me because I'm sick, I'm going to watch TV, I'm going to play some crossword puzzles or something, and that's my life, to all of a sudden people having a desire to go back to school or own a home or get married, you know, real life things, getting into life, joining a bowling league.

Trial Tr. 326.

V.

The Experts

In many ways, this case is a battle of the experts.

A. The United States' Clinical Review Team

The United States retained six experts for its Clinical Review Team (CRT). The CRT was comprised of Dr. Drake,[24] Dr. Carol VanderZwaag,[25] Mr. Daniel Byrne,[26] Dr. Beverly Bell-

[24] Dr. Drake is a medical researcher and psychiatrist. He was admitted as an expert in serious mental illness and mixed methods research on mental health services. *See* Trial Tr. 104. His expert report was admitted as PX 404.

[25] Dr. VanderZwaag is a psychiatrist. She was admitted as an expert in psychiatry and community-based mental health services assessments. *See* Trial Tr. 373. Her expert report was admitted as PX 402.

[26] Mr. Byrne is a clinical social worker. He was admitted as an expert in clinical social work and assessments for community-based mental health services. *See* Trial Tr. 588. His expert report was admitted as PX 401.

Shambley,[27] Dr. Judith Baldwin,[28] and Ms. Burson.[29] Dr. Drake led the CRT. The United States also hired experts in other fields to assist the CRT.

Dr. Todd MacKenzie, a statistician,[30] worked with Dr. Drake to draw a randomized, stratified sample of 299 individuals (out of nearly 4,000 total) who were hospitalized at least once between October 2015 and October 2017. PX 404 at 5. Dr. Drake conducted a literature review on the state of community-based services around the country and worked with the CRT to design a study.[31] The CRT then sought to interview

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[27] Dr. Bell-Shambley is a psychologist. She was admitted as an expert in psychology, serious mental illness, and community-based mental health assessments. *See* Trial Tr. 809. Her expert report was admitted as PX 408.

[28] Dr. Baldwin is a registered nurse and a board-certified specialist in psychiatric nursing. She was admitted as an expert in psychiatric nursing, serious mental illness, and assessments for community-based mental health services. *See* Trial Tr. 949. Her expert report was admitted as PX 403.

[29] Ms. Burson is a board-certified occupational therapist. She was admitted as an expert in psychiatric occupational therapy, serious mental illness, and community-based mental health assessments. *See* Trial Tr. 1064. Her expert report was admitted as PX 406.

[30] Dr. MacKenzie was admitted as an expert in statistics and biostatistics. *See* Trial Tr. 276. His expert reports were admitted as PX 405 and PX 405A.

[31] The State argues that the CRT study is unreliable because two of the six CRT members could not identify a similar model used by other states or published in a peer-reviewed journal. Docket No. 232 at 10–11. But those two CRT members were not responsible for designing the study—*Dr. Drake* was the expert in research methods, and he testified that the system CRT used is similar to the methods he has employed in hundreds of articles he has published in peer-reviewed journals. *See* Trial Tr. 98–103 and 166; PX 404 at 5. Interestingly, the State's attorneys did not ask Dr. Drake whether he knew of any peer-reviewed studies that used a similar model.

154 of the 299 individuals in the sample. *Id.* at 1. The CRT also reviewed medical records for the 154 individuals and, in certain instances, spoke with their family members and community service providers. After the interviews and review, the CRT answered four questions for each individual:

1. Would this patient have avoided or spent less time in the hospital if reasonable community-based services had been available?
2. Is this patient at serious risk of further or future hospitalization in a state hospital?
3. Would this patient be opposed to receiving reasonable community-based services?
4. What community-based services are appropriate for and would benefit this patient?

Id. at 4. Finally, Dr. MacKenzie used a weighted analysis to draw conclusions about the population of adults with SMI. *See* Trial Tr. 296.

The experts found that "nearly all, if not all, of the 154 patients would have spent less time or avoided hospitalization if they had had reasonable services in the community."[32] Trial Tr. 107; *see* PX 405 at 5. Of the 150 persons in the sample who were still living, 149 of them (~99%) were not opposed to receiving community-based services. PX 405 at 5. And of the 122 persons who were not living in an institution during their

[32] "Reasonable community-based services" was defined as the evidence-based practices described earlier in this opinion. *See* Trial Tr. 107–08.

interview, 103 of them (~85%) were at serious risk of re-institutionalization. PX 405A.[33]

The response to the fourth question was not quantified, because it was not a "yes or no" question. Instead, the CRT described which community-based services would benefit and were appropriate for the individual. Here are some of the CRT's findings on question four:

1. Person 133, interviewed by Ms. Burson, had been admitted to a state hospital 16 times at the time of his interview. He has a work history and supportive family, and because of that support and desire to work, he would benefit from community-based services. Yet, Person 133 had never received community-based services. *See* Trial Tr. 1071–76. At the time of his interview, he was appropriate for and would have benefited from PACT, supported employment, peer support, and mobile crisis services. PX 406 at 76–80.

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[33] The State contends in its post-trial brief that these findings are not scientific. The argument, which was not presented alongside the State's other *Daubert* challenges, *see* Docket No. 148, is difficult to accept. To the extent the State's argument turns on nomenclature, it is perfectly acceptable for an expert to describe herself as a "clinician" rather than a "scientist." *See, e.g.*, Trial Tr. 487 ("I'm a clinician, and I deal with individuals."). To the extent the State's argument goes to the merits, however, Dr. Drake specifically testified that the "most scientific way to address the questions" DOJ asked was the "mixed-method approach" he used with the CRT. Trial Tr. 156. The truth is that both parties did an excellent job of not attempting to pass off unqualified testimony as expertise. The United States' experts wrote reports fully satisfying the standards of *Daubert* and Rule 702, *see Hodges v. Mack Trucks, Inc.*, 474 F.3d 188, 194 (5th Cir. 2006), then testified in accordance with those reports.

2. Person 3, interviewed by Dr. Bell-Shambley, was in an acute state at the time of his interview. He was not receiving any community-based services, nor had he after any of his three hospital admissions. *See* Trial Tr. 825–26. At the time of his interview, he was appropriate for and would have benefited from PACT, mental health therapy, and medication management. PX 408 at 19–22.

3. Person 58, interviewed by Mr. Byrne, had been in and out of state hospitals five times over a two-year span at the time of her interview. Mr. Byrne testified that she was not receiving any community-based services between hospitalizations. *See* Trial Tr. 591–93. At the time of her interview, she would have benefited from PACT and permanent supported housing. PX 401 at 25.

4. Person 46 was interviewed by Dr. VanderZwaag at the MSH. He had been admitted to the state hospital 18 times in the previous seven years and would have benefited from PACT—but had never received it. *See* Trial Tr. 414–16. At the time of his interview, he was appropriate for and would have benefitted from PACT and permanent supported housing. PX 402 at 71.

5. Person 41 was interviewed by Dr. VanderZwaag while he was living with his father. He was struggling to find work and gain financial independence. He had several prior admissions and would not show up to the CMHC for months at a time, which would lead to hospitalization. He would benefit from a service like PACT but had never received it. *See* Trial Tr. 418–21. At the time

of his interview, he also would have benefitted from permanent supported housing. PX 402 at 55.

6. Person 108, interviewed by Dr. Baldwin, was 27 years old at the time of his interview but had been hospitalized eight times in the past nine years. He would have benefited from crisis services when his symptoms became acute, particularly because he had a good grasp of his own symptoms. Without such a service, he had to rely on hospitals. *See* Trial Tr. 999–1001. At the time of his interview he was appropriate for and would have benefitted from PACT, crisis stabilization, and community support services. PX 403 at 155–56.

7. Person 132, interviewed by Ms. Burson, has a high school diploma, some college education, and a work history. He had been in state hospitals on three separate occasions. He was not receiving community-based services, but would have benefited from them because of his work history and desire to be active in the community. *See* Trial Tr. 1082–85. At the time of his interview, he was appropriate for PACT and supported employment. PX 406 at 85.

8. Person 125, interviewed by Ms. Burson, used to work as a commercial truck driver and fisherman. He has been committed to state hospitals on three separate occasions. Community-based services could have helped him avoid hospitalization but he was not receiving any such services. *See* Trial Tr. 1086–90. At the time of his interview, he was appropriate for and would have benefited from PACT and permanent supported housing. PX 406 at 25.

Dr. Drake was "surprised" to find that most of the 154 individuals the CRT reviewed did not receive the community-based services that the State claims to have in its policy manuals. Trial Tr. 105. Ms. Burson, the psychiatric occupational therapist, testified that most of the people she interviewed were not receiving any sort of community-based services. Trial Tr. 1080–81. The State's experts have offered no opinions as to why so many of the 154 were without community-based services between hospitalizations.

B. Mississippi's Clinical Experts

Mississippi, of course, hired its own experts.

The State hired a group of psychiatrists to review the medical records of patients within the sample that the CRT evaluated.[34] Those experts were Dr. Mark Webb,[35] Dr. Benjamin

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[34] The State also retained Dr. Joe Harris, a psychiatrist at South Mississippi State Hospital. Dr. Harris testified via deposition that as many as half of the people at SMSH do not need to be hospitalized. *See* Harris Dep. 26. The State has emphasized that its hospitals do not have control over who arrives at their doors because of the statutory commitment process, and should not be held accountable for the number of hospitalizations. It is a valid point. The state hospitals must take who is committed to them and have little recourse to push back, despite clinical opinions that might differ with a chancellor's determination. *See C.W. v. Lamar Cty.*, 250 So. 3d 1248 (Miss. 2018) (holding that the director of a state hospital may not refuse to admit civilly-committed patients sent for alcohol and drug therapy, even if those services are not provided at the hospital). This may be an area where DMH could advocate for a change in the commitment process and secure state hospital clinicians a right to appeal.

[35] Dr. Webb is a board-certified psychiatrist whose expert report was entered as DX 307. *See* Trial Tr. 1815. Dr. Webb, Dr. Root, and Dr. Younger practice together at the Mississippi Neuropsychiatric Clinic.

Root,[36] Dr. Ken Lippincott,[37] Dr. Roy Reeves,[38] Dr. Philip Merideth,[39] Dr. Susan Younger,[40] and Dr. William Wilkerson.[41] These experts did not conduct interviews and did not evaluate community-based services. *E.g.*, Trial Tr. 1878. Instead, they evaluated whether, based on their review of the medical records, the individuals were appropriate for care in a hospital *at the time of admission*.[42] The experts came to the same

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[36] Dr. Root is a board-certified psychiatrist whose expert report was entered as DX 306. *See* Trial Tr. 1863.

[37] Dr. Lippincott is a board-certified psychiatrist and the clinical director at North Mississippi State Hospital. He did not submit an expert report. He testified about the care he provided to the patients he evaluated. *See* Trial Tr. 1902.

[38] Dr. Reeves is a psychiatrist and the clinical director at South Mississippi State Hospital. He did not submit an expert report. His testimony was about the appropriateness of admission of those who were within his care. *See* Trial Tr. 1931.

[39] Dr. Merideth is a board-certified psychiatrist whose expert report was admitted as DX 305. *See* Trial Tr. 1987.

[40] Dr. Younger is a board-certified psychiatrist whose expert report was admitted as DX 309. *See* Trial Tr. 2116.

[41] Dr. Wilkerson is a board-certified psychiatrist whose expert report was admitted as DX 308. *See* Trial Tr. 2144.

[42] An excerpt of Dr. Webb's testimony helps show the scope of his analysis in this case:

> Q: So do you not -- you do not have an expert opinion today as to whether any of the 13 received adequate community-based mental health services. Right?
> A: That is correct. I was not provided the records.
> Q: And you don't have an opinion on whether the 13 individuals should have received additional community-based mental health services, I take it?

conclusion: all of the individuals had SMI and the hospital was the least restrictive setting at the time they were admitted. *E.g.*, Trial Tr. 1875–76.

The State's team then uniformly opined that the individuals they reviewed could not have been properly served in the community at the time of their hospitalization. Dr. Younger explained that the people she reviewed "have severity of illness to such a degree that they cannot be treated adequately in the community most of the time despite real good services, medicine, support." Trial Tr. 2119.

The State's experts also testified that the standard of care was met while in the hospital, and that discharge planning was "adequate[]." *See* Trial Tr. 1825–40 and 1990.

C. Expert Testimony on Costs and Management Issues

In addition to the experts who evaluated the 154 individuals in the sample, both sides retained experts to provide more sweeping analyses of the mental health system.

The United States called Kevin O'Brien, a healthcare consultant, who was admitted as an expert in health systems cost analyses.[43] *See* Trial Tr. 1246. Mr. O'Brien created three scenarios of what it would cost the State to expand community-based services. His conclusion was that community-based care is generally less expensive than hospitalization. PX 409 at 10. This, in large part, is due to the fact that most community-

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A: Correct. I would defer to other experts.

Trial Tr. 1841.

[43] Mr. O'Brien's expert reports were admitted as PX 409 and PX 410.

based care is Medicaid-reimbursable, while hospitalization is not.[44] *See* Trial Tr. 1584.

The State brought Dr. Lona Fowdur, a healthcare economist, to challenge Mr. O'Brien's cost analysis.[45] *See* Trial Tr. 1717. She testified that Mr. O'Brien did not account for the fixed costs associated with inpatient care, so he overstated the cost of inpatient care and underestimated the cost of community care. *See* Trial Tr. 1722. She corrected what she perceived as his errors and ultimately concluded that there is not much difference between the costs of community care and hospitalization. *See* Trial Tr. 1744; DX 301 at 4 ¶ 9 ("the average costs of each modality of care are comparable"). Dr. Fowdur nevertheless encouraged the Court to not compare the costs because patient populations in hospitals and in the community are not the same.[46] *See* Trial Tr. 1720 and 1732.

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[44] Currently, the "IMD exclusion" generally prevents state hospitals from receiving Medicaid reimbursement. The parties seem to agree that if Congress repealed the IMD exclusion, the State would have more money available for the system as a whole. *But see* Trial Tr. 1331 (describing new federal IMD waiver and explaining that the IMD exclusion has not prevented other states from shifting care to community-based services).

[45] Dr. Fowdur's expert report was admitted as DX 301.

[46] The Court must respectfully disagree, in part, with Dr. Fowdur. This case is not primarily about the population of persons at either end of the spectrum—those that will be hospitalized most of the time or those that will never be hospitalized. The testimony and exhibits showed that this case is about the significant number of persons in the middle: those who cycle repeatedly between their communities and hospitals, who could be served less restrictively with community-based services. That is where the cost comparison is most useful.

Reviewing the expert opinions, the most conservative estimate is that the costs of community-based care and hospitalization are about equal. This opinion was reiterated by Dr. Jeffrey Geller, another of the State's experts.[47] "One very good study of this showed they were about the same," he said. Trial Tr. 2409.

The parties then presented expert testimony about the management of the mental health system. Melodie Peet was the United States' systems expert.[48] Ms. Peet found that Mississippi's mental health system is not administered in a way that prevents unnecessary hospitalizations.[49] *See* Trial Tr. 1336. The theme of her testimony was that Mississippi has identified the correct community-based services, but a lack of

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[47] Dr. Geller is a board-certified psychiatrist and was admitted as an expert in psychiatry. *See* Trial Tr. 2399. In preparing his report, Dr. Geller reviewed medical records and visited each of the four state hospitals, as well as the Central Mississippi Residential Center. His expert report was admitted as DX 303.

[48] Ms. Peet was admitted as an expert in the field of mental health administration. *See* Trial Tr. 1320. To prepare her report, she conducted a literature review, visited EMSH, and met with representatives from seven CMHCs, the CHOICE housing providers, community social service providers such as Stewpot, mental health advocates, and a chancery court clerk. Her expert report was admitted as PX 407.

[49] *See* Trial Tr. 1336 ("There were three primary themes that led to that conclusion. One was the insufficiency of community services throughout the state. Second was, I would say the state still has a hospital-centric view of their system. And thirdly, there is a complete lack of coordination between the hospitals and the community systems which really means significant disruptions in care for the people who are using the system.").

effective oversight and data utilization has failed to put that system into practice. *See* Trial Tr. 1337.

One helpful illustration of the problem came when Ms. Peet compared PX 419, a map showing the home addresses of the top 30% of state hospital bed utilizers, with PX 413, a map showing where PACT teams—which she called "ACT programs"—are available. *See* Trial Tr. 1338–39. The overlay showed gaping holes in coverage. She explained that "the people represented by the red dots are the very people who are targeted as the ideal patient to be served by an ACT program. So this isn't a theoretical analysis. These are real human beings who have demonstrated by their pattern of service utilization that they would be benefited by an ACT program. And many of them are in the unserved areas of the state." Trial Tr. 1339.

Ms. Peet pointed out that the PACT program is not just unavailable for many Mississippians, but is an example of DMH's inability to use data and strategic planning to expand services. In its most recent end-of-year report, for example, DMH discussed its goal of expanding PACT utilization by 25%. *See* JX 50 at 8. The goal was conservative, and DMH did not meet it. The number of PACT users went from 328 in 2017 to only 384 in 2018. *See* Trial Tr. 1340. Ms. Peet said,

> The fact that over three years after the establishment of the last ACT program, the ACT services are still significantly under-enrolled, I would say operating at about 50 percent capacity, *while the state has been paying the rate for a fully subscribed ACT program* means a lot of things, but

> mostly that people who need the service desperately aren't getting it.

Trial Tr. 1341 (emphasis added).

This problem extends beyond PACT. Ms. Peet explained with precision how certain services are not available in certain regions, and how statewide there is a gross underutilization of available community-based services. *See* Trial Tr. 1345–46 (discussing underutilization of Medicaid billing for community support services), 1351–53 (discussing underutilization of mobile crisis services), 1354 (discussing lack of capacity for supported employment), 1354–55 (discussing lack of capacity for supported housing), and 1356–57 (discussing underutilization of Medicaid billing for peer support services).

Finally, Ms. Peet concluded that Mississippi, having already identified the correct services, is capable of changing the system to make services more available and effective. She suggested expanding community-based services statewide, actively using data to target future services, and increasing oversight of and technical assistance to providers. *See* Trial Tr. 1377–84.

In response, the State called Ted Lutterman, an expert in "policy analysis regarding the financing and the organization of state mental health systems."[50] Trial Tr. 1493. He concluded that when compared with other states in the region, Mississippi has increased its spending on community-based

[50] Mr. Lutterman's report was entered as DX 302. He used self-reported state and national data sets to compare Mississippi's use of hospitalization and community-based services to other states in the region.

services more rapidly than others.[51] *See* Trial Tr. 1509. "Between 2001 and 2015," he wrote in his report, "Mississippi nearly doubled its investment on community-based services, increasing its expenditures during this period by 98%. Only one state in the southern region, Georgia, surpassed Mississippi's rate." DX 302 at 6. This testimony suggests that Mississippi should receive credit for its growth.

Dr. Geller presented similar testimony. He said that when Mississippi's "distribution of funding" is compared to other states, "Mississippi's not an outlier." Trial Tr. 2413. Yet Dr. Geller also agreed that Mississippi has one of the highest per-capita rates of psychiatric beds in the country. *See* Trial Tr. 2425. One table he reviewed from the witness stand showed that only the District of Columbia and Missouri have higher rates of psychiatric beds than Mississippi. PX 393 at 41–42.

Dr. Geller's comparisons were not always reliable. His expert report had admonished the United States, claiming that its "assessment of Mississippi's mental health spending has no relationship to facts." Trial Tr. 2427. Dr. Geller supported that conclusion by asserting that "Mississippi was spending 19%

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[51] Mr. Lutterman also testified that when states expand Medicaid, they see a larger increase in people served by community-based services. *See* Trial Tr. 1496. Mississippi, of course, has not made such an expansion despite its high demand for Medicaid services. *See* Center on Budget and Policy Priorities, *How Would the Medicaid Expansion Affect Mississippi?*, https://www.cbpp.org/sites/default/files/atoms/files/medicaid_expansion_mississippi.pdf (last visited Aug. 23, 2019) (concluding that Medicaid expansion in Mississippi would render an additional 231,000 adults eligible for health care). The evidence nevertheless showed that Mississippi need not expand Medicaid, but can satisfy the requirements of *Olmstead* by better utilizing existing Medicaid rules. *See* Trial Tr. 1230.

of its mental health dollars on state hospitals and 80% on the community." Trial Tr. 2427. But Dr. Geller's assertion was based on the spending data for a state labelled "MI"—Michigan. Trial Tr. 2428. In truth, the data for Mississippi—"MS"—was the inverse; Mississippi was spending 77% of its mental health dollars on state hospitals and 21% on community-based care. Trial Tr. 2428; *see also* PX 395 at 15.

Finally, Dr. Geller cautioned the Court that health disparities are related to poverty, and opined that because Mississippi is a very poor state, even an increase in funds might not solve Mississippi's mental health problem. "Mississippi had one of the lowest rates of providers per capita of any state. This means that if you put in funds, you still might not get the services because you don't have the people to provide the services, that poverty, being in a rural area, lack of providers, access to services, puts Mississippi at a high ranking for poor access to services." Trial Tr. 2407.

VI.

Mississippi Is Violating the ADA

The stipulations and testimony establish the basics. Thousands of Mississippians suffer from SMI and are qualified individuals with disabilities under the ADA. The State is required to comply with Title II of that law. Yet the State's mental health system depends too much on segregated hospital settings and provides too few community-based services that would enhance the liberty of persons with SMI. The "great majority" of those Mississippians "would prefer to receive

their services in the communities where they are living." Trial Tr. 1331.[52]

Even understanding these basics, though, the sheer number of expert opinions, witnesses, and legal arguments can obfuscate whether Mississippi's system actually violates the Supreme Court's mandate in *Olmstead*. For guidance, then, it is important to return to the text of that case.

Olmstead's final holding says that "States are required to provide community-based treatment for persons with mental disabilities when" (1) "treatment professionals determine that such placement is appropriate," (2) "the affected persons do not oppose such treatment," and (3) "the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." 527 U.S. at 607. Each of these elements will be discussed in turn.

First, the treatment professionals on the CRT determined that the individuals they interviewed would be appropriate for community-based services. They described exactly which community-based services would be beneficial to the patient's current and future needs.[53] The State's experts, in

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[52] The great majority of Mississippi's hospitalized persons are also on Medicaid. *See* PX 488; Trial Tr. 2284 ("85.3% of women in the [MSH] receiving unit [have] Medicaid or Medicaid plus another form of insurance.").

[53] The State complains that none of the CRT members splintered their findings on the first question: would the individual have avoided hospitalization *or* spent less time in a hospital. The State observes that avoiding hospitalization and spending less time there are two different things. That is true. But the way the CRT designed question one is consistent with

contrast, limited their review to the hospitalizations of the past. They did not address whether the individuals are presently suited for community-based services. In other words, they answered a question about the past despite this being a case about the past *and* the future. They did not refute the CRT's findings on this element of *Olmstead*.

Second, the CRT found that everyone they interviewed, except for one individual, was not opposed to treatment in the community. The State's experts never addressed this question and did not refute the CRT's findings on this point.

Third, the United States' experts showed that providing community-based services can be reasonably accommodated within Mississippi's existing mental health system. Ms. Peet testified that the State already has the framework for providing these services, and can more fully utilize and expand that framework to make the services truly accessible. The State's experts did not refute this testimony. While they testified that Mississippi is doing well when compared to others in the region, that is not the applicable standard. And the State's own experts admitted that institutional and community care cost the system the same amount of money, so the State cannot claim that the resources are not available or that the costs constitute an unreasonable accommodation.

Overall, when the evidence is evaluated under the precise standard set forth in *Olmstead*, the United States has proven

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Olmstead. Community-based services are a less-restrictive environment than state hospitals, and therefore are appropriate if they can help persons with disabilities avoid or minimize hospitalization.

that Mississippi's system of care for adults with SMI violates the integration mandate of the ADA.

VII.

Mississippi's Defenses

A state is excused from having to make reasonable modifications if it "can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7)(i).

Mississippi argues that the United States' proposed modifications would "fundamentally alter" the nature of its mental health system. Docket No. 232 at 64. Under *Olmstead*, the State has the burden "to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental [illness]." 527 U.S. at 604.

The Supreme Court has explained that one way a state can take advantage of this defense is by demonstrating "*a comprehensive, effectively working plan* for placing qualified persons with mental [illness] in less-restrictive settings, and a waiting list that moved at a reasonable pace." *Id.* at 605–06 (emphasis added). A sufficient plan is one that "set[s] forth reasonably specific and measurable targets for community placement" and demonstrates a "commitment to implement" its terms. *Frederick L. II*, 422 F.3d at 158 (rejecting Pennsylvania's fundamental alteration defense).

DMH's senior executives testified that Mississippi does not have such a plan. Deputy Executive Director Steven Allen, a 30-year veteran of DMH, said he had never seen an *Olmstead*

plan at DMH. He added that even if he had, it would be "useless." Trial Tr. 2025. Executive Director Diana Mikula, a 24-year veteran of the agency, defended her deputy by claiming that he would not need to read an *Olmstead* plan in his job because "he knew the vision." Trial Tr. 2381. Somewhat confusingly, she then claimed that DMH's *Olmstead* plan is "a collection of documents" such as annual strategic plans and budget requests—documents that Mr. Allen *has* read. *See* Trial Tr. 2316–17 and 2381.

This latter testimony was not persuasive. In the two-and-a-half years Mr. Allen has served as Deputy Executive Director, he has been "in charge of the programmatic responsibilities of the agency, whether it be the programs [it] directly operate[s] that provide services, or through the grants or the certification process, those divisions and bureaus." Trial Tr. 2025. If he has never seen an *Olmstead* plan at DMH, this Court is inclined to believe him, since he has the longest tenure of the executives and is in the best position to know.

Ms. Mikula's eagerness to defend her staff, her agency, and to some extent herself is understandable. But it would be very odd for Mr. Allen, a person whose judgment she trusts, and a person with substantial experience in the mental health field, to be unaware that the strategic plans and budgets he reviews are, in fact, an *Olmstead* plan. It is more likely that DMH simply lacks an *Olmstead* plan.

In any event, the Court also cannot accept the alternative suggestion—that any plan Mississippi has is "comprehensive" and "effective[]." *Olmstead*, 527 U.S. at 605–06. A collection of smaller, routine documents is hardly "comprehensive." And the evidence discussed above showed that the existing

documents are not effectively meeting the State's own goals. Among other examples, PACT planned to expand over 2017-2018 and failed to meet its modest goal; supported employment is below the level DMH recommended in 2011; and despite the State's best intentions about shifting from hospitalization to community-based care, the number of state hospital beds has been stable since 2014.

If a comprehensive, effective plan would satisfy *Olmstead*, Mississippi's scattered, ineffective assemblage of documents cannot.

The State's attorneys then press that the cost of community-based services is itself a fundamental alteration. But as already mentioned, by the admission of its own experts, community-based services and hospitalization cost the system approximately the same amount of money, though community-based services receive federal Medicaid reimbursement that hospitalization does not. The worst case is that the State would spend the same amount of money it does now—just redirected to more cost-effective services. The best case for the State is that the movement from hospitalization to community-based services would save money.

The case law further weakens the State's argument. The weight of authority indicates that "budgetary constraints alone are insufficient to establish a fundamental alteration defense." *Pa. Prot. & Advocacy, Inc. v. Dep't of Pub. Welfare*, 402 F.3d 374, 380 (3d Cir. 2005) (collecting cases); *see also M.R.*, 697 F.3d at 736; *Frederick L. v. Dep't of Pub. Welfare (Frederick L. I)*, 364 F.3d 487, 495 (3d Cir. 2004); *Fisher*, 335 F.3d at 1183 ("If every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the

ADA's integration mandate would be hollow indeed."). "Congress and the courts have recognized that compliance with *Olmstead* may require 'substantial short-term burdens, both financial and administrative' to achieve the goal of community integration." Dinerstein & Wakschlag, *supra* note 4, at 951 (citations omitted).

For these reasons, Mississippi has not proven an affirmative defense.

VIII.

Moving Forward

People living with SMI face very real, and sometimes very dangerous, symptoms that can make daily life extraordinarily difficult. With those individual challenges comes a system that, even in its best form, will have problems.

As the State has pointed out, at no point during the four weeks of trial was any expert willing to parade their home state as an example of a mental health system without flaws. States from every corner of the country have struggled to provide adequate mental health care services. Mississippi has its own unique challenges due to its rural nature and limited funding.[54]

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[54] The themes that emerged in this trial have been repeated in a variety of legal challenges to Mississippi's large institutions. It is obvious that low-paying, dangerous, and difficult jobs are often hard to fill. *See generally Dockery v. Fisher*, 253 F. Supp. 3d 832, 840 (S.D. Miss. 2015) (alleging, in part, that constant staffing shortages have contributed to constitutional violations at privately run prison); *Olivia Y. v. Bryant*, No. 3:04-CV-251-TSL-FKB, Docket 570 at 41 (S.D. Miss. June 29, 2012) (in case alleging systemic deficiencies in the State's foster care system, a follow-up Monitor's report explains, "[a]s described in the Monitor's prior reports, persistent staffing

Despite all of these challenges, the people that care for Mississippians suffering from SMI should be recognized for their efforts to expand community-based care. The State has made some strides. Part of the difficulty of this case is to simultaneously acknowledge that progress and ensure that community-based services ultimately live up to DMH's promises. The fact remains that neither Congress nor the Supreme Court have made a state's good intentions a defense to an *Olmstead* claim. "General assurances and good-faith intentions . . . are simply insufficient guarantors in light of the hardship daily inflicted upon patients through unnecessary and indefinite institutionalization." *Frederick L. II*, 422 F.3d at 158–59.

Perhaps the central difficulty of this case is the question of time. What timeline for expanding community-based services might constitute a reasonable accommodation? The State

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deficits have compromised defendants' ability to satisfy certain key Settlement Agreement requirements. . . . [U]nderstaffing has affected both the pace at which the practice model can be implemented and whether implementation efforts are effective."); *Depriest v. Walnut Grove Correctional Auth.*, No. 3:10-CV-663-CWR-FKB, 2015 WL 3795020, at *15 (S.D. Miss. June 10, 2015) (finding, in case regarding violations of the Eighth Amendment at State-run prison, that "Walnut Grove continues to have a problem with understaffing, a condition linked to staff resignations and terminations. The Court understands the challenge of retaining employees given the salaries offered and the dangers that the job presents. . . . Regardless, being adequately staffed is imperative to Defendants providing a reasonably safe environment."). The evidence demonstrated that state mental hospitals face these same staffing difficulties. It should come as no surprise that when the State underfunds its large systems, whether schools, social service agencies, prisons, or mental health providers, the systems become ripe for constitutional violations. If it remains uninterested in fixing this problem, the State will be doomed to repeat it—and repeatedly have to defend it in federal court.

argues that no timeline at all should be imposed—it is getting there and should be left alone to do the job.

The problem is that the State has known for years that it is over-institutionalizing its citizens. Eleven years ago, the Mississippi Legislature's PEER Committee found that "[a]lthough the mental health environment in the United States has dramatically changed from an institution-based system to a community-based system in recent years, Mississippi's mental health system has not reflected the shift in service delivery methods." PX 363 at 1. Eight years ago, the United States Department of Justice released a comprehensive findings letter and started what would ultimately be five years of fruitless negotiations. DMH's long-range strategic plan for 2010-2020 declared a goal of "creating a community-based service system," but testimony showed that it was not until 2018 that the Department first moved money from hospitals to community services. *Compare* JX 63 at 7 *with* Trial Tr. 1418. No, the history of this case shows that DMH's movement toward community-based services has only advanced alongside the United States' investigation and enforcement litigation.

This Court is keenly aware of the judiciary's limitations in a systems case such as this. A mental health system should be run by experts and overseen by state officials who respect the law. The only role of this Court is to consider whether Mississippi's mental health system is operating in compliance with that law. The weight of the evidence proves that it is not. The United States has met its burden and shown that despite the State's episodic improvement, it operates a system that unlawfully discriminates against persons with serious mental illness. That discrimination will end only when every

Mississippian with SMI has access to a minimum bundle of community-based services that can stop the cycle of hospitalization.

Since the United States has proven its case, the Court could order the remedy proposed at trial by the Department of Justice and its experts. Acknowledging and understanding the complexity of this system, the progress that the State has made, and the need for any changes to be done in a patient-centered way that does not create further gaps in services for Mississippians, however, the Court is not ready to do so. The Court is hesitant to enter an Order too broad in scope or too lacking in a practical assessment of the daily needs of the system. In addition, it is possible that further changes might have been made to the system in the months since the factual cut-off.

This case is well-suited for a special master who can help the parties craft an appropriate remedy—one that encourages the State's forward progress in a way that expedites and prioritizes community-based care. The evidence at trial showed what the State needs to do. The primary question for the special master is how quickly that can be done in a manner that is practical and safe for those involved.

The parties are therefore ordered to submit, within 30 days, three names of potential special masters and a proposal for the special master's role. A hearing will be held this fall. The proposals and lists may be separate, but the parties should confer prior to that date to see if there might be any agreed-upon candidates respected, competent, and neutral enough to do the job.

This has been a long process. The parties have put nearly a decade's worth of work into this matter. There has been "a lot of talk," "a lot of planning," and "a lot of people . . . hurt in the process." Trial Tr. 348. But the Court is optimistic that the parties can achieve a system that provides Mississippians struggling with mental illness "the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, [and] the opportunity to blend fully and equally into the rich mosaic of the American mainstream."[55]

SO ORDERED, this the 3rd day of September, 2019.

s/ CARLTON W. REEVES
United States District Judge

[55] President Bush, *supra* note 2.

Capacity Assessments in California Conservatorship Proceedings

Improving Clinical Practices and Judicial Procedures to Better Protect the Rights of Seniors and People with Disabilities

A Report to the Chief Justice, Governor, and Legislature

Thomas F. Coleman
Legal Director
Spectrum Institute

July 1, 2020

https://spectruminstitute.org/capacity/

Contents

About Spectrum Institute

Spectrum Institute is a nonprofit operating foundation incorporated in California in 1987. It has tax exempt status under section 501c3 of the Internal Revenue Code. Through research, education, and advocacy, the organization promotes justice, equal rights, and respect for human diversity. Over the years, Spectrum Institute has championed a variety of human rights issues and causes: protecting the right of personal privacy; combating hate crimes against sexual minorities; promoting respect for family diversity; challenging discrimination on the basis of marital status and sexual orientation; stopping the abuse of teenagers by boarding schools and boot camps; promoting risk reduction and developing effective responses to the physical, sexual, and emotional abuse of people with intellectual and developmental disabilities; and advocating for systemic reforms to the probate conservatorship system in California and the adult guardianship systems in other states.

About the Report

This report is the culmination of 15 months of research, writing, and collaboration. Likely the most comprehensive study ever done on state standards and assessment practices involving decision-making capacities, the report offers dozens of recommendations to officials in California to improve this area of the law. Current legal standards and capacity assessment practices are sorely outdated. Seniors and adults with intellectual and developmental disabilities deserve to have their rights protected by judges, attorneys, and professionals who are involved in legal proceedings that place their freedoms at risk based on allegations of incapacity. This report documents deficiencies in current policies and practices and provides recommendations to address those deficiencies. It gives public officials the information they need to make the necessary adjustments to ensure that such legal proceedings comply with the requirements of due process and are conducted in a manner consistent with state and federal laws prohibiting discrimination on the basis of disability.

About the Author

Thomas F. Coleman is the founder of Spectrum Institute and serves as its legal director. The primary focus of his 47-year career as an attorney has been improving the administration of justice and securing equal rights for disadvantaged populations. In addition to his advocacy in state and federal courts and his lobbying efforts in Congress and state legislatures, Coleman has written numerous public policy reports on a wide range of topics involving access to justice and the protection of civil and constitutional rights.

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REVIEW

By Cheryl Mitchell, J.D.

Capacity Assessments in California Conservatorship Proceedings

Improving Clinical Practices and Judicial Procedures to Better Protect the Rights of Seniors and People with Disabilities

By Thomas F. Coleman, Legal Director, Spectrum Institute
Released July 1, 2020 / https://spectruminstitute.org/capacity/

Spectrum Institute and Thomas F. Coleman have done a masterful job of researching and writing *Capacity Assessments in California Conservatorship Proceedings*. This report is replete with citations to legal authorities, as well as actual examples of conservatorship cases gone awry. Its recommendations establish a clear and concise path that can be used to significantly improve the current conservatorship system.

This report is a must-read for anyone who wants to have a better understanding of why the current conservatorship system is broken and the steps that must be taken to improve it. Those who suffer under the current system frequently find themselves without redress to the courts and they may find themselves stripped of all their constitutional rights — including the right to vote. As is made clear in this report, without the right to vote, conservatees are deprived of their right to help elect their representatives and to have a voice in legislative changes that might improve the conservatorship system.

Spectrum Institute has demonstrated that it is a powerful and persuasive advocate for those who have been deprived of their legal rights without adequate due process and in violation of the Americans with Disabilities Act. This report makes it abundantly clear that there has been a massive failure of the courts, the legislature and the executive branch to implement rules to explore and put in place less restrictive alternatives to conservatorship.

While this report focuses on California, it can be used as a model in other states as well. The improvement of the legal process for those with physical or mental disabilities or cognitive impairments should be of paramount concern for everyone who believes in a fair and impartial system of justice.

About Cheryl C. Mitchell

Cheryl Mitchell received her BA in psychology from George Mason University; her MPA from Golden Gate University and her law degree from the McGeorge School of Law. She is an elder law attorney in Spokane, Washington, having been in practice for thirty-five years. Cheryl and her husband, Ferd H. Mitchell, are partners and authors of seven volumes of *Washington Practice* – a series of books on Washington State law for attorneys. They are authors of four volumes of *Methods of Practice,* two volumes on elder law and one volume on Washington probate and practice. *Washington Practice* is published by Thomson Reuters WestLaw, the largest publisher of legal books in the nation. Cheryl and Ferd developed the Care Management Trust as an alternative to guardianship.

Cheryl has participated in approximately 100 adult guardianship proceedings in Spokane County, Washington. She has been appointed and served as a guardian for several individuals. Cheryl has represented petitioners in guardianship cases, has served as a guardian ad litem, and has represented alleged incapacitated persons who opposed having a guardian. She has successfully argued for less restrictive alternatives to guardianship in several cases. Cheryl has lectured on guardianship at various continuing legal education programs over the years.

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REVIEW

By Sam Sugar, M.D.

Capacity Assessments in California Conservatorship Proceedings

Improving Clinical Practices and Judicial Procedures to Better Protect the Rights of Seniors and People with Disabilities

By Thomas F. Coleman, Legal Director, Spectrum Institute
Released July 1, 2020 / https://spectruminstitute.org/capacity/

Why is America's guardianship system so badly broken? Why have advocates across the country been able to document thousands of cases of egregious abuse, neglect and exploitation of vulnerable elderly citizens conscripted into guardianship purgatory? Why hasn't any branch of government been responsive to the torrent of legally valid complaints arising from abuse of the state-based guardianship machine?

Answering these questions requires a deep dive into the origins and roots of the system and why it has become a stain on our country.

Spectrum Institute's report, written by Tom Coleman, is a tour de force. *Capacity Assessments in California Conservatorship Proceedings* is a landmark document. It offers a sobering and cogent analysis of how this "system" intended to assist those in need has instead become a tool of government overreach.

Since appeals by wards/conservatees almost never occur, justices of the Supreme Court and Court of Appeal are generally clueless about the countless failings of their own broken system which they are, nonetheless, charged to manage.

As just one glaring example of the courts' failure to manage itself, theoretically, current law in many states clearly favors the use of alternatives to conservatorship. But in practice, viable less invasive and less costly alternatives like supported decision-making are almost never seriously explored by court appointed attorneys, court investigators, and judges.

As Coleman states "*Judges and attorneys in California should move away from doing what is expedient and instead do what is statutorily and constitutionally required. Less restrictive alternatives should be investigated and evaluated with due diligence*."

Coleman documents many blatant deficiencies in California's system. Seeing them so clearly laid out, eloquently explained, and thoroughly documented, raises the question of why the judiciary with its unparalleled latitude and resources has been unable, or more likely unwilling, to recognize the urgency of correcting this long-standing abuse of power.

Until the status quo is no longer tolerated and these courts are held accountable for their actions, closely monitored, and the solutions put forth by Coleman are enacted, there will continue to be a great need for guardianship advocacy to expose the danger faced by any vulnerable individual who grows old in America.

Kudos to Tom Coleman for this outstanding effort.

Sam J. Sugar, M.D. is a board-certified specialist in internal medicine residing in Hollywood, Florida. He is the founder and director of Americans Against Abuse Probate Guardianship. Dr. Sugar has been extensively published and quoted in the media on his activism against probate guardianship elder abuse and has been instrumental in developing and passing guardianship reform laws in Florida. He is a frequent lecturer and contributor to social media on the subject of abusive guardianship.

Dr. Sugar is the author of *Guardianship and the Elderly: The Perfect Crime*. (2018) The book is designed to explain the guardianship process clearly and make the reader aware of the common violations carried out by court insiders and their affiliates.

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July 1, 2020

Hon. Tani Cantil-Sakayue
Chief Justice of California / Chairperson of the Judicial Council
350 McAllister Street
San Francisco, CA 94102

Re: *Capacity Assessments in California Conservatorship Proceedings*
A Report to the Chief Justice, Governor, and Legislature

Dear Chief Justice / Madam Chairperson:

The enclosed report is being sent to you in your administrative capacity as Chief Justice of the California Supreme Court and as Chairperson of the California Judicial Council. Please share this report with members of both of these entities since some of its recommendations are directed to each of them.

The people of the State of California will be celebrating Independence Day on July 4. Independence has great meaning not only for a nation such as the United States of America, but also for the individuals who collectively form and govern it. Having said that, there are tens of thousands of seniors and people with developmental and other disabilities in California who are not in a position to celebrate their independence. These individuals lost their personal autonomy when superior court judges entered orders taking away many of their freedoms. Thousands of others whose cases are in pre-adjudication stages also have no grounds for celebration. Their cherished liberties have been placed in jeopardy with no guarantee they will receive access to justice during the legal process.

The issue of legal capacity for decision-making forms the very foundation on which the probate conservatorship system rests. Unfortunately, the enclosed report – based on 15 months of analysis of constitutional requirements, statutory standards, and judicial, legal, and professional practices – shows this foundation to be fundamentally flawed. Current capacity assessment standards and practices need a thorough review by officials in all three branches of state government.

Recommendations in the report have been made to guide state officials on ways to bring this foundational aspect of the conservatorship system into conformity with the requirements of due process and the mandates of state and federal nondiscrimination laws. We urge you, the governor, and leaders in the legislative branch to take the necessary actions to bring about such a result.

Respectfully,

Thomas F. Coleman
Legal Director

cc: Governor Gavin Newsom
Assembly Speaker Anthony Rendon; Senate President Pro-Tem Toni Atkins

Disability and Guardianship Project
1717 E. Vista Chino A7-384, Palm Springs, CA 92262
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July 1, 2020
Governor Gavin Newsom
Attn: Ms. Ana Matosantos
1303 10th Street, Suite 1173
Sacramento, CA 95814

Re: *Capacity Assessments in California Conservatorship Proceedings*
A Report to the Chief Justice, Governor, and Legislature

Dear Governor Newsom:

With this letter we are transmitting to you the above-entitled report. The report is also being sent to leaders in the other two branches of government.

This report is intended to assist the State of California in developing ways to improve clinical practices and judicial procedures to better protect the rights of seniors and people with disabilities in probate conservatorship proceedings. The enclosed letter to the Chief Justice provides additional context to current shortcomings in these proceedings and the need to adopt major reforms.

There is a role for you as governor and for several executive branch agencies and departments under your supervision to play in this reform process. We, therefore, urge your legal affairs secretary to review the report and for your cabinet secretary to share it with the following officials: Director of the Department of Developmental Services and the Secretary of the Health and Human Services Agency; Director of the Department of Fair Employment and Housing and the Secretary of the Business, Consumer Services and Housing Agency; and the Director of the Department of Aging. Because several recommendations in the report will require new legislation to be passed, we also encourage your legislative affairs secretary to review the report.

We would be pleased to have conversations with your staff or with the above-mentioned department directors or agency secretaries about how to best implement the recommendations in this report.

Respectfully,

Thomas F. Coleman
Legal Director

cc: Chief Justice Tani Cantile-Sakauye
Assembly Speaker Anthony Rendon
Senate President Pro-Tem Toni Atkins

Disability and Guardianship Project
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July 1, 2020

Hon. Anthony Rendon, Assembly Speaker
State Capitol, Room 219
Hon. Toni Atkins, Senate President Pro Tem
State Capitol, Room 205
Sacramento, CA 95814

Re: *Capacity Assessments in California Conservatorship Proceedings*
A Report to the Chief Justice, Governor, and Legislature

Dear Speaker and President Pro Tem:

With this letter we are transmitting the above-entitled report to the Legislature. The report is also being sent to leaders in the other two branches of government.

This report is intended to assist the State of California in developing ways to improve clinical practices and judicial procedures to better protect the rights of seniors and people with disabilities in probate conservatorship proceedings. The enclosed letter to the Chief Justice provides additional context to current shortcomings in these proceedings and the need to adopt major reforms.

There is a major role for the Legislature to play in this reform process. The report recommends the passage of seven pieces of new legislation. We, therefore, encourage you to share the report with the most relevant legislative committees and special committees.

In the Assembly, the report should be reviewed by members and staff of the following standing committees: Judiciary; Aging and Long Term Care; Human Services. It should also be reviewed by the Select Committee on Intellectual and Developmental Disabilities.

In the Senate, the report should be reviewed by members and staff of the following standing committees: Judiciary; Health; Human Services. It should also be reviewed by the Select Committee on Mental Health.

We would be pleased to have conversations with the chairpersons and staff of these committees and select committees about crafting legislation to implement the recommendations in this report.

Respectfully,

Thomas F. Coleman
Legal Director

cc: Chief Justice Tani Cantile-Sakauye
Governor Gavin Newsom

Prologue

In response to a series of articles published by the Los Angeles Times in 2005 exposing rampant abuses in the probate conservatorship system, the legislative and judicial branches of government initiated investigations.

After some oversight hearings were conducted, an Assembly report found that probate conservatorship proceedings were operating in a "closed system" that had allowed abuses to go undetected for too long. That same closed system exists today.

Chief Justice Ronald George responded to the newspaper stories by convening a Probate Conservatorship Task Force in January 2006. Taking testimony, consulting experts, and reviewing records, members studied the conservatorship system for 18 months. A report was issued – mostly focusing on seniors in general conservatorships of the person or estate – that was very unflattering to the conservatorship system and those who operate it.

The report described a system that was out of control. A subsequent report acknowledged that the Judicial Council did not have basic data about probate conservatorships because there was no statewide case management system in place. This problem continues today.

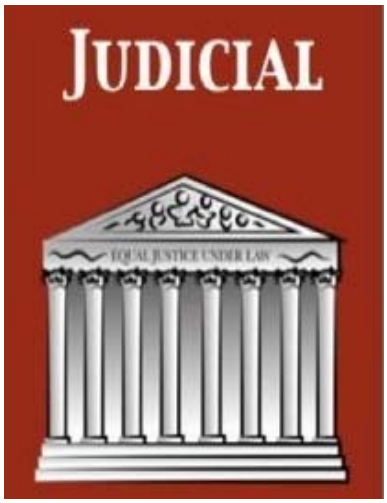
The regular involvement of an executive branch agency in legal proceedings brings a degree of accountability to the judicial system. Unlike an individual litigant who is involved in one case only, an agency may be involved in scores of cases and therefore can monitor what is systematically occurring in those cases. This routinely happens in criminal and child welfare proceedings. It also occurs in mental health conservatorships. Unfortunately, that source of accountability is generally lacking in probate conservatorship cases.

The information that appears above is taken from an amicus curiae brief filed by Spectrum Institute in a conservatorship case under review by the California Supreme Court. Much of the brief calls the court's attention to the broken conservatorship system – one in which the actions and inactions of unaccountable judges and attorneys determine the fate of thousands of seniors and people with disabilities each year.

This report focuses on one part of probate conservatorship proceedings – a part that should be at the core of each case and which should be handled with the utmost professionalism and concern for due process. That part is the capacity assessment process.

If this part of conservatorship proceedings were to be done properly – following statutory directives and constitutional imperatives – the rest of the process would improve and just results would occur more frequently. But in order for that to happen, government officials who are responsible for how conservatorship cases are processed would have to acknowledge deficiencies in policy and practice and then take steps to address them.

The Legislature has established the policies under which the conservatorship system operates. It also funds most aspects of the system. The chairpersons of the judiciary committees in the Assembly and Senate are the legislative leaders who could hold hearings to identify systemic deficiencies in conservatorship proceedings and solicit testimony for improvements in conservatorship policies and practices. The chairpersons of the fiscal committees of both chambers are the key legislators who can identify funding deficiencies that contribute to a lack of due process or unjust results for seniors and people with disabilities whose lives are upended by these proceedings.



The Chief Justice leads the judicial branch. She presides over the Supreme Court which promulgates rules of ethics for judges and rules of professional conduct for attorneys. With her leadership, the Supreme Court could modify these rules to address some of the major deficiencies in conservatorship proceedings. The Chief Justice is also the chairperson of the Judicial Council. That body promulgates procedural rules for legal proceedings, including conservatorship proceedings, and adopts standards for judicial education. With leadership from the Chief Justice, the Judicial Council could adopt new rules and standards to address many of the deficiencies in judicial practices that occur all too frequently in probate conservatorship proceedings.

The Governor is in charge of the executive branch. Departments in that branch are mostly missing in action when it comes to helping seniors and people with disabilities get a fair shake in conservatorship proceedings. That can be changed. The Governor could direct several state entities to become more involved in protecting the rights of conservatees and proposed conservatees. There is much that could be done by the Department of Aging, Department of Developmental Services, Department of Consumer Affairs, the Department of Fair Employment and Housing, and Department of Social Services. These actions could be coordinated by the Health and Human Services Agency and the Business, Consumer Services, and Housing Agency.

This report calls on officials in all three branches to study this report and formulate actions to improve the conservatorship system, including the capacity assessment process.

Foundational Considerations

1. Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. (Article 12, United Nations Convention on the Rights of Persons with Disabilities.)

2. People with developmental disabilities have the same constitutional rights as all other citizens and residents of California, including the right to make choices in their own lives. (Cal. Welf. & Inst. Code § 4502.)

3. There shall exist a rebuttable presumption affecting the burden of proof that all persons have the capacity to make decisions and to be responsible for their acts or decisions." (Cal. Prob. Code § 810.)

4. Since probate conservatorship proceedings place fundamental liberties at risk, proposed conservatees are entitled to due process of law in these proceedings. (*Conservatorship of Sanderson* (1980) 106 Cal.App.3d 611.)

5. Government actions that infringe fundamental constitutional rights must not only serve a compelling state interest, they must use the least restrictive means to achieve the intended goal. (*R.A.V. v. St. Paul* (1992) 505 U.S.377.)

6. A conservatorship is not allowed unless the court makes an express finding that the granting of the conservatorship is the least restrictive alternative needed for the protection of the conservatee. (Prob. Code § 1800.3, subd. (b).)

7. The Americans with Disabilities Act applies to guardianship proceedings. The need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity. Guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective. (2018 Policy Statement, National Council on Disability.)

8. Probate conservatorship proceedings operate in a "closed system" that allows abuses to go undetected. (AB 1363, Assembly Floor Analysis, Jan. 25, 2006.)

9. The Judicial Council does not have data on probate conservatorships because there is no statewide case management system in place. (Probate Conservatorship Task Force, Final Report, Sept. 18, 2007.)

10. Self-examination is difficult and often risky. Nonetheless, it is essential for reasoned progress. A recent national survey commissioned by the American Bar Association (ABA) Commission on Law and Aging notes that basic guardianship data is unavailable, "offering courts, policymakers, and practitioners little guidance for improving the system." Policymakers are unable to make informed policy and practice decisions without an adequate knowledge base of what exists and what trends are evident. (Judge David Hardy, Second Judicial District Court, Washoe County, Nevada.)

Preface

I was first introduced to the probate conservatorship system in California when I was asked to become involved in a case where a conservatee with intellectual and developmental disabilities was allegedly being abused by conservators who were his parents. Although adult protective services and law enforcement initially intervened, the probate court failed miserably to protect the man, whom I refer to as "Mickey."

After an autopsy was done, the coroner concluded that the manner of Mickey's death was inconclusive, implying that further investigation by law enforcement or other agencies was necessary to determine whether the conservators had been negligent. Neither the probate court nor the sheriff did a follow-up investigation. The manner of his death remains an unsolved puzzle to this day. However, several pieces of the puzzle suggest that his medical care was quite deficient.

Although aspects of Mickey's case were inconclusive, my interviews of family members and review of records caused me to believe that the probate court judge was not diligent in protecting Mickey even though he was a person under the court's "protection." I also came to believe that the attorney appointed by the court to investigate and make recommendations did not represent Mickey effectively. Had the attorney done a thorough investigation or had the court accepted the recommendation of the court investigator to remove Mickey from the allegedly abusive home environment, I believe Mickey might be alive today.

My involvement in Mickey's case was in 2012. In the following two years, I was asked to intervene in two other conservatorship cases. Each of these matters involved young men with autism. I thoroughly investigated each case and in both instances I found judges who were violating the constitutional rights of these men and appointed attorneys who were providing woefully deficient legal services.[1]

The pattern in these cases made me wonder whether these were isolated instances of judicial abuses and attorney malfeasance or whether there was something systemically wrong with the probate conservatorship system. Were there policy deficiencies at the state level? Was there a pattern and practice of judges and attorneys failing to follow statutory mandates as they processed these cases at the local level? Or perhaps both problems existed.

With these questions in mind, I decided to embark on an investigative journey – one that began in 2014 and continues to this day. I have researched California state laws pertaining to probate conservatorship proceedings. I have looked into how due process

protections and nondiscrimination laws apply to conservatorship cases.

I have read numerous law review articles and other professional publications that address and analyze the ways in which state guardianship systems *should* operate. I have conducted audits of dozens of conservatorship cases in the Los Angeles County Superior Court to determine how cases are handled in actual practice by judges and appointed attorneys. I have submitted many administrative records requests and have reviewed the court documents that were produced. I have interviewed many individuals who have participanted in these proceedings.

I have also attended many training seminars for court-appointed attorneys to learn firsthand what they were being told to do or not do by the presenters, many of whom were the judges before whom these attorneys appear in court and on whom they rely for financial payments and a steady stream of income.

Based on this ongoing research, I have written policy reports[2], filed complaints,[3] published commentaries,[4] reached out to public officials, and attended meetings of several state and local agencies.

My legal research, factual investigations, and case audits have caused me to conclude that the probate conservatorship system is badly broken. It has been for many years. My conclusions are consistent with those made by a Probate Conservatorship Task Force convened by the Chief Justice in 2006 and by legislative reports arising out of oversight hearings around the same time. Most of the recommendations made by the task force and the legislative reports have never been implemented.

The probate conservatorship system lacks accountability.[5] There are almost never any appeals by conservatees, mostly because they don't know how to appeal and when they have attorneys the attorneys won't appeal since they themselves have participated in the violation of their client's rights. As a result, California's appellate courts rarely have an opportunity to see how seniors and people with disabilities are routinely being denied access to justice.

The Judicial Council has taken little action to reform the system, despite its authority to do so through court rules, even though it has been informed repeatedly about systemic flaws and a pattern of injustices. Likewise, the current Chief Justice has not lent the prestige and power of her office to stimulate reform, much less probe into the problem. The State Bar has not engaged in any pro-active measures to deal with systematic deficiencies in legal services for conservatees and proposed conservatees.

There is no agency in the executive branch with clear authority to investigate or remedy legal abuses by judges and attorneys in probate conservatorship proceedings. There is one exception, and that is the Fair Employment and Housing Department which has authority to investigate violations of the Americans with Disabilities Act by judges and court-appointed attorneys. This jurisdiction is conferred on DFEH by Government Code Section 11135. However, despite having this authority, and despite receiving requests to conduct investigations, DFEH has yet to investigate any of these problems.

The Legislature conducted what was called an "oversight hearing" in 2015, but declined to take testimony on or review the problems mentioned above.

It is with this background in mind that this investigation into the capacity assessment process was initiated. The issue of incapacity is at the core of the probate conservatorship system. It is only when a proposed conservatee lacks the functional capacity to make decisions regarding basic life necessities that a conservatorship proceeding arises. It is only when no less restrictive alternative than a conservatorship will suffice to protect a proposed conservatee that an order of conservatorship should be entered.

Even though the Legislature clearly intended capacity assessments to be a central focus of both general and limited conservatorship proceedings – a function in which judges and appointed attorneys would play a central role – the reality is that capacity assessments are not occurring as legislatively intended or as constitutionally required.

Why is this so? It is because the probate conservatorship system lacks accountability. Because judges with overloaded dockets are not inclined to appoint experts or conduct evidentiary hearings that will further clog their dockets. Because attorneys in low-fee cases are not inclined to delve into the issue of capacity and those in high-fee cases often ignore less restrictive alternatives that would keep an individual out of probate court altogether.

As this report explains, the issue of legal capacity to make decisions has evolved over many decades. What was once considered an all-or-nothing matter and what was previously based on a psychiatric diagnosis is now more nuanced. The standard of preponderance of evidence has been replaced by that of clear and convincing evidence. Recognition that liberty interests are jeopardized in these cases has caused courts to declare that conservatees are entitled to due process of law. The capacity assessment process must be fundamentally fair.

Courts are just now grudgingly acknowledging that disability nondiscrimination laws apply to conservatorship proceedings. The ADA requires that the capacity assessment

process ensure that the individuals being evaluated have effective communication and meaningful participation in the process. Judges, lawyers, and mental health professionals must learn how to make the process accessible to people with cognitive and communication disabilities.

The Chief Justice was recently informed that the deficiencies in California's conservatorship system were exposed on a world stage. They were brought to the attention of hundreds of delegates from all parts of the globe at the World Congress on Adult Guardianships in 2018. Once a leader in protecting civil rights, California has been left behind by dozens of nations that have revamped their guardianship systems to bring them into conformity with the requirements of the United Nations Convention on the Rights of Persons with Disabilities. California officials have yet to embrace the principles on which this treaty is based or to consider how the conservatorship system should be adjusted to incorporate them.

This report and recommendations are intended to call attention to evolving standards of capacity and incapacity, international trends, best practices recommended by professional associations, federal and state constitutional considerations, and the applicability of disability nondiscrimination laws to conservatorship proceedings and capacity assessments.

Even though no specific state official has administrative responsibility to ensure that the probate conservatorship system, and the capacity assessment process within that system, are informed by international trends and comply with federal and state constitutional mandates, the State of California as public entity does have this obligation.

There are opportunities for leadership. The Chief Justice could ask the California Judicial Council to direct superior courts to cooperate with surveys and workgroups examining ways to improve conservatorship proceedings. Having centralized data on individuals and assets under conservatorships would be a good start. The Governor could create a task force and direct the Department of Aging and Department of Developmental Services to participate in a reform inquiry. The Legislature could hold public hearings.

It is my hope that this report, when considered along with other reports distributed by Spectrum Institute on the probate conservatorship system, will stimulate officials in all three branches of government to address issues affecting seniors and people with disabilities throughout the state. Meaningful reforms are not only needed, they are long overdue.

Thomas F. Coleman

Capacity Assessment Workgroup

A Capacity Assessment Workgroup was convened last year to assist Spectrum Institute in reviewing capacity assessment procedures currently used in probate conservatorship proceedings in California. The workgroup was informed that the underlying goal of this investigation is to ensure that seniors and people with disabilities retain as much independence as feasible and that due process and access to justice are afforded to them in proceedings that threaten their decision-making rights.

The workgroup has been receiving reports from the legal director of Spectrum Institute on issues relevant to capacity assessments. Members of the workgroup have had opportunities to share their observations and insights regarding deficiencies that have been identified in policy and practice and to recommend ways to improve the capacity assessment process.

The reports submitted to the workgroup for review have focused on the role of petitioners, medical and mental health professionals, social workers, judges, court investigators, ADA coordinators, court-appointed attorneys, professional fiduciaries, public guardians, and regional center employees as they conduct assessments of a respondent's capacity to make various types of decisions.[6]

Members of the workgroup include physicians, mental health professionals, attorneys, elder care consultants, disability rights advocates, public agency officials, and people whose lives have been directly affected by the probate conservatorship process. Members live and work in nine counties in various regions of the state.

Although this report is being issued after it was submitted to members of the workgroup for review, and after consultations with board members of Spectrum Institute, the comments, findings and recommendations of the report are those of the author and do not necessarily reflect the views of others.

REVIEW

By Kevin Bigelow

Capacity Assessments in California Conservatorship Proceedings

Improving Clinical Practices and Judicial Procedures to Better Protect the Rights of Seniors and People with Disabilities

By Thomas F. Coleman, Legal Director, Spectrum Institute
Released July 1, 2020 / https://spectruminstitute.org/capacity/

Thank you for the opportunity to review this report. I will confess that I have not had time to read the report in full, but from what I have read you have pursued this topic with the same combination of professionalism and ability to explain complex issues clearly that I have seen in your other work. Such a report is long overdue, and the workgroup for the project will, I believe, lend great authority to your conclusions and your recommendations.

Although it was some years ago, I recall that we, as Adult Protective Services workers, dreaded having cases where there were allegations of abuse or neglect by a conservator against their conservatee. The conservatee seldom felt safe in telling us the truth due to fear of reprisals from the very person who controlled their lives.

In addition, even if clear abuse or neglect was found it was nearly impossible to do anything about it. Attorneys and judges did not seem interested in responding to the allegations, and often we would later receive reports of the same or new abuse or neglect by the same conservator against their conservatee and we would realize that although the judge or other authority who had promised to 'look into' the abuse or neglect had done nothing to protect the conservatee.

I hope that your very thorough report will be a catalyst that can bring about the badly needed changes and awareness of the all too common problems and inequities faced by conservatees.

Thank you for all of your hard work on this Tom!

<u>About Kevin Bigelow</u>

Kevin Bigelow is the Coordinator for the Certificate Program of the National Adult Protective Services Association.

Kevin is a trainer and consultant specializing in the abuse, neglect, and exploitation of vulnerable populations and disaster preparedness for elderly persons and persons with physical or mental challenges.

Working for Orange County CA government for 25 years, Kevin was an APS worker and supervisor, and later served as the Adult Services Training Coordinator and Emergency Management Coordinator for Orange County. Social Services. He also worked with Behavioral Health clients where he supervised social workers who investigated elder and dependent adult abuse, neglect, and exploitation.

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** These opinions do not necessarily reflect those of the National Adult Protective Services Association nor those of San Diego State University's APS Workforce Innovations.*

Introduction

This report focuses on probate conservatorship proceedings in California and how judges, lawyers, and other participants in these proceedings have been evaluating the capacity of seniors and other adults with disabilities to make important decisions in their lives.

The report looks at current policies and practices in California associated with capacity assessments to determine how they comply with federal and state constitutional and statutory nondiscrimination requirements. It also compares them with international trends and best practices recommendations of professional associations in the United States.

Conservatees and proposed conservatees include adults whose cognitive functioning is declining due to the aging process, adults with intellectual and developmental disabilities, and other adults whose cognitive disabilities may be the result of medications, mental illnesses, medical conditions, or traumatic brain injuries.

To properly evaluate how the capacity of individuals to make decisions is assessed in probate conservatorship proceedings in this state, it is necessary to understand the historical development of guardianship and conservatorship proceedings as well as the manner in which other states and nations currently conduct such evaluations and what they do with the results of such assessments.

It is only by placing California's capacity assessment policies and practices in historical, national, and international context that judges, legislators, and other elected officials can fully appreciate the significance and urgency of the recommendations made in this report.

Historical Background

Each state has a system for evaluating the mental and functional capacity of adults to make important personal and financial decisions and, when such capacity is found to be lacking, transferring authority to make those decisions to another person. Most states call it guardianship. California once used that term but later renamed it conservatorship.

The notions of capacity and incapacity inherent in these systems have changed quite dramatically over time.[7] The earliest status-based model, derived from English common law protections for persons deemed to be "lunatics" or "idiots," was binary. A person either had legal capacity or did not. If not, the person's decisions had no legal effect because the authority for such decision-making was transferred to another person for all purposes.

Over time, this status-based model transformed into a more nuanced and functional approach. It viewed capacity as something grounded in cognitive functioning rather than a psychiatric diagnosis. The assessment of incapacity focused on an individual's inability to understand information relevant to making a decision as well as the inability to appreciate potential consequences of making that decision. Incapacity was no longer considered an all-or-nothing situation since evolved standards recognized that capacity could vary over time and exist or not depending on circumstances. Therefore, the law allowed for a guardianship or conservatorship to either be plenary or limited depending on the functional abilities of an individual for a wide range of decisions. Capacity was no longer an all-or-nothing concept.

Evolution in California

The history of California's conservatorship system was summarized in a background paper written by a legislative analyst in 2005. The paper explained:[8]

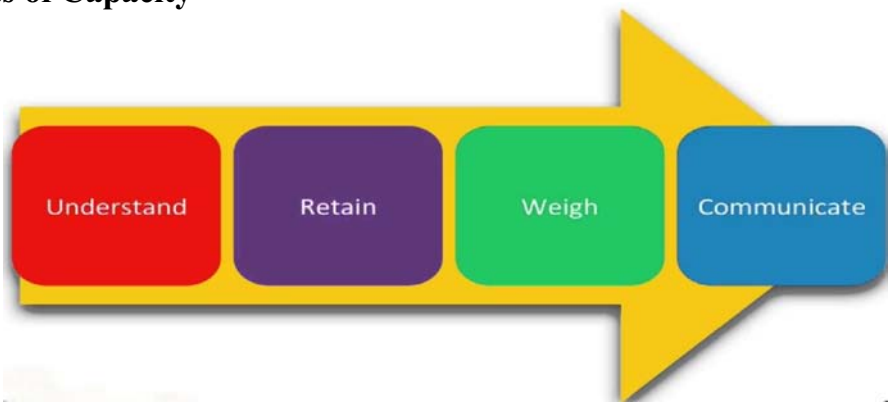
> "California adopted its first 'conservatorship' statute in 1957. Prior to that time, the court appointed a 'guardian' for any person, child or adult, who was deemed 'incompetent' to manage his or her daily affairs. In a 'guardianship of the person,' the guardian took charge of the 'ward's' basic needs, including food, shelter, and medical care. In 'a guardianship of the estate,' the guardian managed the ward's money, property, and financial affairs. In most instances, both types of guardianship existed simultaneously. After 1957, the law distinguished between a 'guardianship,' created for a minor, and a 'conservatorship,' created for an adult. In 1967, under the Lanterman-Petris-Short Act, California created a special adult conservatorship for persons who were considered 'gravely disabled' by reason of mental illness or chronic alcoholism and subject to confinement in a locked psychiatric facility. In 1980, California created a 'limited conservatorship' for 'developmentally disabled adults.' Under a 'limited conservatorship,' the court limits the conservator's power so as to preserve the maximum amount of independence and self-sufficiency for the conservatee."

After conducting oversight hearings in 2005 into this "evolved" conservatorship system, the Legislature concluded that it was plagued by policy flaws and deficient practices, stating: "the conservatorship system in California is fundamentally flawed and in need of reform."[9] Unfortunately, that same statement could be made today. In fact, the system may be in worse shape today than it was back then.[10]

This "progressive" evolution of the conservatorship system in California may look good on paper, but the reality of the way in which it operates in practice is something quite different. Studies and reports over the past few years reveal a system that continues to ignore the rights of seniors and people with disabilities – a system that is failing to meet the stated goals and expectations of probate statutes, state and federal nondiscrimination laws, and constitutional protections that should inform and guide the practices of the judges and attorneys who operate this system.

"It is one thing to be progressive on paper, quite another to make sure reality matches the words. After all, rights can be ignored; they can be waived; and sometimes they can turn into a caricature of themselves."[11]

Components of Capacity



A general understanding of the components of capacity is the very foundation of the assessment process. While the technical legal aspects of capacity will vary from jurisdiction to jurisdiction, from a psychological perspective there are three main components. They were clearly explained in a recent professional publication: input, reasoning, and output:[12]

> "**Input.** The individual must possess the ability to understand that a decision-making situation is present and comprehend information relevant to making that decision. This may involve receptive language (spoken or written) or understanding gestures or symbols. The individual must also be able to retain the relevant information long enough to complete the decision-making process.
>
> "**Computation/Reasoning.** The decision-making process involves: awareness of one's limitations/current situation (insight); the ability to review past experience as a guide; the ability to perform emotional, arithmetical, spatial, or chronological (i.e., when a decision should be implemented) computations depending on the type of decision; the ability to anticipate the consequences

> of one's actions; and the capability to draw reasonable conclusions from experience and new information being provided (judgment).
>
> "**Output.** Once a decision has been reached, the individual must demonstrate the ability to communicate (orally, in written form, or by gesture) and implement the decision."

These are the main areas upon which a capacity assessment professional will focus from a clinical and forensic perspective. However, the legal standards by which these functional abilities must be compared will depend on the laws in each nation or each state. As explained below, the legal standards have been undergoing major transformation internationally over the last few decades. Whether these international changes will stimulate changes in California law remains to be seen.

Chapter One

International and National Views

If California were its own nation, it would have the fifth largest economy in the world. The population of California is greater than that of Canada and 200 other countries. The state is larger geographically than 140 nations.

California has been a leader in terms of recognizing and protecting civil rights. It was among the first few states to give women the right to vote. California was years ahead of Congress in prohibiting race and sex discrimination in employment. California took the lead as one of the first states to pass laws against water and air pollution. It was the first state to pass a no-fault divorce law and among the first to enact domestic partner benefits.

Over the course of several decades in the 20th Century, California courts developed a reputation for being the most innovative of state judiciaries, setting precedents in areas such as criminal justice, civil liberties, and consumer protection.[13]

California has strong and expansive laws prohibiting discrimination against people with disabilities. It has the largest civil rights enforcement agency of any state in the nation. State laws prohibiting discrimination on the basis of disability are more robust than the federal Americans with Disabilities Act.

Despite having this reputation and having strong laws against disability discrimination, California cannot claim to be a leader when its probate conservatorship system is compared with other nations and states. In terms of protecting the rights of seniors and people with disabilities in such proceedings, and seriously exploring less restrictive alternatives, California is lagging behind much of the developed world.

Whether they want to be innovative leaders or just good followers, the Governor and cabinet members, the Chief Justice and Judicial Council, and officials in the Legislature should pay attention to evolving international trends that are emerging as nations are reforming their guardianship and conservatorship systems. California has a lot of catching up to do.

California's laws are intended to provide a safety net for its most vulnerable residents. As this report reveals, however, unintended results from the failure to make necessary reforms violate the constitutional and civil rights of these individuals, especially people with disabilities, when the safety net tears or wasn't adequate in the first place.

A. United Nations Treaty

A United Nations treaty titled "Convention on the Rights of Persons with Disabilities" (CRPD) was approved by the General Assembly in 2006. It was signed by President Barack Obama in 2009. The United States Senate debated the treaty in 2012, but fell a few votes short of ratifying it. However, it has been ratified by177 other nations.

The treaty rejects the idea that the disabilities of some people are so significant that they lack the capacity to make decisions. The treaty challenges the very notion of the type of substituted decision-making that is used in guardianship and conservatorship proceedings.

Articles 12, 13, and 16 are the provisions most applicable to guardianship and conservatorship proceedings. Article 12 addresses the issue of legal capacity. It requires states that adopt the treaty to ensure that the legal capacity of persons with disabilities are recognized and that appropriate measures are taken to enable such persons to exercise legal capacity. Article 13 requires states to ensure meaningful access to justice in court proceedings, including during investigative and other preliminary stages. Article 16 requires ratifying states to protect persons with disabilities from abuse and exploitation. While the United States has not yet ratified the treaty, these provisions are evidence of international human rights norms and should help inform American courts when they interpret state and federal statutory and constitutional provisions that protect the rights of people with disabilities.

Article 12, which directly relates to the issue of legal capacity, has five components:

> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
>
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
>
> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
>
> 4. States Parties shall ensure that all measures that relate to the exercise of

> legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
>
> 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

While this treaty in general, and this section in particular, are not legally binding on California courts, the principles enunciated therein establish an international understanding and agreement that an individual's disability should not be a basis for denying that person the right to exercise choices and to have those choices respected. While it also recognizes the authority of states to protect vulnerable individuals from abuse and exploitation, the process of doing so must be narrowly tailored to a demonstrable need and occur in the least intrusive manner reasonably possible.

California statutes make no direct reference to the CRPD or the principles contained therein. Nor do California appellate decisions. Educational materials provided by the Judicial Council for judges do not cite or refer to this treaty. It appears that judges and legislators in California are not aware of this landmark international agreement – one that has been embraced by all major countries in the world.

✓ **It is recommended** that the Judicial Council direct its Center for Judicial Education and Research to include the CRPD, especially sections 12, 13, and 16, into all training programs and materials for judicial officers and court personnel regarding probate conservatorship proceedings or the assessment of capacity in any legal context.

✓ **It is recommended** that the chairpersons of the Assembly and Senate judiciary committees direct all staff members to become acquainted with the CRPD, especially sections 12, 13, and 16, so that any proposed legislation coming before those committees for approval can be evaluated by legislators and staff with these

principles in mind.

So far, California officials have chosen not to exercise leadership in terms of protecting the rights of seniors and people with disabilities in conservatorship proceedings. The least they can do is to follow the rest of the developed world by considering the CRPD when formulating legislation or conducting judicial proceedings involving issues of capacity.

Austria: A Model to Consider

In addition to ensuring that judicial proceedings and proposed legislation in California conform to the policies contained in Articles 12, 13, and 16 of the CRPD, officials should also study how those policies are actually being implemented by other nations as they revamp their guardianship systems. One such place to look is Austria.

Austria recently modernized its adult guardianship system to bring it into conformity with the principles of Article 12. The reform, which became effective in July 2018, requires all protective measures to focus on the will and preferences of persons with disabilities. It also contains comprehensive safeguards to prevent abuse.

The two main features of the reform were explained in a paper written by André Bzdera, Public Curator of Quebec:[14]

> "First, the traditional 'best interests' rule for decisions-making involving adults with intellectually disabilities is put aside. Henceforth, decisions must respect their will and preferences, whether such decisions are made by disabled adults with the help of a trusted supporter or whether they are made on their behalf, either by a personal representative named by the adult or by a court appointed representative. Only when such adults put their welfare in 'serious and significant danger' may their will and preferences be overridden.
>
> "Secondly, the Austrian reform includes a new type of 'representation agreement' that vastly improves on the model first developed in the Canadian province of British Columbia in the mid-1990s. This model provides a way to empower adults who do not have the necessary contractual capacity to prepare a regular or enduring power of attorney because of an intellectual disability, but can nevertheless make

> their wishes known. Such persons in British Columbia may designate a trusted relative or friend to assist and represent them in their financial, legal and personal affairs – to the exclusion, however, of important financial affairs involving real estate and investments. The new Austrian law improves on this idea by ensuring that such representatives are held accountable for their actions by requiring that representation agreements be registered and that annual reports be filed with the local authority responsible for supervising adult protective measures. Such agreements may cover any subject matter and may also be of an enduring nature."

It is the second provision of the Austrian model that legislators should especially consider adopting in California. Powers of attorney and durable powers of attorney are already embedded in California law. However, in order for such documents to be legally recognized, an individual must have the capacity to contract.

The representation agreement in Austria bypasses this hurdle – one that many adults with intellectual disabilities cannot overcome. It only requires an individual to have the ability to make their wishes known about who should make medical decisions or ordinarily financial decisions for them. It allows them to choose someone they trust for these purposes, even though they may not understand the complexities of those decisions themselves or have the capacity to contract. The model is a disability-accessible procedure that allows someone with a cognitive disability to designate a personal representative for such transactions. It is an accommodation for those who cannot meet the higher standard of capacity to contract.

This provision of the new law in Austria states:

> "Insofar as a person of full age cannot take care of his or her own affairs due to mental illness or a comparable impairment of their decision-making ability, has no representative and can no longer prepare a power of attorney, but is still able of understanding the meaning and consequences of a power of attorney in broad terms, express his or her will and act accordingly, that person may choose one or more friends or family members as adult representatives to take care of his or her affairs."

The Austrian representation agreement can take one of various forms, including:[15]

> "Informational support. The agreement can be narrowly focused on giving the representative access to the principal's personal information held by clinics, schools, tax and welfare offices, banks and other

third parties so that the representative can help the principal to make an informed decision.

"Co-decision-making. The agreement can stipulate that the representative cannot legally act without the principal's consent. This form of representation agreement appears to have been inspired by the example of the Canadian provinces of Saskatchewan and Alberta, although co-decision-making in Canada does not cover financial affairs."

✓ **It is recommended** that legislators in California review the representation agreement statute in Austria. The Legislature should pass a bill giving adults with cognitive or mental disabilities a method of selecting someone to make medical decisions and conduct ordinary financial transactions for them. Powers of attorney should be made available to adults who lack the capacity to contract but who nonetheless can understand in general terms the concept of appointing another person to make such decisions on their behalf. The lack of capacity to contract should not be used as a barrier to receiving the benefits of a simplified power of attorney.

B. World Congress on Adult Guardianship

The Fifth World Congress on Adult Guardianship was held in Seoul, South Korea in October 2018. Representatives from more than two dozen nations exchanged views about issues such as guardianship reform, supported decision-making, and abuse of seniors and people with disabilities.

I attended the conference and was fortunate to speak to the group at a plenary session. I was sad to explain that no judges or legislators in California have shown leadership in terms of promoting comprehensive conservatorship reform. Officials have not even started a serious conversation about promoting safe and legal supported decision-making arrangements as a substitute for conservatorship. No one is advancing a model based on the wishes and choices of seniors and people with disabilities instead of what attorneys and judges believe are in their best interests. No one is investing resources to develop a model that thoroughly investigates less restrictive alternatives.

Various papers were submitted and presentations made to those who attended the World Congress.[16] A review of those papers shows that the California conservatorship system is outdated and that government officials here have much to learn from many of the

progressive policies and practices adopted by other nations.

✓ **It is recommended** that the Legislature authorize funding for a Governor's Commission on Alternatives to Conservatorship. The purpose of the commission would be to review international trends in reforming guardianship and conservatorship systems with a view to developing improvements and alternatives to the conservatorship system in California. The commission should be housed in the executive branch since it plays little or no role in conservatorship proceedings and therefore would not have a real or apparent conflict of interest that could hinder an honest and thorough consideration of moving away from the status quo of the current conservatorship system. Commissioners would be appointed by the Governor, Legislature, and Chief Justice. The commission would be staffed by the Department of Aging and the Department of Developmental Disabilities. It would take testimony from scholars, advocates, service providers, and most importantly from persons who have participated in conservatorship proceedings, including seniors and people with disabilities and their family members. The commission would submit a report and recommendations to the Governor, Legislature, and Chief Justice within two years of its first meeting. Without a properly funded study, conservatorship reform may remain perpetually stagnant and elusive.

C. Rethinking Guardianship Nationally

State guardianship and conservatorship systems have come under scrutiny by many national organizations in recent years. Some of them have directly addressed the issue of capacity.

The National Council on Disability (NCD) issued a report in 2018 calling on the United States Department of Justice to issue guidance to state courts on their legal obligations under the Americans with Disabilities Act in guardianship cases.[17] One NCD recommendation that specifically mentions the issue of incapacity states:

> "The Department of Justice (DOJ), in collaboration with the Department of Health and Human Services (HHS), should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the Americans with Disabilities Act (ADA). Such guidance should address NCD's position that: 1) the ADA is applicable to guardianship proceedings; 2) the need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity; and 3) guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective."

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities issued a joint policy statement in 2016 on the need for guardianship and conservatorship reform. The statement endorsed the principles on legal capacity adopted in the Convention on the Rights of Persons with Disabilities. It stated:[18]

"All individuals with intellectual and/or developmental disabilities (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006).The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime."

The American Bar Association's House of Delegates approved a resolution in 2017 that encourages states to adopt provisions requiring supported decision-making arrangements to be considered as a less restrictive alternative to guardianship:[19]

"RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed; and urges courts to consider supported decision-making as a less restrictive alternative to guardianship; and;

FURTHER RESOLVED, That the American Bar Association urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights; and urges all courts to consider available decision-making supports that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights."

The United States Department of Health and Human Services, Administration for Community Living (ACL) gave a grant to the American Bar Association to help it produce education and advocacy materials for a network of state agencies called WINGS. These Working Interdisciplinary Networks of Guardianship Stakeholders are partnerships convened by state courts to explore changes in guardianship policies and practices.

One action tool focuses on court assessments of individual abilities and limitations.[20] Ten strategies were recommended by this ACL project to WINGS to promote improvements in capacity assessments by state courts in guardianship and conservatorship proceedings:

> Highlight the Issue: Structure a presentation or panel discussion with judges, guardians ad litem, clinicians, and lawyers on current practices, solutions, and obstacles in getting better assessments and drafting limited orders.
>
> Conduct a File Study: Design and implement a file study of assessments that courts use to determine the need for, and scope of, adult guardianship orders.
>
> Revise Assessment Forms: Determine whether courts in your state use different forms for clinical assessments and court orders, or whether there is a standard state form. Evaluate the form/s for their focus on individual functioning and specific areas of decision making. See the "Model Clinical Evaluation Report" in the handbook for judges developed by the ABA Commission on Law and Aging, the American Psychological Association, and the National College of Probate Judges (one in a series of three assessment handbooks).
>
> Promote Training for Clinicians: Reach out to state medical societies and state chapters of the American Psychological Association to include them in WINGS discussions. Join with them to sponsor educational sessions or produce educational materials for physicians, psychologists, psychiatrists, social workers, or other clinicians that might conduct guardianship assessments. Use the ABA Commission on Law and Aging & American Psychological Association handbook for psychologists on assessment.
>
> Promote Training for Court Investigators/Guardians Ad Litem: Examine current materials and training programs for court investigators and guardians ad litem in assessing an individual's abilities, limitations, and

need for supports. Make any needed improvements to refine or update the trainings.

Conduct Training for Judges: Work with your state's court judicial educator to develop and conduct training for judges on assessing abilities, understanding clinical reports, gathering evidence, identifying less-restrictive options, recognizing the need for supports and supported decision making, and restoring rights. Start by reviewing the ABA/APA/NCPJ handbook for judges on assessment.

Conduct Training for Lawyers: Use the ABA/APA handbook for lawyers on assessment, and the ABA PRACTICAL Tool for Lawyers to educate lawyers throughout the state about identifying supports and less-restrictive options.

Identify and Support Statutory Changes: Study your state's statutory definition of "incapacity" or comparable term triggering need for appointment of a guardian. Determine if any changes are needed, and engage selected WINGS stakeholders in pursuing legislative action.

Raise Awareness about Supported Decision Making: The concept of supported decision making is shifting our understanding of "capacity" and the need for a guardian. Sponsor educational and training sessions for multiple audiences.

Raise Awareness about Restoration of Rights: Conduct a file study of restoration of rights, or conduct interviews with stakeholder groups to learn about awareness of the option and need for advocacy.

It is recommended that the Judicial Council convene an ongoing WINGS agency to advance each of these action items in California for the purpose of improving the capacity assessment process used in probate conservatorship proceedings.

National Probate Court Standards

The National College of Probate Court Judges released a revised version of National Probate Court Standards in 2013.[21] Standard 3.3.9 on the "Determination of Incapacity" states:

"A. The imposition of a guardianship or conservatorship by the probate court should be based on clear and convincing evidence of the incapacity of the respondent and that a guardianship or conservatorship is necessary to protect the respondent's well-being or property.

"B. The court may require evidence from professionals or experts whose training and expertise may assist in the assessment of the physical and mental condition of the respondent."

A commentary to this standard explains its intent. These are some of the key points emphasized in the commentary:

• Evidentiary rules and requirements are needed to ensure that due process is afforded and that competent evidence is used to determine incapacity.

• To obtain competent evidence, probate courts should allow evidence from professionals and experts whose training qualifies them to assess the physical and mental condition of the respondent.

• Although a physician may provide valuable information regarding the capacity of the respondent, incapacity is a multifaceted issue and the court may consider using other professionals whose expertise and training may give them greater insight into representations of incapacity.

• Evaluation by an interdisciplinary team can provide probate courts with a fuller and more accurate understanding of the alleged incapacity of the respondent that includes cognition, everyday functioning, values and preferences, risk and level of supervision, and the means to enhance capacity as well as the respondent's medical condition.

• Where a party objects to submitted documents that contain the opinion of a professional or expert, e.g., the written medical report of an examining physician, that professional or expert should appear and be available for cross-examination.

• An evaluation of incapacity should be based upon an appraisal of the

functional limitations of the respondent. Among the factors to be addressed in the report are: the respondent's diagnosis; the respondent's limitations and prognoses, current condition, and level of functioning; recommendations regarding the degree of personal care the respondent can manage alone or manage alone with some assistance and decisions requiring supervision of a guardian or conservator; the respondent's current incapacity and how it affects his or her ability to provide for personal needs; and whether current medication affects the respondent's demeanor or ability to participate in proceedings. Prescribing such content avoids the unfortunate practice of professionals and expert examiners providing cursory, conclusory evaluations to the court.

• Oral testimony from family and friends of the respondent is often helpful to round out the picture presented by the written reports and oral testimony of professionals. These lay witnesses may be more familiar with the functional adaptations not evident in clinical environments that enable respondents to meet their needs at home.

Current policies and practices in California do not conform to these national standards. A professional evaluation is only necessary when a petitioner is seeking to remove an individual's right to make medical decisions. Otherwise, judges are allowed to strip an individual of other fundamental decision-making rights based solely on observations and opinions of lay witnesses.

On the issue of incapacity to make medical decisions, a declaration can be filed by any licensed physician or psychologist. These professionals are not required to have any specialized education or training in forensic assessments. There are no legal standards established as to how these assessments should be performed. There are no explicit requirements that assessment procedures comply with requirements of the Americans with Disabilities Act (ADA) to ensure that the persons being evaluated can meaningfully participate in the process and that they have effective communication with the evaluator.

It is recommended that the Judicial Council direct its Probate and Mental Health Advisory Committee to review current policies and practices for capacity assessments regarding all areas of decision-making involved in probate conservatorship proceedings. The committee should determine whether any new court rules or statutes should be enacted to make current policies and practices conform to the letter and spirit of Standard 3.3.9 of the National Probate Court Standards, due process, and requirements under the ADA.

It is recommended that the Legislature enact a law requiring courts to inform conservatees or proposed conservatees of their right to request the appointment of an interdisciplinary team to evaluate relevant areas of the individual's capacity, with or without ancillary supports and services, prior to the court limiting any area of the individual's decision-making authority. As contemplated by this statute, an interdisciplinary team should include a physician, licensed mental health professional, and social worker or regional center case worker.

In many nations, interdisciplinary teams are a standard procedure for determining whether a guardianship or conservatorship is needed or whether a supported decision-making arrangement would be sufficient to protect the individual, while at the same time respecting his or her right to self-determination. It is time for California to modernize its antiquated capacity assessment process and to bring its procedures into conformity with international trends.

Chapter Two

Standards Suggested by Professional Associations

A Working Group on the Assessment of Capacity in Older Adults was jointly established by the American Psychological Association and the American Bar Association in 2003. Over the next five years, the workgroup produced three handbooks: one for attorneys, another for judges, and a third for psychologists.

Handbook for Psychologists

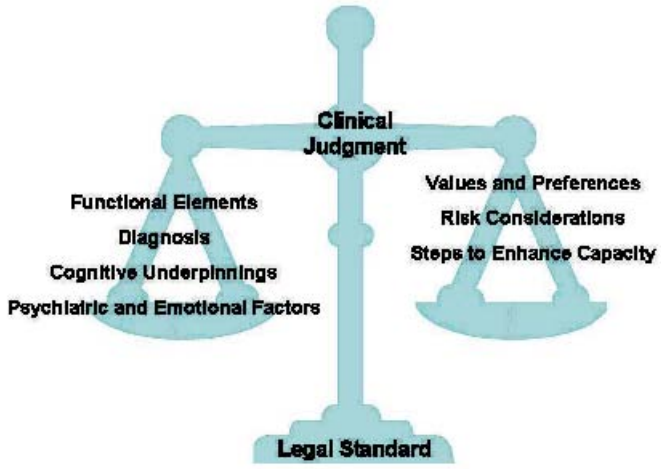
The third handbook contains information to guide psychologists evaluating capacities of older adults regarding their ability to make and execute decisions involving medical care, sexual activities, financial transactions, and testamentary matters, as well as their capacity to drive and capacity to live independently.[22]

It emphasizes that the assessment process focuses not only on decision-making capacity, but also on the ability to execute decisions.

The handbook states that its purpose "is to promote sound assessment of older adults, which lead to appropriate interventions that balance promotion of autonomy and protection from harm" by providing "a framework and assessment examples that psychologists may find useful and effective in capacity evaluation."

One chapter of the handbook identifies nine conceptual elements that psychologists should consider when conducting capacity assessments: (1) identifying the applicable legal standards; (2) identifying and evaluating functional elements constituent to the capacity; (3) determining relevant medical and psychiatric diagnoses contributing to incapacity; (4) evaluating cognitive functioning; (5) considering psychiatric and/or emotional factors; (6) appreciating the individual's values; (7) identifying risks related to the individual and situation; (8) considering means to enhance the individual's capacity; (9) making a clinical judgment of capacity.

Another chapter describes the assessment process for each of the six areas of decision-making listed above, namely, medical, financial, sexual, etc. Each of these sections reviews up-to-date relevant clinical literature and assessment tools, using the nine-part framework in light of that specific area of capacity.



The handbook explains that nine elements form the framework for a capacity assessment. (1) legal standard, (2) functional elements, (3) diagnosis, (4) cognitive underpinnings, (5) psychiatric and emotional factors, (6) values and preferences, (7) risk considerations, (8) steps to enhance capacity, and (9) clinical judgment of capacity or incapacity. Although these elements are described in some detail in the handbook, the following excerpts provide a short summary of them.

> Legal Standard. Clinical evaluations of capacity are grounded in a clinician's opinion about a person's ability to make a decision or perform a task that has a specific definition in the law. Therefore, the legal standard for the capacity in question forms the foundation of a capacity assessment.
>
> Functional Elements. Distinct from a neuropsychological assessment, a functional evaluation focusing on "everyday functioning" involves some type of tailored evaluation—with interview questions and, when possible direct assessment and observation of the individual's functioning—on the specific task in question.
>
> Diagnoses. Documentation of the medical diagnoses is a key element in a capacity determination as they may be the causative factors explaining any functional disability. Because legal professionals are not clinically trained, it is critical to spell out information on prognosis in plain language—is the condition likely to get better, get worse, or stay the same, and if a change is likely to occur, when might that be?

Cognitive Underpinnings. The framework for clinical assessment emphasizes three elements of functioning to be separately addressed in clinical evaluation through interview or direct objective measures: cognitive functioning, psychiatric or emotional functioning, and everyday functioning.

Psychiatric and Emotional Factors. When psychiatric or emotional disturbance is significant, such as severe depression, paranoia, or disinhibition, it may limit reasoning and judgment, and therefore impair . Since some conditions may improve with treatment, it is especially critical in the capacity report to recommend treatment interventions and a time frame for reconsidering capacity.

Values and Preferences. "Values" refer to an underlying set of beliefs, concerns, and approaches that guide personal decisions, where "preferences" refer to the preferred option of various choices that is informed by values. A person's race, ethnicity, culture, gender, sexual orientation, and religion may impact his or her values and preferences. Therefore, all of these factors are crucial to consider in capacity assessment.

Risk of Harm. Many capacity evaluations are essentially a risk assessment Thus, the evaluation of the person and his or her medical conditions, cognitive and functional abilities, personal values and preferences, all elements that affect their day-to-day functioning, must be analyzed in reference to the risk of the situation at hand. The level of supervision recommended as a result of the capacity assessment must match the risk of harm to the individual and the corresponding level of supervision required to mitigate such risk, and must include a full exploration of the least restrictive alternatives.

Means to Enhance Capacity. An essential component of a capacity assessment is a consideration of what can be done to maximize the person's functioning. Practical accommodations (such as vision aids, medication reminders) and medical, psychosocial, or educational interventions (such as physical or occupational therapy, counseling, medications or training) may enhance capacity.

Clinical Judgment. As illustrated in the scales figure shown above, the heart or center of a capacity assessment is the clinical judgment. In some evaluations, the bottom line is clear. A person either has or does not have

> capacity in a particular area. However, the most challenging situation is that of individuals whose capacity impairment is not obvious—and these are the cases that psychologists are most likely to be asked to assess. These individuals in the "middle ground" of capacity may have moderate impairments in many areas, or significant impairment in some areas but not others, or, significant impairment, concerns about that are mitigated by consideration of the person's values, preferences, social supports, and risks.

With respect to guardianship and conservatorship proceedings, the handbook reminds mental health professionals that their role is to offer expert information to assist the court in deciding whether or not to grant the petition and if so which areas of decision-making the adult should retain. Their role also includes determining whether measures less restrictive than a guardianship or conservatorship would suffice to protect the adult. The professionals are reminded to become aware of who the parties are in the proceeding and to keep in mind that they have their own agendas. The evaluation and recommendations of these professionals should be objective and guided by the evidence discovered during the evaluation. This information should include documents relevant to the adult's functional abilities and medical and mental health conditions.

While the handbook is specifically geared toward capacity assessments of older adults, most of the information in the book is also relevant to the evaluation of adults of all ages, including individuals with intellectual and developmental disabilities. With respect to the latter, more will be said in the section of this report focusing on the role of regional centers.

This handbook, and the best practices it recommends, are not binding on capacity assessment professionals involved in California conservatorship proceedings. However, since it is so thorough and is the product of these national legal and psychological associations, evaluators involved in California proceedings should be familiar with the handbook and the valuable advice it offers. Judges and attorneys in conservatorship proceedings should question capacity assessment experts about whether they have read the handbook and whether they used or deviated from the best practices it suggests.

It is recommended that training programs for attorneys who represent proposed conservatees should reference the APA/ABA Handbook for Psychologists and urge the attorneys to become familiar with the best practices it offers. As competent advocates for proposed conservatees, these attorneys should question any expert who offers an opinion on capacity about the procedures and standards they used, whether they are familiar with the handbook, and whether the expert used or deviated from any of the suggested practices.

✓ **It is recommended** that if a court has a list of experts qualified for appointments in conservatorship proceedings or for capacity assessments in other proceedings, the court should require a professional to disclose whether he or she has received specialized training in capacity assessments and whether the methodology used in the evaluation conforms to the best practices suggested by the APA/ABA psychologists handbook in their evaluation process.

✓ **It is recommended** that the Legislature enact a law stating that, absent exceptional circumstances, courts shall only appoint experts to conduct capacity assessments in conservatorship proceedings if they have received specialized education or training on capacity evaluations within five years of the date of the appointment. If a court appoints an expert without such training, the court should be required to state on the record the reason for doing so. Since capacity assessments should be essential to a court's decision in a conservatorship proceeding, professionals without training in capacity assessments should not be appointed to conduct such evaluations. While the initial training of a professional regarding the capacity assessment process could have been many years before the date of appointment, the professional should have more current training to ensure that he or she has been educated on new developments, improvements, or recent trends in the capacity evaluation process.

Handbook for Lawyers

"Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers" was the first work product of the ABA/APA Assessment of Capacity in Older Adults Project Working Group.

Although lawyers seldom receive formal training in capacity assessment, they sometimes make judgments on the issue of capacity. In the context of litigation, capacity may be the only issue in controversy – such as in a conservatorship proceeding or a challenge to a will or trust. In this context, the lawyer's role is rather clear – to advocate zealously for the interests of the party he or she represents.

This handbook is premised in large part on Rule 1.14 of the Model Rules of Professional Conduct adopted by the ABA. The rule allows attorneys to interact with clients who have diminished mental capacity differently than they do with clients who do not have such mental challenges.

A few years ago, the California State Bar asked the Supreme Court to adopt Model Rule

1.14 in California. The Supreme Court declined to do so.[23]

Under the Rules of Professional Conduct in California, a lawyer has the same professional and ethical duties to all clients, regardless of whether they have diminished capacity. A duty of loyalty and confidentiality exists for all attorney-client relationships.

Lawyers should advocate for the wishes of their clients, even if the lawyer disagrees with the client's wishes and believes that the direction given by the client to the attorney is not in the best interest of the client. As a result of the differing rules of the ABA and the California State Bar, much of the material in this handbook is not appropriate for California lawyers.

Furthermore, there is virtually nothing in the handbook about how lawyers can use capacity assessments to strengthen their client's case in a conservatorship proceeding or how a lawyer can challenge capacity assessments by medical and mental health professionals that recommend a conservatorship for their client. The excerpts that appear below are some of the generic information that is relevant to California despite its divergence from the ABA model rule on diminished capacity.

It is clear that lawyers appointed to represent conservatees and proposed conservatees in California should treat clients who may have diminished capacity the same way as they treat all other clients regardless of their personal feelings about the mental or functional abilities of their client. There are no exceptions.

A lawyer representing a client in a conservatorship proceeding must advocate for the stated wishes of the client. If those wishes cannot be determined then it is the lawyer's duty to protect the client's existing rights. The lawyer must adhere to ethical duties of loyalty and confidentiality. The lawyer may not insert his or her opinion about what is best for the client and then advocate for the lawyer's own opinion on this matter.

This is a huge departure from Model Rule 1.14 and therefore anything in the ABA handbook for lawyers premised on that rule should be ignored by California attorneys and should be omitted from any training programs on the role of attorneys in proceedings involving the issue of capacity.

The following are some excerpts from the handbook for lawyers that are consistent with the California Rules of Professional Conduct.

> Lawyers need to be familiar with three facets of diminished capacity: (1) Standards of capacity for specific legal transactions; (2) Approaches to capacity in state guardianship and conservatorship laws; (3) Ethical

guidelines for assessing client capacity.

There are four varying tests of incapacity under state guardianship law: • Disabling condition. • Functional behavior as to essential needs. • Cognitive functioning. • Finding that guardianship is necessary and is "least restrictive alternative." State guardianship laws today *permit or prefer limited forms* of guardianship rather than plenary guardianship**.**

Lawyers who draft proposed court orders need to understand and identify those specific areas in which the person cannot function and requires assistance. Under the principle of the least restrictive alternative, the objective is to leave as much authority in the hands of the individual as possible.

The refusal of the California Supreme Court to incorporate Model Rule 1.14 into the California Rules of Professional Conduct was an indirect signal by the court to attorneys about their duties to clients with diminished capacity. Lawyers can infer what the court intended by this omission, but clients with cognitive challenges or mental disabilities need attorneys who are clear about their advocacy obligations. The rights of these clients should not be left to inferences or guesswork.

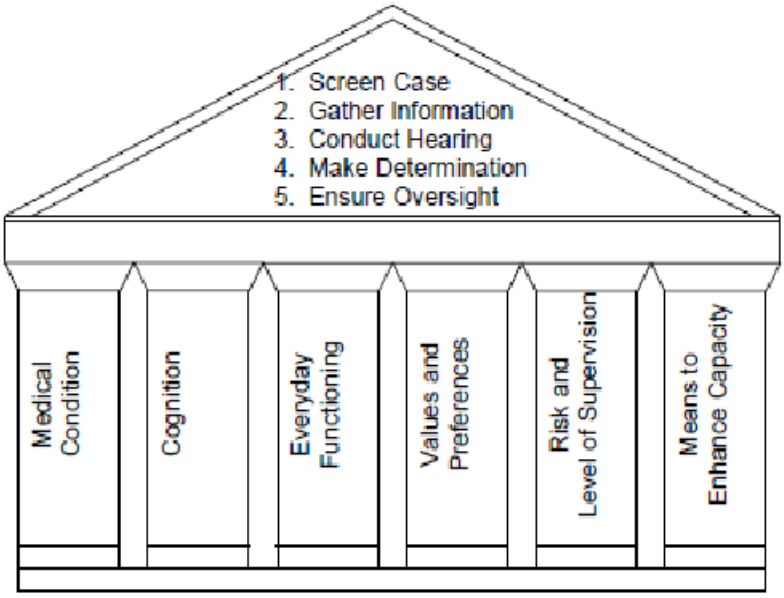
✓ **It is recommended** that the California State Bar develop a new rule regarding the professional duties of attorneys representing clients in conservatorship proceedings or other litigation where the legal capacity of the client is at issue. In addition to clearly stating that lawyers have the same ethical and professional duties to these clients as they do to all clients, comments to the rule should offer guidance regarding investigative, advocacy, and defense activities and provide examples of what attorneys should and should not do.

Clients with diminished capacity are often not able to give clear instructions to their attorneys regarding strategic matters. They are also generally unable to determine if their attorneys are deviating from general rules of professional conduct or to complain about such deviations. It is therefore important for the State Bar to give attorneys more clear and concise direction than is contained in the current Rules of Professional Conduct. A new rule with appropriate commentary would accomplish this.

Handbook for Judges

The American Bar Association, American Psychological Association, and National

College for Probate Judges jointly published a Handbook for Judges on capacity assessment in 2006. While the material focuses on older adults, most of the information in the handbook is also relevant to capacity determinations for young and middle-aged adults who have cognitive or functional disabilities.[24] Excerpts of some of the more pertinent passages appear below.



Graphic from the Handbook for Judges

When it comes to capacity determinations, especially in the context of guardianship and conservatorship proceedings, the handbook reminds judges that they have multiple goals to consider: (1) decide capacity in a manner that balances well-being and rights; (2) promote self-determination; (3) identify less restrictive alternatives; (4) provide guidance to guardians and conservators; (5) make determinations of restoration; and (6) craft limited guardianship and conservatorship orders when appropriate.

In an overview of capacity assessment in guardianship and conservatorship proceedings, judges are advised to collect information on six factors which the handbook refers to as the "Six Pillars of Capacity Assessment." Judges can obtain information about these factors from health care professionals, court investigators, guardians ad litem, family members, adult protective service workers, and other involved parties.

Many probate conservatorship cases in California are not so clear cut that it is obvious that the proposed conservatee lacks the capacity to make decisions on a global basis and

that no less restrictive options are feasible to protect the individual from harm while at the same time respecting individual rights and promoting self-determination.

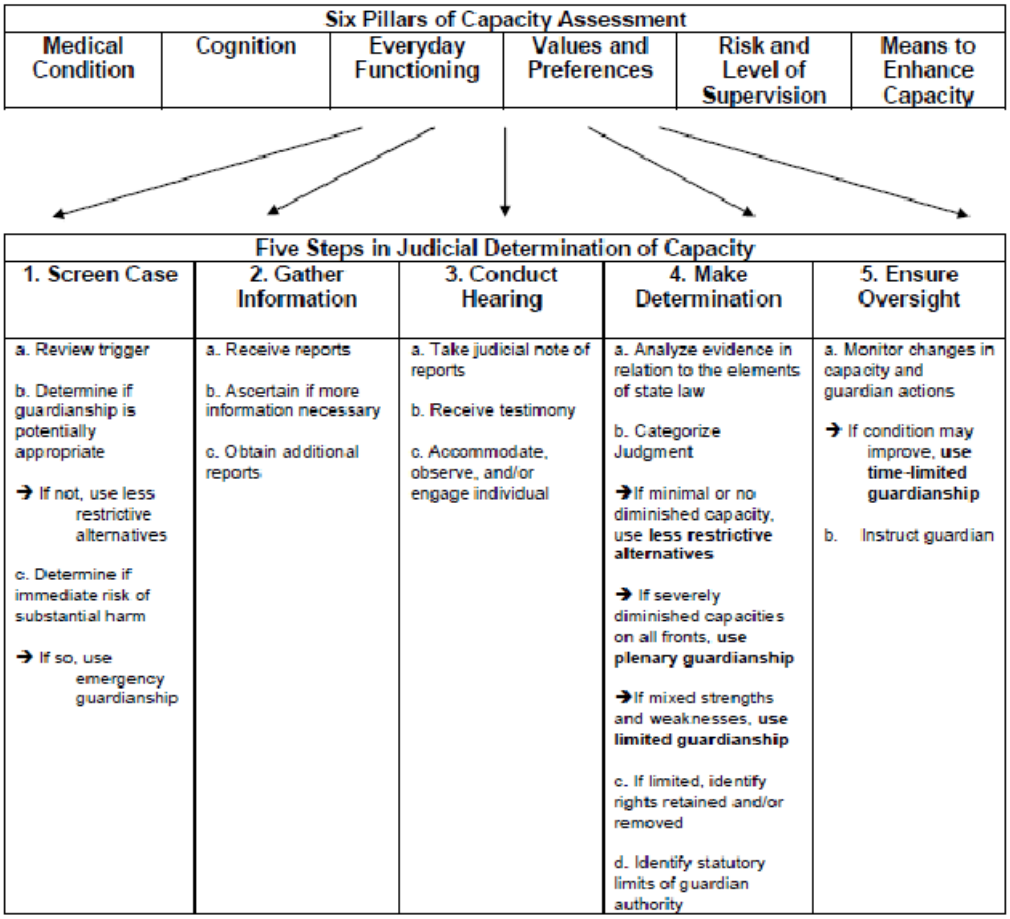
However, despite the fact that many cases fall into a gray zone – one where some areas of decision-making should be retained by the proposed conservatee, especially with the help of proper supports and services – seldom do judges seek information from all available sources. Too often the nuances of capacity, less restrictive alternatives, and limited orders remain unexplored.

As the handbook states, judges should start with a legal presumption of capacity. They should remember that determinations of capacity should be task specific, not global. Capacity can fluctuate with time and vary according to circumstances. Capacity is contextual in that someone may exhibit capacity in a comfortable and safe environment but display incapacity in a strange or anxiety-producing environment such as the office of a psychiatrist or in a courtroom.

Professionals who may be involved in observing or evaluating the capacity of a proposed conservatee include medical doctors, nurses, geriatric experts, occupational therapists, or social workers. Each of these professionals has a particular strength. The most complete picture a judge can receive on capacities and alternatives would come from an interdisciplinary team of professionals.

Seldom do judges in California refer an individual to such a team for evaluation. Usually, the only professional assessment a judge receives is from a physician or psychologist who may have seen the proposed conservatee in an office setting for a short evaluation.

When the proposed conservatee is an adult with a developmental disability, a judge often receives a report from a regional center. But not always. A regional center report is required in a limited conservatorship proceeding. Some petitioners have found a way to bypass this requirement by filing for a general conservatorship. Not only does this obviate the need for a regional center assessment and report, it also makes the appointment of an attorney optional rather than mandatory. The rights of proposed conservatees to have an attorney and to have a regional center evaluation and report should not depending on strategic decisions made by petitioners.



Graphic from the Handbook for Judges

✓ **It is recommended** that the Legislature enact a statute declaring that regional center reports must be filed in all cases involving proposed conservatees with developmental disabilities and attorneys must be appointed in all such cases regardless of whether petitioners have filed for a general or a limited conservatorship. The regional center report should be reviewed by the court prior to an adjudication of any capacity issues. Proposed conservatees should always have an attorney appointed to ensure they receive due process, have access to justice as required by the ADA, and receive the benefit of a proper and thorough capacity assessment – one that includes the serious exploration of less restrictive alternatives.

Regional centers have a mechanism for convening an interdisciplinary team of professionals, service providers, and family members to evaluate the capacities of adults with developmental disabilities who are involved in conservatorship proceedings and exploring less restrictive alternatives. It is called an IPP or Individual Program Plan

review process. An IPP review must be initiated by a regional center on the request of a client or authorized representative. More will be said about the value of IPP reviews in a later section of this report.

There is no IPP review process readily available to seniors and other adults with cognitive disabilities that are not developmental. This gap in the current conservatorship process should be addressed to provide equal protection to all persons subject to a conservatorship.

It is recommended that the Assembly Committee on Aging and Long Term Care hold hearings to inquire into amending state law to entitle proposed conservatees to have an interdisciplinary assessment of capacities and alternatives. Just as adults with developmental disabilities are entitled to an IPP review for such purposes, seniors and other adults with disabilities should have access to a similar process. The committee should ask the Department of Aging to develop a report outlining procedures that may be available under existing law and recommendations for legislation that may be needed to make interdisciplinary assessments readily available to proposed conservatees. Judges will make better and more reliable decisions on issues of capacity and alternatives to conservatorship if they have the benefit of the opinions of a multidisciplinary team of professionals.

Chapter Three

Considerations for the Judicial Branch

When it established a system for probate conservatorships, the Legislature placed responsibility for the administration and operation of the system solely within the judicial branch. Judges are authorized to appoint attorneys to represent proposed conservatees. They have the authority to appoint experts to conduct capacity assessments. They have the final word as to whether a conservator is appointed or not, and if so, what powers are granted to the conservator or retained by the conservatee.

Departments and agencies within the state's executive branch have virtually no role in the conservatorship process. The only local agency that is sometimes involved – perhaps in 10% of the cases – is the county office of the public guardian and conservator.

Other than providing funds to superior courts for general operational purposes, the Legislature has taken a "hands off" approach to probate conservatorships, deferring to the judiciary to run the system. In reality, the manner in which probate conservatorship proceedings are conducted in California, it should not be called a "system" since this term implies an organized scheme that has a degree of accountability and that undergoes periodic self-evaluation for purposes of correction and improvement.

The probate conservatorship "system" lacks meaningful accountability. The Judicial Council has no administrative responsibility other than to adopt rules for procedural matters in such proceedings. Even with this limited authority, statewide rules for conservatorship proceedings are minimal.[25] As a result of vague statutes, lack of appeals, and few state court rules, almost absolute control of conservatorship proceedings is left to the discretion of superior court judges in all 58 counties.

State leaders of the judicial branch are so out of touch with the way conservatorship proceedings occur in actual practice at the local level that they do not even know how many seniors and other adults are under living under an order of conservatorship. Since appeals by conservatees almost never occur, justices of the Supreme Court and Court of Appeal are generally unaware of the failings of this system. Likewise, since conservatees have disabilities that preclude them from filing complaints against their attorneys for

ethics violations of malfeasance, the State Bar is unaware of the failings of attorneys who represent conservatees and proposed conservatees.

Even though issues of capacity and alternatives should be the focal point of conservatorship proceedings, these matters are generally handled in a superficial manner. Judges are so swamped with these and other cases they do not have the time to ensure that proper capacity assessments are done and that alternatives to conservatorship are thoroughly explored. In too many cases, the judges do not appoint attorneys to represent proposed conservatees, so there is no lawyer to insist that these issues are explored. When attorneys are appointed, they rush the cases for indigent clients due to financial disincentives for private attorneys and due to heavy caseloads for public defenders.

As a matter of due process, thorough capacity assessments should be done in all conservatorship proceedings. But constitutional protections often yield to expedient realities. Title II of the ADA requires public entities to ensure meaningful access to the services they provide. In conservatorship proceedings, access to a capacity evaluation and investigation of less restrictive alternatives are statutorily required services that are part and parcel of a conservatorship proceeding. Yet, the way in which these issues are handled provides proposed conservatees less than meaningful access.

The first consideration for improving the conservatorship process, in terms of providing proposed conservatees meaningful access to professional evaluations of capacity and alternatives to conservatorship, would be better judicial education.

Rule 10.462 of the California Rules of Court states: “All trial court judges and subordinate judicial officers regularly assigned to hear probate proceedings must complete additional education requirements set forth in rule 10.468. All trial court judges and subordinate judicial officers should participate in more judicial education than is required and expected, related to each individual's responsibilities and particular judicial assignment or assignments and in accordance with the judicial education recommendations set forth in rule 10.469.”

Rule 10.468(b)(1) states: “Each judicial officer beginning a regular assignment to hear probate proceedings . . . must complete, as soon as possible but not to exceed six months from the assignment's commencement date, 6 hours of education on probate guardianships and conservatorships, including court-supervised fiduciary accounting.”

Subdivision (b)(3) says that the education required in subdivision (1) must be provided by the Center for Judicial Education and Research (CJER), the California Judges Association (CJA), or the judicial officer's court. CJER is responsible for identifying content for this education and will share the identified content with CJA and the courts.

The education required in (1) may be by traditional (face to face) or distance-learning means, such as broadcasts, video conferences, or online course work, but may not be by self-study.

If half of the time is devoted to guardianship and half to conservatorships, a judge without prior experience or training in the area of conservatorships – either as an attorney or a judge – can hear such cases and decide the fate of seniors and people with disabilities with as little as three hours of training. This is unacceptable. Furthermore, the rule does not specify the issues that must be included in trainings approved by CJER or CJA. Therefore, there is no guarantee that judges hearing conservatorship cases will have adequate training on the capacity assessment process. This is also unacceptable.[26]

Spectrum Institute received only five documents from the Judicial Council in response to a request for all "educational or training materials the judicial council or CJER have regarding assessment or adjudication of legal capacity to make decisions."

One of those documents was a medical capacity declaration form (GC-335) and another was an attachment form for proposed conservatees with major neurocognitive disorders. Neither of those documents are educational in nature. They are simply forms that are often used in conservatorship proceedings.

The other three documents had some educational value. One was a 2017 webinar on testamentary and contractual capacity. It contained references to statutes and judicial opinions and gave some hypothetical examples for discussion purposes.

Another document was a PowerPoint slide show used for a 2019 presentation at a Probate and Mental Health Institute (PMHI) on "Capacity and Undue Influence in California." The presentation was given by Harry Morgan, M.D., a medical doctor specializing in geriatric medicine, and retired judge Glen Reiser.[27] The presentation was very thorough and helpful regarding the issues that it addressed. However, the medical component did not reference the ABA/APA handbooks on capacity assessments. The legal part did not address constitutional considerations. Mandates of the ADA were not mentioned.

Although the presentation had a generic title, it was very specific to capacity issues associated with aging and seniors. No mention was made of people with developmental disabilities in either portion of the presentation.

The third document was a PowerPoint from a 2019 forum sponsored by CJER on "Capacity Declaration Improvements." Presenters were Judge David Cowan, Commissioner Jane Lee, Bonnie Olson, Ph.D., and Judicial Council staff attorney Corby Sturges. The institute was open to judicial officers, probate court research attorneys, and

probate court examiners.

The PMHI presentation focused heavily on work being done by a workgroup of the Probate and Mental Health Advisory Committee to evaluate the current capacity declaration form (GC-335). The workgroup was seeking to improve the form by making sure the information contained in it adequately informs the court of facts pertaining the issues of capacity and alternatives. This main aspect of the presentation was preceded by a brief explanation of three national projects focusing on capacity as well as a discussion of some misunderstandings and criticisms of conservatorships in California.

It is recommended that the Rules of Court be amended to require a full-day of training on conservatorship issues before a judge is allowed to hear and decide such cases. The amendment should specify the issues to be covered in such a training, including the requirements of due process, best practices specified in the ABA/APA Handbook for Psychologists, and the sua sponte duties of courts to litigants with cognitive and other disabilities under Title II of the ADA. The Rules of Court should also be amended to require that judges hearing and deciding probate conservatorship cases must participate in a half-day training program each year. These annual refresher courses should focus on recent developments in conservatorship law in California, nationally, and around the world.

It is recommended that the Judicial Council direct the Center for Judicial Education and Research (CJER) and the Probate and Mental Health Institute (PMHI) to expand their trainings on capacity assessments and conservatorships to include the following legal topics: constitutional considerations in capacity assessment and adjudications and the application of the ADA to the capacity assessment process. The use of interdisciplinary teams should be included in the clinical aspect of trainings, with special emphasis on the use of social workers and service providers in identifying supports and services that may enhance or strengthen a person's functional abilities to make a conservatorship unnecessary. An intensive training should be developed on capacity assessments and alternatives to conservatorship for adults with intellectual and developmental disabilities.

It is recommended that the Judicial Council adopt rules pertaining to pre-adjudication conservatorship proceedings. Judges need specific guidance on what they should do to comply with due process and what they must do, sua sponte, under the Americans with Disabilities Act (ADA) to afford proposed conservatees access to justice. Access to justice is required not only inside the courtroom but also in ancillary services such as capacity assessments and investigations by court investigators. The absence of guidance in state court rules leaves too much room for errors and abuses of discretion by judges at the local level.

Chapter Four

Due Process Plus: Application of the ADA

Before delving into how the Americans with Disabilities Act applies to conservatorship proceedings in general and the capacity assessment process in particular, it is important to emphasize that a proposed conservatee has a right to due process in both of these matters.

Giving a conservator authority to restrict a conservatee's place of residence implicates constitutional rights of travel and association. (*People v. Bauer* (1989) 211 Cal. App.3d 937, 944.) Where a probate court restricts the right of an adult to make his or her own educational decisions, constitutional issues can be raised. The right to make medical decisions is constitutionally protected (*People v. Petty* (2013) 213 Cal.App.4th 1410.) As is the right to marry. (*Obergefell v. Hodges* (2015) 135 S. Ct. 2584, 2600.) The right to contract is constitutionally guaranteed by Article I, Section 1 of the California Constitution. (*People v. Davenport* (1937) 21 Cal.App2d 292, 296.)

Constitutional rights are also implicated by orders restricting the sexual choices of conservatees. (*Foy v. Greenblott* (1983) 141 Cal. App.3d 1.) Government actions that infringe fundamental constitutional rights must not only serve a compelling state interest, they must use the least restrictive means to achieve the intended goal.. (*R.A.V. v. St. Paul* (1992) 505 U.S.377.) If a person's capacity to make some or all of major life decisions can be enhanced to an acceptable level through the use of less restrictive means other than a conservatorship, then the state does not have a compelling interest in removing the individual's right to make decisions in that area.

The ADA goes even further, mandating that public entities such as courts take proactive steps to ensure meaningful participation and effective communication in those services for individuals with known disabilities that may impair equal access. Since the ADA is grounded in constitutional considerations, but goes beyond them to require even more of public entities, the measures to be taken by courts in conservatorship proceedings could be called "Due Process *Plus*."

Before an adult may be placed into a conservatorship, the probate code requires a judge to find that less restrictive alternatives are not feasible. Such a determination must be based on facts. Such evidence is elicited in a variety of ways, including through a capacity assessment process that is conducted by a qualified professional.

The Americans with Disabilities Act also comes into play. The ADA is one way that Congress has chosen to implement the requirements of due process when the state is restricting the autonomy of someone with a disability. The process of imposing restrictions on a person's life – in this case through a conservatorship proceeding – must meet the standards of the ADA. The result must also be ADA compliant.

The principles underlying the integration mandate of the United States Supreme Court's Olmstead decision logically apply to conservatorship proceedings.[28] *(Olmstead v. L.C.* (1999) 527 U.S. 581.)[29] Federal law requires that court proceedings – a government service that is subject to the requirements of Title II of the ADA – must ensure that a proposed conservatee is provided the necessary accommodations to maximize effective communication and meaningful participation throughout the proceedings. This would include providing reasonable accommodations for participation in the process used to determine capacity to make decisions and whether less restrictive alternatives are feasible.

Before delving further into the specifics of how the ADA would apply to conservatorship proceedings and the capacity assessment process, it is important to note that the response of the judicial branch in California to the mandates of the ADA are sorely lacking. The very foundation of that response – Rule 1.100 of the California Rules of Court – is flawed. This rule for disability accommodations in court proceedings is based on a premise that the duty of courts to provide such accommodations to litigants and other participants in judicial proceedings arises only upon request. That is not true.

Courts have a duty to initiate an inquiry into the necessity of reasonable accommodations when judges or court staff become aware that an individual has a disability that may impair effective communication or meaningful participation in court proceedings. It is the knowledge of this condition that triggers a duty under the ADA. Websites and educational materials of the judicial branch contain similar erroneous assumptions that courts have no ADA duty absent a specific request for an accommodation.

Spectrum Institute brought this flaw to the attention of the judicial branch in a report to the Judicial Council.[30] A presentation was also made to the Chief Justice and other members of the judiciary at a Judicial Council meeting. To date, the court rule and erroneous educational materials have not been revised.

It is recommended that the Judicial Council revise Rule 1.100 and its educational materials to clarify that more is required than merely responding to requests for accommodations. The rule and materials should specify that courts have a duty on their own motion to initiate an interactive process to determine what accommodations to provide when judges or court staff become aware that a litigant,

witness, or other participant may require an accommodation to maximize effective communication and meaningful participation in the proceeding. This clarification is especially important for conservatorship proceedings where judges and court staff are informed from the start that a proposed conservatee has, or is perceived to have, one or more serious disabling conditions that impair cognitive or communication functions.

California courts have not received technical guidance on their ADA duties to litigants and witnesses with cognitive disabilities. Judges and court staff are aware of duties to individuals with mobility or hearing disabilities. They know about curb cuts, disability parking spaces, restroom design, elevator access, courtroom structure, and sign language interpreters. Unfortunately, they have not received education or technical advice on what they should do to accommodate the needs of litigants with cognitive disabilities.

The United States Department of Justice is the federal agency with responsibility to investigate ADA violations by state and local courts. When violations are identified, the DOJ can attempt to secure compliance through a settlement agreement. If that does not occur, a lawsuit can be filed in federal court against the offending state or local court.

To minimize the necessity for formal investigations or litigation of this type, the DOJ has provided some guidance to such courts about their ADA duties to litigants with cognitive disabilities involved in the criminal justice system. It has also provided guidance to courts involved in state child welfare cases. While these guidance memos and technical advice are not directly on point, they do provide insights as to what California courts should do to fulfill their ADA duties in conservatorship proceedings.[31]

✓ **It is recommended** that the Judicial Council direct staff to study the Department of Justice (DOJ) guidance memos on court responsibilities in criminal and child welfare proceedings and to prepare educational materials for judges and court staff about analogous duties in probate conservatorship and other mental health proceedings. The current void in education and training on these issues should be filled without delay.

California Government Code Section 11135 requires state-funded public entities, including courts, to comply with the mandates of Title II of the ADA. There is an acute need for interpretation and enforcement of Section 11135 in connection with probate conservatorship and other mental health proceedings.

The Fair Employment and Housing Council has authority to adopt substantive regulations to interpret and implement Section 11135. It is currently in the process of doing so.[32] The Fair Employment and Housing Department has authority to receive complaints and investigate alleged violations of Section 11135.[33] It may also adopt procedural

regulations regarding the filing and processing of complaints.

It is recommended that the Fair Employment and Housing Council include in its new regulations a specific section on the application of the ADA and Section 11135 to court proceedings, including and especially conservatorship and other mental health proceedings.

It is recommended that the Fair Employment and Housing Department develop educational materials on the application of the ADA and Section 11135 to court proceedings, with special guidance to judges, court staff, and public defenders and other attorneys appointed to represent conservatees and proposed conservatees. The department should notify the State Bar, local bar associations, presiding judges of all 58 superior courts, Center for Judicial Education and Research, California Judges Association, and Public Defenders Association, that such materials are available online.

Last year, the Judicial Council of California adopted new mandatory training requirements for attorneys appointed to represent conservatees and proposed conservatees. Topics to be included in the training include capacity assessments, less restrictive alternatives, and the applicability of the ADA to conservatorship proceedings.

It is recommended that the State Bar reach out to, and work with, disability rights organizations to identify specific topics, references, and resources that should be mentioned in any trainings authorized by the State Bar for credit under its mandatory continuing education program. The quality of new trainings programs for these topics should not be left to chance.[34]

Chapter Five

Evaluating Supported Decision-Making Alternatives

Supported decision-making (SDM) is being promoted internationally as an alternative to guardianship.[35] The concept of SDM rests on a philosophy that, with proper supports and services, adults can make their own decisions.

Supported decision-making arrangements, and related legal documents such as medical and financial powers of attorney, are being explored by legislators, judges, and professional associations, and are being discussed at state, national, and international conferences. However, current literature on the subject generally lacks a sufficient discussion of the risks of SDM, including significant risks in some very sensitive areas of decision-making.[36]

There is a place for private contracts -- which is what SDM agreements and powers of attorney are – for *some* seniors and *some* people with disabilities. . . **if** they have the capacity to understand the nature and consequences of an agreement when it is signed, **if** there is no undue influence, **if** they have independent legal counsel to review such documents, and **if** implementation of an agreement is effectively monitored by a neutral third party. It is important that any SDM process should aim to minimize the risk of abuse and exploitation.

When SDM is both *safe* and *legal*, it becomes a potentially viable and good alternative to a probate conservatorship. Seniors with cognitive disabilities and adults of all ages with developmental disabilities are legally entitled to have judges, attorneys, court investigators, regional center staff, and capacity assessment professionals seriously explore supported decision-making arrangements. This is constitutionally required as a matter of due process.[37] It is also inherent in the nondiscrimination mandates of the Americans with Disabilities Act.[38] The less restrictive alternative dictates of California's probate code also contemplate an investigation into the feasibility of supports and services that would make a conservatorship unnecessary.[39]

In theory, current law favors alternatives to conservatorship. In practice, however, alternatives such as supported decision-making are not being *seriously* explored by court-appointed attorneys, court investigators, and judges. Petitioners check a box in the petition and allege that less restrictive alternatives will not suffice. Beyond that, not much else occurs.

Public defenders have such large caseloads they can't give the time to such an investigation. Appointed attorneys in low-fee cases for indigent clients don't take the time to ask for experts such as a social worker to be appointed to explore such options. These attorneys are often told, or even directed, to keep their hours to a minimum. If they do not heed this admonition they may not be reappointed to future cases.

Judges have too many cases on their dockets. Exploring options such as supported decision-making would require appointing experts, perhaps as an interdisciplinary team, to evaluate the proposed conservatee and identify services available in the community that may make semi-independent decision-making feasible and a conservatorship unnecessary. Expediency usually trumps thoroughness. Most judges do not take the time to look beyond the box on the petition that says less restrictive alternatives are not feasible. Most judges will not question a public defender or appointed attorney to inquire about the alternatives they have investigated. In the end, most judges simply check off the box on the adjudication order which finds that such alternatives do not exist.

Judges and attorneys in California should move away from doing what is expedient and instead do what is statutorily and constitutionally required. Less restrictive alternatives should be investigated and evaluated with due diligence.

Since legal procedures and funding sources for determining less restrictive alternatives already exist in California law, the recommendations on this topic are mostly directed to the judiciary. The Legislature has declared that conservatorships should only be used when less restrictive options are not available. The Legislature has authorized judges to appoint experts to assist the court when it is necessary or helpful to the resolution of a case.[40]

The funds to pay such experts do not come out of the court's budget. If the proposed conservatee is indigent, the court may order the county to pay for the expert's services. If the proposed conservatee has assets, the court may set a reasonable fee and order that it be paid from the assets of the proposed conservatee. When the proposed conservatee is a person with a developmental disability, the court may order the regional center to conduct an IPP review to determine if any supported decision-making arrangements would obviate the need for a conservatorship. An IPP review does not affect the court's own budget.

Since the court's budget is not affected – other than its time budget in managing the flow of cases on its docket – there is no financial reason for courts failing to use the services of experts to determine whether less restrictive alternatives to conservatorship are feasible. The question that needs to be answered – in view of statutory and constitutional mandates requiring a serious exploration of alternatives – is why judges are not appointing experts or ordering IPP reviews for this purpose.

It is recommended that the Judicial Council conduct a survey of all 58 superior courts to inquire into: (1) the number of new probate conservatorship proceedings that were filed in the previous three years; (2) the number of times experts were appointed in these cases; (3) the number of IPP reviews the court requested or ordered from regional centers; (4) any procedures the court has in place for evaluating less restrictive alternatives; and (5) an explanation as to why such appointments or IPP reviews are not ordered more frequently.[41]

It is recommended that the Chief Justice, in coordination with the Judicial Council, convene a Task Force on Alternatives to Conservatorship. The Task Force should investigate how judges who process probate conservatorship cases throughout the state are complying with statutory and constitutional requirements that alternatives to conservatorship be seriously considered. The Chief Justice should direct the presiding judges in all 58 counties to cooperate with this investigation. The Task Force should issue a report to the Judicial Council and the Legislature within one year of its first meeting.

It is recommended that the Department of Developmental Services include in its contracts with regional centers a clause requiring that an IPP review process be conducted for clients who are proposed conservatees in probate conservatorship proceedings and include a line item in the regional center's budget to provide funding for such reviews.

It is recommended that the Legislature provide funding to the Judicial Council to conduct the survey and to operate the Task Force as well as providing funding to the Department of Developmental Services to reimburse it for the funding it would provide regional centers throughout the state to conduct IPP reviews for clients who are involved in probate conservatorship proceedings.

Chapter Six

Role of Regional Centers

There are 21 regional centers in the state. Each one is a separate nonprofit corporation. Each center receives funding from the State of California through contracts with the Department of Developmental Services. Together they have formed a trade association known as the Association of Regional Center Agencies. ARCA has a lobbyist in Sacramento.

Regional Centers have been assigned a statutory duty to assess the abilities of clients for whom probate conservatorship proceedings have been initiated. When a petition for limited conservatorship is filed, the court must obtain an assessment of the proposed conservatee from the relevant regional center. When a petition for general conservatorship is filed, the regional center assessment is optional.

Some petitioners file for a general conservatorship in order to bypass this assessment and also to avoid the necessity of an attorney being appointed for the proposed conservatee. In limited conservatorship proceedings it is mandatory for the court to appoint an attorney for the proposed conservatee. In general conservatorship proceedings, appointment of counsel is not mandatory. No assessment and no attorney usually results in an expedited procedure almost always concluding with an order granting a conservatorship.

Although the Department of Developmental Services contracts with regional centers to provide services to people with developmental disabilities – and provides substantial funding for these services – there are no provisions in these contracts regarding conservatorship assessments. DDS allows each regional center to do whatever it wants in connection with conducting capacity assessments and submitting reports to the courts. DDS provides absolutely no education, guidance, or oversight with respect to this statutory duty of the regional centers.[42]

As a result of the lack of oversight and monitoring, the practices of regional centers vary greatly from one part of the state to another. A survey of regional centers confirmed such variations.[43]

The state constitution declares that laws of a general nature shall be uniform in operation. Because of the lack of DDS oversight and monitoring in this area, the statute mandating

regional center evaluations of clients who are involved in limited conservatorship proceedings is not being administered uniformly throughout California. Clients are not receiving equal protection of the law.

There is a role for court-appointed attorneys in the regional center evaluation process. They should demand an Individual Program Plan (IPP) review for each client.[44] An IPP review for conservatorship evaluations would involve convening a multi-disciplinary team, including a qualified capacity assessment professional, to determine the client's ability to make decisions in each of seven areas of decision-making.

The IPP review team would also evaluate whether, with proper supports and services, a less restrictive alternative to conservatorship would be feasible. Unfortunately, attorneys are not demanding IPP reviews and regional centers are not conducting them in connection with conservatorships.

Regional centers should be playing a major role when adults with intellectual and developmental disabilities are involved in probate conservatorship proceedings. The quality and scope of regional center evaluations should not vary from one part of the state to another nor should they depend on whether a petitioner has filed for a general or a limited conservatorship. The need exists for a proper evaluation of capacities in a variety of areas of decision-making, and for a thorough exploration of less restrictive alternatives, regardless of which type of conservatorship proceeding is initiated.

It is recommended that all three branches of government work together to review the current process used for evaluating the capacities of proposed conservatees with intellectual and developmental disabilities and investigating the feasibility of alternatives to conservatorship. The governor should take the lead by convening a task force to determine what increases in funding would be required to ensure that regional centers have adequate resources to conduct such assessments and that DDS has sufficient resources to provide the necessary direction to and oversight of regional centers to assure quality and uniformity throughout the state.

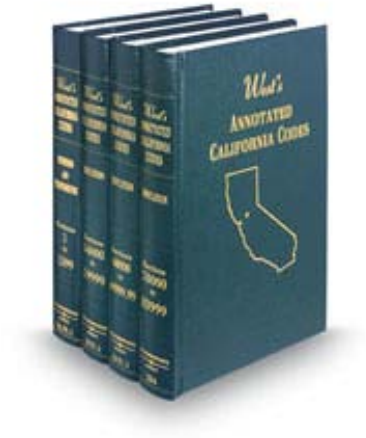
Members of the task force should include individuals from the following agencies and organizations: DDS, ARCA, DFEH, Judicial Council, California Judges Association, The Arc of California, Public Defender's Association, and Disability Rights California. The task force should issue a report to the Governor, Chief Justice, and Legislature within one year from its first meeting.

Other recommendations to improve the regional center role in conservatorship proceedings have been made elsewhere in this report.[45]

Elected and appointed officials in all three branches of government should provide direction to and funding for regional centers so they can assist the judiciary in finding alternatives to conservatorships or limiting orders to minimize intrusion into the rights of adults with intellectual and developmental disabilities.

Chapter Seven

State Laws Relevant to the Assessment Process



Several state statutes are relevant to the assessment of capacities and abilities of individuals who are targeted in probate conservatorship proceedings. In order to render a valid opinion, a capacity assessment expert must be aware of the legal criteria for each particular area of capacity on which an opinion is offered.

For example, whether an individual has the mental capacity to enter into a contract is a legal determination and therefore is a mixed question of law and fact. *(In re Estate of Sexton* (1926)199 Cal. 759, 770.) A declarant, including a physician, cannot give his or her opinion as to an individual's capacity to enter into a contract without having knowledge of the legal criteria of capacity. (Id. at p. 769.)

Lanterman Act Rights

Welfare and Institutions Code Section 4502 declares that people with developmental disabilities have the same constitutional rights as all other citizens and residents of California. In addition to rights that have a foundation in the state and federal constitutions, Section 4502 declares that people with developmental disabilities have "a right to make choices in their own lives, including, but not limited to, where and with whom they live, their relationships with people in their community, the way they spend their time, including education, employment, and leisure, the pursuit of their personal future, and program planning and implementation."

Since capacity assessments will be used as evidence to curtail statutory and constitutional rights, they should not be biased, they must utilize scientifically valid procedures, they must comply with the requirements of the Americans with Disabilities Act and corresponding state laws prohibiting discrimination on the basis of disability. Opinions regarding incapacity in any area must be supported by clear and convincing evidence. Although the Lanterman Act rights only apply to adults with developmental disabilities, the same requirements would apply to capacity assessment of other adults as a matter of due process since the constitutional rights of these adults would also be curtailed by an order of conservatorship.

Constitutional Considerations

Capacity assessments are used as evidence to curtail fundamental constitutional rights. As a result, the due process clause of the California Constitution would require that factual findings of incapacity be supported by clear and convincing evidence.

Disability Rights Statutes

Government Code Section 11135 incorporates Title II of the Americans with Disabilities Act into state law. It requires state-funded agencies, organizations, and individuals to provide accommodations to persons with known disabilities that may interfere with participation in the service being provided.

Civil Code Section 51, known as the Unruh Civil Rights Act, prohibits privately-paid service providers from discriminating on the basis of disability. This would apply to capacity assessment professionals who are not appointed by the court and who are not paid with government funds.

Capacity assessment professionals who are appointed by the court or who are paid by government funds for the assessment must comply with Section 11135. Those experts who are privately retained must comply with Civil Code Section 51. Both types of professionals must provide accommodations to assist the individual to have effective communications and meaningful participation in the assessment process.

Presumption

Probate Code Section 810 declares "there shall exist a rebuttable presumption affecting the burden of proof that all persons have the capacity to make decisions and to be responsible for their acts or decisions."

A capacity assessment professional should begin the evaluation process with a presumption that the individual has the capacity to make all decisions in a responsible manner. The process should not start with a predetermined bias against capacity.

Standard of Proof

Probate Code Section 1801(e) states that the standard of proof for appointment of a conservator shall be by clear and convincing evidence.

The appointment of a conservator of the person requires a showing, by clear and convincing evidence, of the inability to provide properly for personal needs. For the

appointment of a conservator of the estate, a showing must be made by clear and convincing evidence, of the substantial inability of a proposed conservatee to manage financial resources.

The "clear and convincing evidence" test requires a finding of high probability, based on evidence that is so clear as to leave no substantial doubt. (*Conservatorship of Wendland* (2001) 26 Cal.4th519, 552.) Therefore, a capacity assessment professional must be able to say, with a high degree of probability, that there is no substantial doubt that the proposed conservatee lacks capacity in each specific area under review.

Appointment of Capacity Experts

Evidence Code Section 730 states: "When it appears to the court, at anytime before or during the trial of an action, that expert evidence is or may be required by the court or by any party to the action, the court on its own motion or on motion of any party may appoint one or more experts to investigate, to render a report as maybe ordered by the court, and to testify as an expert at the trial of the action relative to the fact or matter as to which such expert evidence is or maybe required. The court may fix the compensation for such services, if any, rendered by any person appointed under this section, in addition to any services as a witness, at such amount as seems reasonable to the court."

The costs of medical experts appointed to assist counsel representing a proposed conservatee who is indigent would be paid for by the county. (Evidence Code Section 731; *Conservatorship of Scharles* (1991) 233 Cal.App.3d 1336, 1341.)

Attorneys for proposed conservatees can and should ask for the appointment of a psychologist, psychiatrist, or other qualified mental health professional to assist the attorney in evaluating the capacities of the client in each area of decision-making where capacity arguably exists. When counsel has a good faith belief that a less restrictive alternative to conservatorship may be appropriate, counsel should ask for the appointment of a social worker to identify local supports and services that would make such an alternative feasible.

When such experts are needed to explore capacity issues and alternatives for an indigent client, and the attorney wants to hire such professionals directly, the court should be consulted in advance if counsel wants to receive reimbursement from the county for the costs. (*Conservatorship of Ben C.* (2006) 137 Cal.App.4th 689.)

Qualifications of Expert Witness

Evidence Code Section 720 states that a person is qualified to testify as an expert if he

has special knowledge, skill, experience, training, or education sufficient to be qualified as an expert on the subject to which his testimony relates. Faced with an objection by a party, such special knowledge, skill, experience, training, or education must be established before the witness may testify as an expert.

Professionals who conduct capacity assessments and submit reports to the court or testify in a conservatorship hearing must have sufficient education and experience to qualify as an expert on the disabilities of the person in question and how those disabilities limits the individual's functional capacity to care for personal or financial needs and decision-making abilities in those areas.

Court Investigator

Probate Code Section 1826 requires a court investigator to issue a report to the court indicating, among other things, whether the proposed conservatee has "mental function deficits" that would interfere with his or her ability to understand the consequences of actions taken in connection with functions described in Section 1801(a) [properly providing for personal needs] or Section 1801(b) [unable to manage financial resources or resist undue influence].

General Conservatorships

Probate Code Section 1801(a) authorizes a superior court judge to appoint a conservator of the person for any adult "who is unable to provide properly for his or her personal needs for physical health, food, clothing, or shelter." Subdivision (b) authorizes appointment of a conservator of the estate "for a person who is substantially unable to manage his or her own financial resources or resist fraud or undue influence." Subdivision (c) authorizes a conservator of the person and estate to be appointed for anyone who meets the criteria of both subdivision (a) and (b). However, neither form of conservatorship may be ordered "unless the court makes an express finding that the granting of the conservatorship is the least restrictive alternative needed for the protection of the conservatee."(Prob. Code § 1800.3, subd. (b).)

A conservatorship of the person focuses on an individual's ability to provide for certain specific personal needs. A conservatorship of the estate focuses on a person's substantial inability to manage his or her finances or resist undue influence. These are the criteria that should guide any assessment of capacity to make decisions in these areas of daily living. A capacity assessment must also consider the viability of less intrusive means to protect the individual in these areas.

Limited Conservatorships

The same findings must be made by the court before a petition can be granted. However, there is a difference between general and limited conservatorships in terms of the retention of rights. Probate Code Section 2351.5 states that a limited conservatee retains rights in several areas of decision-making unless the petitioner seeks those powers and the court expressly grants such a request when an order granting the petition is entered. These powers include access to confidential records and papers of the conservatee, as well as the authority to make decisions regarding residence, marriage, contracts, medical care, education, sexual relations, and social contacts.

This statutory presumption of the retention of certain rights suggests that a capacity assessment professional should be careful in evaluating the functional ability of someone with a developmental disability to make decisions in these areas of personal living.

DDS Conservatorships

Health and Safety Code Section 416.8 states that whenever the court is considering appointing the director of the Department of Developmental Services to act as a conservator of the person of a regional center client, the regional center shall conduct a complete evaluation of the client. This shall include "a current diagnosis of his physical condition prepared under the direction of a licensed medical practitioner and a report of his current mental condition and social adjustment prepared by a licensed and qualified social worker or psychologist."

In a limited conservatorship proceeding when someone other than the DDS director is the potential conservator, the Welfare and Institutions Code Section 4646.5 requires an evaluation by a "qualified individual." While the statute does not define that term, Section 416.8 is relevant to fill this definitional void since it provides some specificity about who the Legislature considers qualified to evaluate the client's mental condition and social adjustment.

Functioning Versus Diagnosis

Probate Code Section 810 declares "A person who has a mental or physical disorder may still be capable of contracting, conveying, marrying, making medical decisions, executing wills or trusts, and performing other actions." It also states: "A judicial determination that a person is totally without understanding, or is of unsound mind, or suffers from one or more mental deficits so substantial that, under the circumstances, the person should be deemed to lack the legal capacity to perform a specific act, should be based on evidence of a deficit in one or more of the person's mental functions rather than on a diagnosis of a

person's mental or physical disorder."

A capacity assessment professional should base opinions on evidence of mental functioning, not the fact that an individual has a diagnosis of a mental or physical disorder.

Evidentiary Requirements

Probate Code Section 811 states: "(a) A determination that a person is of unsound mind or lacks the capacity to make a decision or do a certain act, including, but not limited to, the incapacity to contract, to make a conveyance, to marry, to make medical decisions, to execute wills, or to execute trusts, shall be supported by evidence of a deficit in at least one of the following mental functions, subject to subdivision (b), and evidence of a correlation between the deficit or deficits and the decision or acts in question:" (1) alertness and attention; (2) information processing; (3) thought processes; and (4) ability to modulate mood and affect.

Ability to Communicate

Except where otherwise provided by law, including, but not limited to, Section 813 and the statutory and decisional law of testamentary capacity, a person lacks the capacity to make a decision unless the person has the ability to communicate verbally, or by any other means, the decision, and to understand and appreciate, to the extent relevant, all of the following: (a) the rights, duties, and responsibilities created by, or affected by the decision; (b) the probable consequences for the decision-maker and, where appropriate, the persons affected by the decision; and (c) the significant risks, benefits, and reasonable alternatives involved in the decision.

Lack of Accountability

Generally speaking, California has good laws on capacity assessments and determinations and the use of less restrictive alternatives. Policy statements and legislative directives seem to comport with due process and nondiscrimination principles. The problem is not so much with the law as it is with the lack of uniform and effective implementation.

What California needs are methods to ensure that statutory and constitutional requirements are enforced. A reasonable degree of accountability is needed. Without that, judges and attorneys can do whatever they want, without any concern for penalties or discipline for noncompliance.

The question is how to devise procedural mechanisms that provide incentives for judges

and attorneys to follow the law and disincentives for not doing so. The answer will require new legislation to initiate and fund various methods to require more accountability by the judges and attorneys who process conservatorship cases. A system of accountability would involve new administrative functions, at the state level, in both the executive and judicial branches of government.

It is recommended that the Legislature hold hearings to solicit ideas and suggestions about how to make judges and attorneys who process conservatorship cases more accountable. Scholars, advocates, conservatees, and affected families should be invited to suggest and comment on components that should be included in a new system of conservatorship accountability, such as: (1) the Judicial Council having an Office of Conservatorship Research and Planning; (2) the Department of Aging having an Office of Conservatorship Ombudsperson; (3) the Department of Developmental Services having a similar office; (4) the Judicial Council administering a program to manage the appointment, training, payments, and monitoring of attorneys representing seniors and people with disabilities in conservatorship proceedings; and (5) the State Bar taking pro-active measures to ensure accountability for public defenders and private attorneys appointed to represent conservatees and proposed conservatees.

A proposal once considered by the Legislature in 2006 – the Omnibus Conservatorship and Guardianship Act – should be revisited. One provision in the bill would have established the Office of Conservatorship Ombudsman in the California Department of Aging. That office would have collected and analyzed data relative to complaints about conservatorships and investigated and resolved complaints and concerns communicated by or on behalf of conservatees.[46] In addition to now creating such an office in the Department of Aging to monitor how the conservatorship system affects seniors, a similar office should be created within the Department of Developmental Services to monitor systemic deficiencies and individual abuses affecting adults with intellectual and developmental disabilities.

The lack of accountability by judges who process conservatorship cases is partially attributable to them knowing that appeals by conservatees are rare. They know that it is highly unlikely that the Court of Appeal and the Supreme Court will ever learn what happens in their courtrooms in these cases. Therefore, having agencies within the executive branch that can review individual complaints by conservatees, proposed conservatees and families affected by these proceedings will create a semblance of accountability for these judges – something that is currently lacking.

Another way to diminish abuses by judges and court-appointed attorneys in conservatorship proceedings would be to remove from local courts the power to direct and manage legal services involving lawyers who represent clients in these proceedings.

Judges should be adjudicating cases, not recruiting, appointing, approving payments, and coaching the attorneys who appear before them. The Judicial Council should support, and the Legislature should fund a Conservatorship, Representation, Administration, Funding, and Training Program. A presentation on this subject was made to the Judicial Council earlier this year.[47]

It is recommended that the Judicial Council should create, and the Legislature should fund, an Office of Conservatorship Research and Planning within the judicial branch. There is no statewide administrative accountability within the judicial branch with respect to conservatorship proceedings. The Chief Justice and Judicial Council do not even know how many seniors and people with disabilities are living under an order of conservatorship in California.[48] These vulnerable adults are supposed to be under the "protection" of the superior courts. The superior courts are part of a unified statewide judicial system. Therefore, the safety and well-being of these protectees are the responsibility of the State of California via the judicial branch. But how much protection is actually occurring when the Chief Justice and the Judicial Council do not know what the 58 superior courts are doing in these cases, much less how many seniors and people with disabilities are living under orders of conservatorship?

There is also a role for the State Bar in creating a greater degree of accountability by attorneys in conservatorship proceedings. The State Bar should take steps to improve legal services provided by public defenders and private attorneys appointed to represent seniors and adults with disabilities in these cases.

In 2006, the State Bar issued "Guidelines on Indigent Defense Services Delivery Systems."[49] A 10-member workgroup was assembled to study how public defenders and appointed private attorneys were representing indigents in criminal cases. The study and report were conducted under the auspices of the Office of Legal Services, Access and Fairness Programs. It was funded by a generous grant from the Foundation of the State Bar. The project updated guidelines that were issued in 1990.

Topics covered in the report included: independence, standards of representation, qualifications of attorneys, quality control, permissible caseloads, compensation, and ethics.

A study of this nature should be done by the State Bar regarding legal services being provided to conservatees and proposed conservatees by public defenders and appointed private attorneys. Surely seniors and people with disabilities are just as worthy of the State Bar's attention as defendants in criminal proceedings.

The State Bar is an arm of the Supreme Court. That court has been apprised of myriad

systemic deficiencies in probate conservatorship proceedings.[50]

It is therefore recommended that the Chief Justice should put this recommendation on the administrative agenda of the Supreme Court. The justices should direct the State Bar to initiate and conduct a study looking into the manner in which legal services are currently being provided in probate conservatorship proceedings and what should be done to improve these services. Without such a proactive measure, it is likely that the status quo of deficient legal services for seniors and people with disabilities will continue to be the norm indefinitely.

Chapter Eight

Specific Areas of Decision-Making

Capacity is no longer an all-or-nothing proposition. Under current legal standards and psychological evaluation protocols, capacity is time-sensitive and situation-specific. Some areas of decision-making require very little capacity while others need a great deal more.

Someone who has the capacity to make social decisions may not have the ability to enter into complex financial transactions. Someone who has the capacity to know who they want to have authority to making their medical decisions may not have the ability to understand and evaluate the risks and benefits of complex medical interventions. The more risk or danger involved in an area of decision-making, the greater the functional ability to understand and evaluate must be. In low-risk situations, such as what to eat for dinner or what clothes to wear, little comprehension is necessary.

Based on constitutional considerations and statutory directives, evidence that may overcome the presumption of capacity in each area of decision-making should be evaluated separately. Authority in any given area under scrutiny should be retained by an individual absent clear and convincing evidence of functional incapacity in that area.

Since legal and factual considerations in one area may not apply to others, this report focuses individually on several areas of decision-making that are often involved in conservatorship proceedings.

Medical Care

Medical decision-making capacity is a central focus of probate conservatorship proceedings. The issue arises in one of three contexts: (1) filing a petition for a general conservatorship of the person; (2) filing a petition for a limited conservatorship of the person; (3) filing a petition solely for medical decisions.[51]

A limited conservatorship proceeding only involves adults with intellectual and developmental disabilities. A general conservatorship may involve a variety of adult respondents: a

senior alleged to be in cognitive decline; an adult alleged to have dementia; an adult with cognitive issues arising from an injury; and adult with cognitive issues caused by a medical illness; and adults with intellectual and developmental disabilities. A proceeding focused solely on medical issues could involve adults in those same categories.

Regardless of which of these three proceedings are involved, the legal question that must be addressed by a capacity assessment professional and by the court is basically the same. The question is whether the evidence presented by the petitioner and elicited during an assessment process establishes that an adult lacks the capacity to make medical decisions.

There are substantive and procedural legal standards that must be followed for both a clinical assessment and a judicial determination of incapacity. Adherence to these standards is a prerequisite for an order taking away the right to make the medical decisions from an adult and transferring such authority to a temporary or permanent conservator. Professional and ethical standards for capacity assessment professionals also apply.

Professional Ethics and Standards

Since capacity assessments in conservatorship proceedings are often made by psychologists, evaluations done by these mental health professionals should conform to the "Ethical Principles of Psychologists and Code of Conduct" of the American Psychological Association (APA). Psychologists must act only within their boundaries of competence. (Ethical Principles, Section 2.01(a))

In California, licensed psychologists are authorized by statute to administer and interpret tests of mental abilities and functioning of an individual. (Business and Professions Code Section 2903.) However, just because they are authorized to do so does not mean they can render a *reliable* forensic opinion of the medical decision-making capabilities of a senior alleged to have cognitive impairment or an adult with intellectual and developmental disabilities.

If a psychologist does not have sufficient education, training, and experience in the assessment of incapacity to make medical decisions when the cognitive impairment is associated with declining age or may be the result of one or more disabilities, the psychologist should not undertake such an evaluation process. (Ethical Principles, Section 2.01(b).)

Furthermore, when assuming a forensic role, psychologists must be familiar with the judicial or administrative rules governing their roles. (Section 2.01(f).) Therefore, if they are making an assessment of medical capacity decision-making in the context of a

conservatorship proceeding, they must be familiar with statutes and judicial decisions that apply to this context. This would include the client's rights under the Americans with Disabilities Act, the California Lanterman Act, and the California Unruh Civil Rights Act. If payment for the evaluation is coming from state funding, Government Code Sections 11135-11137 also would apply.

Psychologists conducting medical capacity assessments should also be aware of their duty to provide necessary supports, services, and accommodations to ensure that clients with serious disabilities have effective communication and meaningful participation in the evaluation process. Failure to adhere to applicable nondiscrimination laws could result in a challenge to the evaluation, a complaint to the professional licensing board, and a lawsuit for malpractice or unlawful discrimination.

Similar standards, duties, and consequences would apply to physicians and psychiatrists for noncompliance with their codes of ethics and rules of professional conduct.

Probate Code

The Probate Code governs the transfer of authority for medical decisions to a conservator.

General or Limited Conservatorships

The following are summaries of relevant statutes. These provisions should be considered by capacity assessment professionals, keeping in mind the legislative recognition that individuals have a fundamental right to make their own medical decisions.

> Section 1880. If the court determines that there is no form of medical treatment for which the conservatee has the capacity to give informed consent, the court shall (1) adjudge that the conservatee lacks the capacity to give informed consent for medical treatment; and (2) give the conservator of the person the powers specified in Section 2355.
>
> No court order under Section 1880 may be granted unless supported by a declaration executed by a licensed physician or licensed psychologist within the scope of his or her licensure. The declaration must state that the conservatee or proposed conservatee lacks the capacity to give an informed consent for any form of medical treatment and the reasons therefore.
>
> A conservatee is deemed unable to give informed consent to any form of medical treatment pursuant to Section 1880 if, for all medical treatments, the conservatee is unable to respond knowingly and intelligently to queries

about medical treatment or is unable to participate in a treatment decision by means of a rational thought process.

Medical-Only Proceedings

Probate Code Sections 3200-3212 govern the assessment and adjudication of medical capacity decision-making outside of an existing conservatorship proceeding. Sometimes a petition is made for a specific medical procedure. This may occur when a person refuses treatment that a loved one believes is essential to avoid death or serious health consequences. It may also occur when someone wants medical treatment but the health care provider believes the person lacks capacity to give informed medical consent.

When either of these conditions exist, a petition may be filed to determine if the patient has the capacity to make a healthcare decision concerning an existing or continuing condition. It may also be filed to determine if the patient lacks the capacity to make a healthcare decision concerning a specific treatment. (Probate Code Section 3201.)

Capacity Declaration Form

As mentioned above, a court may not issue an order transferring medical decision-making authority from an individual to someone else in a conservatorship proceeding unless a capacity declaration has been filed by a licensed physician or a licensed psychologist. (Probate Code Section 1890.) The Judicial Council has adopted a standard capacity declaration form (GC-335) for mandatory use in conservatorship proceedings.

Judicial Council Advisory Committee

Last year, the Probate and Mental Health Advisory Committee of the Judicial Council formed a Conservatorship and Legal Capacity Subcommittee. The subcommittee has identified several areas of tension between statutory standards for establishing a conservatorship, standards for determining lack of capacity, typical use of the declaration form, and the information and conclusions sought from clinical evaluators from the form. The subcommittee has been soliciting the opinions of medical and mental health practitioners through a team of collaborators in the Keck School of Medicine at the University of Southern California. Recommendations from the subcommittee are likely to be circulated to the public for comment in the spring of 2020.

Medical Capacity Recommendations

Nearly all probate conservatorship petitions are decided without an evidentiary hearing. Some are adjudicated without the respondent having an attorney. In too many cases, the

conservatee or proposed conservatee never appears in court so the judge may not have even one face-to-face encounter with the individual whose rights may be taken away.

The judges who decide these cases and issue orders transferring medical decision-making authority to a conservator rely heavily on the documents in the court file, especially on the capacity declaration form filed by a medical doctor or psychologist.

There is simply not enough information in the standard form to ensure due process and a just result for conservatees and proposed conservatees. The information that is included in the capacity form (GC-335) and attachment (GC-335a) is not sufficient for a judge to make an informed and reliable determination that all of the factual findings required by the Probate Code have been met. There is also inadequate information about the qualifications of the practitioner to render a dependable opinion on the matter and to demonstrate that the evaluation process is fair and reliable.

Since most judicial determinations of capacity to make medical decisions are rendered on the basis of documents without the benefit of testimony, the paperwork before the judge should include much more information than is currently required by these Judicial Council forms.

Additional information should be included in the form to bring to the attention of the court and the parties: potential conflicts of interest of the evaluator, the methodology used, whether there was ADA compliance, the objectivity of the evaluator, and his or her competence.

It is recommended that the Judicial Council require the following information to be provided by a physician or psychologist executing a Capacity Declaration Form:

1) Name of the person who scheduled the appointment;
2) Name and relationship of the person who paid the evaluator's fees;
3) Prior contact of the evaluator with petitioners, proposed conservators, or their attorneys;
4) Names and relationships of individuals present during the evaluation;
5) Extent of prior medical relationship of the evaluator with the person evaluated;
6) What ADA assessment was done prior to the evaluation to determine what supports and services might be necessary to ensure effective communication by the person evaluated and meaningful participation of that person in the evaluation process;
7) Training and experience of the evaluator to interact with and evaluate people with developmental disabilities or seniors with dementia or other adults with cognitive issues;
8) Amount of time that was spent during the evaluation process;

9) Names of persons other than the respondent who were interviewed;
10) Documents that were reviewed;
11) List of all medications the person evaluated has been taking prior to and at the time of the evaluation and whether those medications might have side effects that could affect the performance of the person during the evaluation;
12) Whether the effects of the medications were ruled out as a source of incapacity; and
13) Whether the respondent is suffering from depression and whether such depression was ruled out at the source of some or all of the incapacity; and
14) Whether a thorough medical examination has been performed recently for the person in order to determine if the person had a treatable condition that might have caused his or her inability to successfully complete the evaluation.

It is also recommended that, since judges are so pressed for time, the addendum should contain a short and concise narrative about the practitioner's opinion and the basis for the opinion. It should also state the degree of certainty underlying the practitioner's opinion that there is no form of medical treatment for which the conservatee has the capacity to give informed consent. Is the opinion supported by reasonable suspicion, probable cause, preponderance of evidence, or clear and convincing evidence? The practitioner should know the definition for each degree of proof.

Recommendations on Personal Presence

Form GC-335 asks the practitioner to render an opinion on the whether the conservatee or proposed conservatee is able to attend the court hearing: (1) on a particular date or (2) in the foreseeable future.

An individual has a constitutional right to attend court hearings involving a significant deprivation of liberty. (*People v. Nguyen* (2011) 194 Cal.App.4th 774, 780.) Probate Code Section 1823 also confers a right to attend conservatorship hearings. The ADA places an obligation on the court to ensure that a litigant with disabilities has effective communication and meaningful participation in court proceedings. Such attributes are lacking when someone does not attend a hearing.

Of course, constitutional and statutory rights can be waived. But any waiver of rights must be knowing and intelligent. Therefore, in order to effectively waive the right to personal presence at a conservatorship hearing, a conservatee or proposed conservatee would have to be properly informed by someone, in an ADA- compliant manner, of the purpose of the hearing, the right to attend, and the value to the individual and benefit to the court of the individual being present in court. If the individual does not appear and a court investigator or someone else tells the court that the person does not want to appear at the hearing, the court has no way of knowing whether that decision was truly knowing

and voluntary. There are no procedural safeguards in current law to ensure such.

There are two areas where additional safeguards should be required.

It is recommended that if a practitioner declares that an individual is unable to attend a hearing or hearings due to medical inability, the form should ask the practitioner to describe the specific reasons for that medical inability. To comply with the ADA, there should also be an opinion on whether presence would be possible if certain supports or services were provided by the court to the individual. If the practitioner is unsure of this, the practitioner should recommend that an ADA needs assessment be done by a qualified professional to make this determination.

It is also recommended that the capacity declaration form should ask the practitioner to render an opinion on the individuals's capacity to waive the right to attend court hearings. The practitioner should evaluate the individual's ability to understand the consequences of the proceedings, the benefit to the individual of personal presence, and the value to the court of having the individual at the hearing and the ability to make an informed decision on waiving the right to be present in court. An informed waiver of personal presence would require an understanding of these matters.

There is little attention paid to the presence or absence of respondents in court hearings. It is almost as if the ability of seniors and people with disabilities to see and hear what is happening, and the possibility of them contributing to the process, are irrelevant. Not enough importance is placed the value of personal presence to a judge who must decide the fate of individuals whose capacities are in question.

A recent appellate opinion has emphasized that personal presence is essential to the administration of justice in probate conservatorship proceedings. The opinion which is binding on trial courts throughout California states:[52]

> "A prospective conservatee . . . regardless of the degree of mental impairment, has due process rights. The Legislature has provided protection for a 'special needs' person. Presence in court so that the trial judge may see and hear the person is a necessary component of the process. . . . Section 1825 is like the light switch to the courtroom and until it is turned on (i.e., satisfied), the trial court cannot truly see the big picture. It is precluded from ruling on the merits of a petition to appoint a conservator until it complies with Section 1825."

In many cases, proposed conservatees have issued a power of attorney for health care or a medical directive months or years before a conservatorship proceeding was initiated. The

Legislature intended these documents to survive incapacity. This intent is violated when judges ignore or dismiss such documents without clear and convincing evidence that they were void or defective at the time they were executed, regardless of the individual's current level of medical capacity.

✓ **It is recommended** that if a proposed conservatee has executed a medical power of attorney or health care directive prior to the initiation of the conservatorship proceedings, Form GC-335 should ask the practitioner to assess whether, in his or her professional opinion, the individual had the capacity to execute the document at the time it was signed. Such previously executed documents should not be ignored or lightly dismissed as they often are. If such capacity existed at the time a document was signed, it should be honored and medical decision-making authority should not be delegated to a conservator.

Health Care Proxy

Capacity to make medical decisions requires the ability of a person to give informed consent to various medical procedures. Depending on the complexity of the medical procedure, and the risks involved, such capacity may require a degree of understanding and rational thought processes that a person with mental health challenges may not possess. However, that individual may have sufficient capacity to know who they want making such decisions for them.

There is a difference between capacity to give informed consent to medical procedures and capacity to name a health care proxy (HCP) to make such decisions on one's behalf. Just because capacity for the former is lacking does not mean that capacity for the latter is absent.

Naming a proxy to act on one's behalf is more in the realm of capacity to contract than capacity to give informed medical consent.

Evaluation of capacity to appoint a health care proxy (HCP) was explored in some detail in a manuscript published in the American Journal of Geriatric Psychiatry in 2013.[53] According to the article, "Most statutes do not provide clear legal guidance on capacity to appoint an HCP, but those that do, distinguish this capacity from medical decision-making consent capacity." California law does not give clear guidance.

Having consulted legal definitions in Utah and Vermont, which have specifically

addressed this issue, the article explains:

> "The evaluation of capacity to execute an HCP may consist of 1) capacity to understand the meaning (a) to give authority to another to make healthcare decisions, (b) through the HCP, (c) in the event of future or considering current diminished capacity to consent to treatment and 2) capacity to (a) determine and (b) express a consistent choice (c) of an appropriate surrogate. An appropriate surrogate may be defined as someone with whom the principal has a social (not professional) relationship, who knows the person's values, and who is willing (expresses interest and concern).This approach, we believe, provides a sufficiently high standard to avoid error and allows for completion of an HCP for the provision of care but a low enough standard to avoid burdensome challenges of proof and legitimacy. Furthermore, in situations where the identified individual to serve as healthcare agent has a history of inability to fulfill his or her responsibility. . . it should alert clinicians to ask additional questions and engage in a discussion with the patient about their understanding of the individual whom they have chosen. Situations in which there appears to be fluctuation in choice depending on external influences should also alert the clinician to engage in further investigation. For example, a situation in which an individual appears to change his or her choice of agent in proximity to interactions or visits with potential agents might raise concern about coercion, pressure, or lack of voluntariness."

The Vermont statute says: "An individual shall be deemed to have capacity to appoint an agent if the individual has a basic understanding of what it means to have another individual make healthcare decisions for oneself and of who would be an appropriate individual to make those decisions, and can identify whom the individual wants to make health care decisions for the individual." (Title18, Ch. 231, Sec. 9701(2)(A).)

In Utah, specific guidance is given to capacity assessment professionals and courts on this issue. Probate Code Section 75-2a-105 (Capacity to complete an advance health care directive) states: (1) An adult is presumed to have the capacity to complete an advance health care directive. (2) An adult who is found to lack health care decision making capacity under the provisions of Section 75-2a-104: (a) lacks the capacity to give an advance healthcare directive, including Part II of the form created in Section 75-2a-117, or any other substantially similar form expressing a health care preference; and (b) may retain the capacity to appoint an agent and complete Part I of the form created in Section75-2a-117. (3) The following factors shall be considered by a healthcare provider, attorney, or court when determining whether an adult described in Subsection (2)(b) has retained the capacity to appoint an agent: (a) whether the adult has expressed over time an

intent to appoint the same person as agent; (b) whether the choice of agent is consistent with past relationships and patterns of behavior between the adult and the prospective agent, or, if inconsistent, whether there is a reasonable justification for the change; and (c) whether the adult's expression of the intent to appoint the agent occurs at times when, or in settings where, the adult has the greatest ability to make and communicate decisions.

The New York Center for Elder Law and Justice commented on the issue of whether someone who lacks capacity to make health care decisions nonetheless may have capacity to name a health care proxy: "Every NYS adult is presumed competent to appoint a health care agent unless determined otherwise pursuant to a court order. As such, an individual with dementia may not have the capacity to make health care decisions, but may still have competency to make a decision to appoint a family member to make health care decisions. All that is needed is a 'moment of clarity'."

✓ **It is recommended** that the Legislature pass a law similar to those in Utah and Vermont recognizing a lower threshold of capacity to designate a healthcare proxy than to make one's own medical decisions. An individual may not have capacity to give specific instructions to the proxy on what decisions to make under various circumstances, but he or she may have the capacity to know who the person wants to make such choices. Courts and capacity assessment professionals in California need such statutory guidance.

Finances

California law allows a spouse, relative, interested public agency, or any interested person to file a petition with the superior court asking for appointment of a conservator of the estate of an individual. (Probate Code Section 1820.) The petition must allege "the inability of the proposed conservatee to substantially manage his or her own financial resources, or to resist fraud or undue influence." (Probate Code Section 1821(a)(5).)

The allegations of the petition track the statutory requirements for establishing a conservatorship of the estate of any adult or a limited conservatorship of the estate of an adult with developmental disabilities. (Probate Code Section 1801.) However, substantial inability may not be established solely by evidence of isolated incidents of negligence or improvidence. (Probate Code Section 1801(b).)

If the need is established to the satisfaction of the court and other legal requirements have been met, the court may appoint a conservatorship of the estate. (Probate Code Section

1800.3.) However, before doing so, the court must make an express finding that the granting of the conservatorship is the least restrictive alternative needed for the protection of the conservatee.

Statutory requirements for a conservatorship of the estate must be established by clear and convincing evidence. (Probate Code Section 1801(e).) That is a very high standard of proof, and rightfully so, since taking away an individual's right to make financial decisions and control his or her property infringes on fundamental constitutional rights. The constitution does not allow a person to be stripped of fundamental rights without such a high standard of proof. (*Conservatorship of Sanderson* (1980)106 Cal.App.3d 611, 620.)

Constitutional Rights

The Fourteenth Amendment to the United States Constitution provides that no state shall deprive a person of life, liberty, or property without due process of law. The requirement of due process applies to proceedings to establish a conservatorship of the person or the estate because such proceedings involve a potential deprivation of liberty and because an order imposing a conservatorship places a stigma on the conservatee. (*Sanderson*, supra.)

The California Constitution declares that acquiring, possessing, and protecting property is an inalienable right. (Cal. Const. Art. I, Sec. 1.) Property rights may not be infringed by the state without due process of law. (Cal. Const. Art. I, Sec. 7.)

The California Supreme Court has declared: "To both the citizen and his government the right to contract is the most valuable right known to the law. The Constitution guarantees its inviolability." (*May v. Board of Directors* (1949) 34 Cal.2d 125, 132.) That is why the infringement of that right by an order of conservatorship requires clear and convincing evidence of the need for such intervention and a finding that no less restrictive alternative will suffice to protect the individual.

The clear and convincing evidence test requires a finding of high probability based on evidence so clear as to leave no substantial doubt and must be sufficiently strong to command the unhesitating assent of every reasonable mind. (*Conservatorship of Wendland* (2001) 26 Cal.4th 519, 552.)

This standard should not only govern a judicial finding of the necessity for a conservatorship, it should also guide a capacity assessment professional who renders an opinion that someone is unable to manage finances or resist undue influence. The professional should have no significant doubt on the issue.

Presumptions and Proof

At the beginning of a proceeding to establish a conservatorship of the estate, it is presumed that the individual in question has the capacity to enter into contracts. That is because all persons are capable of contracting unless it is established they are of unsound mind or that a court has taken away their civil rights. (Civil Code Section 1556.)

The Legislature has declared that for purposes of conservatorship proceedings: "[T]here shall exist a rebuttable presumption affecting the burden of proof that all persons have the capacity to make decisions and to be responsible for their acts or decisions." (Probate Code Section 810(a).) The mere fact that someone has a mental disorder does not deprive the person of capacity to handle financial affairs or enter into contracts. (Probate Code Section 810(b).)

Capacity Assessment Criteria

So what should a judge or a professional evaluator focus on to determine whether an individual lacks the capacity to substantially manage financial affairs or resist fraud or undue influence? Subdivision (c) of Probate Code Section 810 explains that such a determination "should be based on evidence of a deficit in one or more of the person's mental functions rather than on a diagnosis of a person's mental or physical disorder." The mere diagnosis of a mental or physical disorder is not sufficient in and of itself to support a determination that a person is of unsound mind or lacks the capacity to do a certain act. (Probate Code Section 811(d).)

The Legislature has clarified that a determination of incapacity in financial management shall be supported by evidence of a deficit in at least one of the following mental functions and evidence of a correlation between the deficit or deficits and the decision or acts in question: (1) alertness and attention; (2) information processing; (3) deficits in thought processes; and (4) inability to modulate mood and affect. (Probate Code Section 811(a).)

A deficit in the mental functions listed above may be considered only if the deficit, by itself or in combination with one or more other mental function deficits, significantly impairs the person's ability to understand and appreciate the consequences of his or her actions with regard to the type of act or decision in question. (Probate Code Section 811(b).)

If there is no significant impairment in mental functioning as defined above, someone can still lack capacity for financial management if they are not able to communicate a

decision, by whatever means, or are not able to understand: (1) the rights, duties, and responsibilities created by the decision; (2) the probable consequences to the individual and others affected by the decision; and (3) the significant risks, benefits, and alternatives involved in the decision. (Probate Code Section 812.)

Capacity Assessment Procedures

California law requires a medical capacity declaration to be filed by a physician or psychologist before an individual's right to make *medical* decisions can be taken away in a probate conservatorship proceeding. It is noteworthy that the right of an individual to manage *financial* affairs can be removed without the court having the benefit of a professional capacity assessment that focuses on the criteria mentioned above. This is often done without any evidentiary hearing whatsoever.

Conservatorship orders are usually issued simply on the basis of paperwork. There is no requirement for a financial capacity declaration to be included. This seems odd, considering the pronouncement of the Supreme Court that "the right to contract is the most valuable right known to the law." (*May*, supra.)

That is not to say that professional assessments of financial capacity are never done; they are. But whether they occur depends on the policies of individual judges or the diligence or lack thereof of attorneys representing proposed conservatees. In too many cases, the proposed conservatee does not even have an attorney so there is no legal advocate to demand a financial capacity assessment.

This gap in the law should be filled. The removal of an individual's right to manage financial decisions is too important to be based merely on the allegations or testimony of lay witnesses.

It is recommended that the Legislature enact a law requiring a financial capacity declaration to be submitted in any proceeding to establish a conservatorship of the estate. The law should specify that the assessment be done by a qualified financial capacity assessment professional with training in conducting such evaluations for the type of proposed conservatee being evaluated. The assessment of seniors with cognitive challenges may be different than the assessment of adults of various ages who have developmental disabilities.

When there is a financial capacity assessment done, there are no guarantees that the professional evaluator will obey federal and state laws prohibiting discrimination on the basis of disability in the delivery of services. Title III of the Americans with Disabilities Act requires businesses to provide accommodations to individuals with disabilities to

ensure meaningful access to professional services. Section 51 of the California Civil Code requires the same. Government Code Section 11135 applies the same mandate to professionals whose services are being paid with state funds.

It is recommended that the Legislature direct the Judicial Council to create a financial capacity assessment form for use in proceedings to establish a conservatorship of the estate. The form should require professionals who conduct financial capacity assessments to declare they are aware of the requirements of the Americans with Disabilities Act, Civil Code Section 51, and Government Code Section 11135 and that they have provided the necessary accommodations to ensure the individual can participate in the evaluation process in as meaningful a manner as reasonably possible.

Financial capacity evaluators are conducting forensic assessments. They should be required to specify the training, education, and experience they have in conducting such assessments. They should adhere to professional ethics and codes of conduct. The same concerns about competence and methodology raised in the section on medical capacity apply here as well.

It is recommended that the Legislature direct the Judicial Council to include in a financial capacity assessment form a requirement that professionals conducting the evaluation certify the training they have received to qualify them to perform such assessments and to certify that they complied with professional ethical requirements in the assessment process.

As mentioned above, a conservatorship of the estate may not be granted if a less restrictive alternative will provide the needed protection for a person who currently lacks capacity to manage financial matters or resist fraud or undue influence. Just as a preexisting health care directive may be a less restrictive alternative to a conservatorship of the person, so too may a preexisting trust or financial power of attorney be a viable alternative to a conservatorship of the estate.

The court and any financial capacity evaluator should be made aware of such existing documents by the petitioner or attorney for the proposed conservatee. These documents should be honored unless the capacity evaluator finds that the individual lacked capacity when the documents were executed or that the documents were signed as a result of undue influence. Dishonoring such preexisting documents without a proper inquiry into their validity at the time they were executed would violate due process.

It is recommended that the Legislature direct the Judicial Council to include in a financial capacity assessment form a place for the evaluator to certify that the

evaluator has considered any preexisting powers of attorney or trusts that may have been executed prior to the onset of the disabilities in question and to render an opinion on whether the individual had the requisite capacity to execute those documents at the time they were signed.

Marriage

The capacity to consent to a marriage is a hybrid question of law and fact. For the legal part of the analysis, federal constitutional law must be considered in addition to state law pertaining to statutory prerequisites to a valid marriage, including the capacity to consent to marriage.

Federal Constitution

The freedom to marry is a fundamental right protected by the constitution. *(Griswold v. Connecticut* (1965) 381 U.S. 479.) All adults, regardless of gender, have a right to marry. The right is protected by the due process clause and the equal protection clause of the Fourteenth Amendment to the United States Constitution. (*Obergefell v. Hodges* (2015) 135 S. Cr. 2584) The Fourteenth Amendment protects "personal choices central to individual dignity and autonomy, including intimate choices that define personal identity and beliefs." (*Obergefell*, at p. 2597) Thus, in when it comes to marriage, what is protected by the constitution is freedom of choice. If an individual lacks capacity to consent to a marriage contract – and marriage is a contract – then the protections of the Fourteenth Amendment would not apply because there would be no freedom of choice.[54]

California Statutes

"Marriage is a personal relation arising out of a civil contract between two persons, to which the consent of the parties capable of making that contract is necessary." (Family Code Section 300.)

"Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution and laws of the State of California." (Welf. & Inst. Code Section 4502.) Assuming they have the capacity to consent to marriage, adults with developmental disabilities have a constitutional right to marry.

"The appointment of a conservator of the person or estate or both does not affect the capacity of the conservatee to marry or to enter into a registered domestic partnership." (Probate Code Section 1900.) "The court may by order determine whether the conservatee has the capacity to enter into a valid marriage . . . ." (Probate Code Section

1901.)

The validity of a marriage depends on whether an adult can supply the necessary consent to the marriage contract. That would depend on two factors: (1) whether the individual has the capacity to consent under the criteria specified in Probate Code Section 810 through 812; and (2) if the individual has such capacity, whether there was actual consent or whether any assent to the marriage was the result of fraud, duress, or undue influence. The ability of an individual to resist undue influence may be a factor that is considered in an evaluation of the individual's capacity to consent to marriage.

Probate Code Section 810 - 813 (Legal Capacity)

Section 810. "(a) For purposes of this part, there shall exist a rebuttable presumption affecting the burden of proof that all persons have the capacity to make decisions and to be responsible for the their acts or decisions."

Section 810. "(b) A person who has a mental or physical disorder may still be capable of contracting . . . marrying . . . and performing other actions."

Section 810. "(c) A judicial determination that a person . . . suffers from one or more mental deficits so substantial that, under the circumstances, the person should be deemed to lack the legal capacity to perform a specific act, should be based on evidence of a deficit in one or more of the person's mental functions rather than on a diagnosis of a person's mental or physical disorder."

Section 811."(a) A determination that a person . . . lacks the capacity to make a decision or do a certain act , including, but not limited to, the incapacity to contract [or] . . . to marry. . . shall be supported by evidence of a deficit in at least one of the following mental functions, subject to subdivision (b), and evidence of a correlation between the deficit or deficits and the decision or acts in question: (1) alertness and attention . . . (2) information processing . . . (3) thought processes . . . (4) ability to modulate mood and affect . . ."

Section 812. "Except where otherwise provided by law, including, but not limited to, Section 813 [medical decisions] and the statutory and decisional law of testamentary capacity, a person lacks the capacity to make a decision unless the person has the ability to communicate verbally, or by any other means, the decision, and to understand and appreciate, to the extent relevant, all of the following: (a) The rights, duties, and responsibilities created by, or affected by the decision. (b) The probable consequences for the decisionmaker and, where appropriate, the persons affected by the decision. (c) The significant risks, benefits, and reasonable alternatives involved in the decision."

Welfare and Institutions Code Section 15610.70 (Undue Influence)

(a) "Undue influence" means excessive persuasion that causes another person to act or refrain from acting by overcoming that person's free will and results in inequity. In determining whether a result was produced by undue influence, all of the following shall be considered: (1) The vulnerability of the victim . . . (2) The influencer's apparent authority . . . (3) The actions or tactics used by the influencer . . . and (4) The equity of the result.

Court of Appeal

"Simply stated, the required level of understanding depends entirely on the complexity of the decision being made. There is a large body of case authority reflecting an extremely low level of mental capacity needed before making the decision to marry or execute a will. Marriage arises out of a civil contract, but courts recognize this is a special kind of contract that does not require the same level of mental capacity of the parties as other kinds of contracts. (*In re Marriage of Greenway* (2013) 217 Cal.App.4th 628, 641.)

Assessment Criteria

A recent article in a professional psychiatric journal discussed assessment criteria for evaluating capacity to consent to marriage.[55]

> "There are four basic elements to assessing capacity, and it is important to keep in mind that capacity is decision specific and can be fluid. . . . The first criterion is that a patient must be able to express a clear and consistent choice. . . . Second, the patient must be able to understand the risks and benefits of the decision, as well as the alternatives. . . . The third prong of a capacity assessment is to be able to apply those risks, benefits, and information regarding the decision to the evaluee . . .[T]his means he would be able to understand how those elements apply in his particular case. . . Finally, the patient must be able to manipulate the relevant information rationally, meaning that there is not, for example, a mental illness such as dementia, psychosis, or severe depression that is hindering rational thought. . . . An individual must meet all four criteria to be deemed to have capacity to make the decision. It is valuable to keep in mind that the capacity threshold changes depending on the implications of the decision. . .With the decision to marry, this capacity threshold also applies, and the higher risk situations are those with more financial or family implications."
>
> "We can see several guidelines emerge as we apply these principles to the

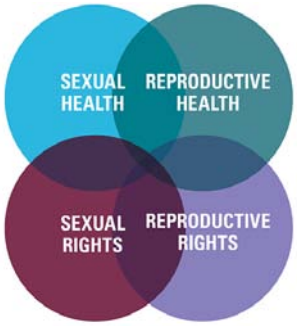
> capacity to marry. First, an individual entering into a marriage must do so voluntarily. There cannot be undue influence or coercion. Second, the individual must have the capacity to do so, as defined above by the four criteria. Finally, the individual must know with whom he is entering into this contract. . . ."

According to this scholarly article, in order to have capacity to marry, "An individual must express a consistent choice, understand the implications of the decision, and be able to reason rationally about the decision." Even though some cases have discussed there being a low level of capacity in order to consent to marriage, the fact is that marriage is a contract that carries with it a wide range of financial implications and obligations. Therefore, an evaluation of capacity to consent to marriage should be done thoroughly and carefully.

According to the presiding judge of the probate division of the Los Angeles Superior Court, some judges in conservatorship proceedings have given little weight to recommendations made by regional centers that proposed conservatees with developmental disabilities should retain the right to marry.[56] In addition to concerns that the recommendations were coming from staff who were not qualified to conduct capacity assessments, Judge Michael Levanas observed that recommendations on marriage capacity seemed to be based more on philosophical or political considerations by regional center staff than on medical or psychological criteria.

✓ **It is recommended** that the Association of Regional Center Agencies develop guidelines for evaluations of the capacity of clients to consent to marriage. These guidelines should be developed in consultation with psychological and medical professionals as well as the Client's Rights Office of Disability Rights California.

✓ **It is also recommended** that the Department of Developmental Services establish criteria for determining the training and experience required for regional center staff or medical or mental health professionals to be considered qualified to conduct assessments of capacity to consent to marriage.



Sexual Activities

The United States Supreme Court has ruled that the due process clause of the Fourteenth Amendment protects the right of two individuals to engage in fully and mutually consensual private sexual conduct. (*Lawrence v. Texas* (2003) 539 U.S. 558.) However, that ruling does not affect a state's legitimate interest and indeed, its duty, to interpose when consent is in doubt.

(*Anderson v. Morrow* (9th Cir. 2004) 371 F.3d 1027, 1032-1033.)

Although the regulation of sexual conduct is generally a matter of state law, now that decisions regarding consenting adult sex are protected by the federal constitution, the issue of consent, and the underlying issue of capacity to consent to sex, also implicate federal constitutional issues.

As an analogy, criminal law is a matter of state law. But search and seizure law, including whether there is consent to a warrantless search, are issues governed by federal constitutional law. This is because the 4th Amendment's prohibition against warrantless searches and seizures is made applicable to the states through the 14th Amendment to the United States Constitution.

State law on consent may help inform the inquiry, but ultimately whether consent to sexual activity or the capacity for such exists is ultimately a matter of federal constitutional law. State actions that infringe on fundamental constitutional rights must be narrowly tailored to serve compelling state interests. Thus, an assessment on an adult's capacity to consent to sex must not be arbitrary, irrational, or overly broad. Such shortcomings would violate due process.

Legal standards on capacity to consent to sex with another adult vary from state to state.[57] Some states require only that an individual must be aware of the nature of the act, namely, that the person is engaging in sexual conduct as opposed to some other type of activity. This is a very low threshold to pass. Other jurisdictions require an understanding of the nature of the act as well as the possible consequences. Most states adopt this approach. A few states have an even stricter requirement that an individual must also understand the moral implications of engaging in such activity. California has adopted the middle approach.[58]

"[L]egal consent presupposes an intelligence capable of understanding the act, its nature, and possible consequences." (*People v. Griffin* (1897) 117 Cal. 583, 585, 49 P. 711, overruled on other grounds in *People v. Hernandez* (1964) 61 Cal.2d 529, 536; *People v. Lewis* (1977) 75 Cal.App.3d 513, 519.) This quote was approved in *People v. Hillhouse* (2003) 109 Cal.App.4th 1612. Put another way, capacity to consent to sex is lacking if a person is "unable to understand the act, its nature, and possible consequences." (*People v. Miranda* (2011) 199 Cal.App.4th 1403.)

Forensic Practices

In an effort to develop uniform clinical criteria for capacity to consent, a US study conducted by Kennedy and Niederbuhl (2001) examined the views of over 300

psychologists on the criteria required for determining capacity to consent to sexual relationships. Participants were asked to grade 56 statements from "most important" to "least important." The results demonstrated that the following abilities were judged absolutely necessary to demonstrate capacity in this area of decision-making:

(1) Individual can say or demonstrate 'no''
(2) Individual knows that having intercourse can result in pregnancy;
(3) Individual can make an informed choice when given options;
(4) Individual knows that having intercourse or other sexual relations can result in obtaining a disease;
(5) Individual can differentiate between appropriate and inappropriate times and places to engage in intimate relations;
(6) Individual can recognize individuals who or situations which might be a threat to him or her;
(7) Individual will stop behavior if another person tells him or her 'no.'

Just as in other areas of capacity assessments, in the context of a conservatorship proceeding an adult is presumed to have capacity to consent to sex and any alleged lack of capacity must be shown by clear and convincing evidence.

Just as capacity to make medical decisions is not an all-or-nothing proposition – a person may have capacity to make some medical decisions but not others– the same is true for capacity to consent to sex. For example, a person may have capacity to make decisions regarding the frequency of solitary masturbation in private or whether to view sexually explicit photos or videos of adult sexual activity. Those are low-risk activities.

In contrast, a person may not have capacity to engage in sexual conduct with another adult, due to the inability to say "no"or to respect the other person's decision to say "no." An individual also may lack an understanding of the potential consequences or risks of certain types of sexual conduct.

Probate Code Section 810 (c) states: "A judicial determination that a person . . . suffers from one or more mental deficits so substantial that, under the circumstances, the person should be deemed to lack the legal capacity to perform a specific act, should be based on evidence of a deficit in one or more of the person's mental functions rather than on a diagnosis of a person's mental or physical disorder."

Rendering an opinion about the capacity to consent to future sexual conduct is a major undertaking with significant consequences and should be done with the utmost of care

and precision. A judge should not restrict an individual's fundamental right to sexual expression without clear and convincing evidence of incapacity.

Because a fundamental right is involved, the evidence should be solid. Allegations or testimony by lay witnesses should not be a sufficient basis for a judge entering an order that restricts a conservatee's right to sexual expression or intimate association indefinitely into the future. Such drastic state intervention should be based on expert testimony from a qualified professional using clinically sound forensic practices.

✓ **It is recommended** that the Legislature enact a law precluding a court from restricting the right of a conservatee to engage in solitary sexual activity or in activity with another adult, unless the individual has been evaluated by a qualified professional who has submitted a report to the court indicating that sexual incapacity exists and the facts and reasons underlying this opinion. The Legislature should specify the necessary training and experience a professional must have in order to be qualified to render such an opinion. In formulating this legislation, the Legislature should consider the views of people with disabilities, family members, advocates, professional associations, scholars, and individual medical and mental health practitioners.

Social Activities

The right to make social decisions arises routinely in limited conservatorship proceedings involving adults with intellectual or developmental disabilities. Courts consider, and regional centers make recommendations, whether a proposed limited conservatee should retain social rights – who to associate with, who not to associate with, and what types of recreational activities to pursue or not.[59] The issue of social rights may also arise in general conservatorship proceedings.

Since a capacity determination is a mixed question of law and fact, it is important for capacity assessment professionals to be aware of constitutional and statutory provisions protecting the social decision-making rights of all Americans, including those with cognitive or other disabilities.

Legal Principles

The following constitutional and statutory principles are implicated in court orders, or

directives from conservators, which restrict the social rights of conservatees.

State Action. The federal Constitution protects individuals from "state action" that infringes on their rights. A judicial order restricting social rights is a form of state action.

Fourteenth Amendment. The Fourteenth Amendment to the United States Constitution protects the "liberty"of United States residents. The Fourteenth Amendment is binding on state governments. It makes First Amendment protections applicable to the states.

The liberty provision in the due process clause of the Fourteenth Amendment protects freedom of choice in certain highly personal areas, including family relationships. A conservatee has a constitutional right to decide which family members to associate with and which ones to avoid.

The parent of an adult child does not have the right to enlist the power of the government to force or pressure an adult child to visit with the parent. The parent has no statutory right to visitation with an adult child, and even if such a statutory right were created, it would violate the federal constitutional rights of the adult child. The same is true regarding visitation rights of an adult child with an elderly parent.

First Amendment. The First Amendment protects freedom of speech and association. Freedom of association includes the freedom not to associate. Freedom of speech includes the freedom from "forced listening." A court order requiring visitation or a conservator's directive pressuring a conservatee to visit with someone he or she does not want to visit is a form of state action violating the conservatee's freedom not to associate and freedom from forced listening. Making a conservatee become a "captive audience" is unconstitutional.

The United States Supreme Court has clarified that: "Freedom of association . . . plainly presupposes a freedom not to associate." (*Roberts v. Jaycees* (1984) 468 U.S. 609.) Adults regularly exercise their freedom of association in connection with family relationships. They may choose to visit their relatives or they may choose to reject contact with them. No one has the right to override an adult's decision to associate with or not associate with a particular person.

Statutory Presumptions. California law presumes that a limited conservatee will retain his or her social rights unless they are affirmatively removed by a court order. California law directs that the limited conservatorship system should encourage limited conservatees to be as independent as possible. The Lanterman Act was passed by the California Legislature decades ago. It affirms that people with developmental disabilities have the same constitutional rights as those without disabilities. (Welfare and Institutions Code

Section 45502.) This includes "a right to make choices in their own lives"including in the area of "social interaction."

Burden of Proof. These constitutional principles and statutory presumptions require that the person seeking to restrict the social rights of a conservatee should have the burden of proof. Those seeking to protect these rights should be able to rely on these presumptions and the court should require the party seeking restrictions to proceed as the moving party. The court should require evidentiary proof that such restrictions are: (1) factually necessary; (2) serve a compelling state interest, as opposed to a private interest or desire of a party; (3) are necessary to further the state interest; (4) are the least restrictive alternative.

Due to the fundamental nature of the constitutional rights being restricted, the court should require clear and convincing evidence. These legal requirements should be taken into consideration when a capacity assessment professional is asked to evaluate capacity to make social decisions. What is the risk of retaining social rights? Is there a history of tangible harm when the individual has made social decisions in the past? Is there a compelling need for restriction? Are there less restrictive alternatives to a complete loss of social rights?

Other Requirements. Even if the court grants authority to a conservator to make social decisions for the conservatee, that authority should never involve the conservatee being required or pressured to visit with someone against his or her will.

It is recommended that the Department of Developmental Services (DDS) amend regulations it has adopted on client's rights to clarify the right of adults with developmental disabilities to exercise their freedom of association. Section 50510 of Title 17 of the California Code of Regulations should be amended to specify that such adults have the right to make choices to associate or not associate with anyone and to have those choices respected and implemented.

The Lanterman Act states unequivocally: "Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution and laws of the State of California." The Statement of Rights also focuses on "personal liberty of the individual" and "least restrictive conditions," as well as a "right to religious freedom and practice," and a "right to social interaction." It also mentions a client's "right to make choices in their own lives" including "relationships with people in their community" and "leisure" activities.

DDS has promulgated regulations interpreting the rights mentioned in the Lanterman Act. With respect to the "right to religious freedom and practice" specified in that Act, the

regulations explain it in greater detail, stating that it encompasses: "A right to religious freedom and practice, *including the right to attend services or to refuse attendance, to participate in worship or not to participate in worship.*" (Section 50510(a)(4).) The italicized language was placed in the regulations to explain the scope of the statutory language.

It is recommended that DDS add the italicized phrase to Section 50510(a)(6) so that it states: "A right to social interaction and participation in community activities, *including the right to associate with specific individuals or not to associate with them.*" The regulation should be abundantly clear that the right to social interaction includes the constitutional right to freedom of association.

Assessment Process

The greater the risk of harm, the greater the level of capacity that should be required to make a decision. Almost everyone has the capacity to decide what clothes to wear or how to style his or her hair. Someone who may lack the capacity to make major medical or financial decisions, may easily have the capacity to make social decisions – especially decisions regarding those with whom they do not want to associate.

While some decisions are rooted primarily in intellect and mental judgment, others are based primarily in emotions. Decisions that are truly social are generally driven by emotions. "I like that woman or I don't like that man and therefore I want to be with her or I don't want to be with him." Especially since there is little harm in not socializing with someone, a person should never be deprived of the right to say "no" to unwanted social interactions.

No one would dare to argue that a judge or a conservator should have the authority to order a person to have sex with someone when they do not want to. The same should be true for social interactions.

While minor children may not have a legal right to choose their friends or who they will interact with, an adult with disabilities should have wide latitude in making social choices. Only for compelling reasons should a person lack the legal capacity to make social decisions. For example, if there has been a history of social decision-making that has actually caused serious harm to the individual, then the risk of future harm may outweigh the right to make social decisions without any restrictions. Absent such evidence, however, a capacity assessment professional recommending the restriction of social rights should be required to show exactly how the retention of these rights will harm the person and specifically what clear and convincing evidence exists to support an opinion that social rights should be restricted.

It is recommended that the Judicial Council include the issues of social decision-making capacity and constitutional rights in conservatorship training programs for judges. These issues should also be included in mandatory training programs for court-appointed attorneys in conservatorship proceedings.

Residence

Government action limiting the right of an individual to choose a place of residence implicates the constitutional right to travel and the constitutionally protected freedom of association. (*People v. Bauer* (1989) 211 Cal.App.3d 937, 944.) Restrictions on a person's choice of living arrangements may also violate the right of privacy under the California Constitution. (*City of Santa Barbara v. Adamson* (1980) 27 Cal.3d 123.)

When a petition for conservatorship is filed, the law presumes that a proposed conservatee has the capacity to make decisions, including a decision about where and with whom to live. (Probate Code Section 810.) Therefore, the burden is on the petitioner to establish by clear and convincing evidence that the proposed conservatee is unable to properly care for physical health, food, clothing or *shelter*.

The granting of an order of general conservatorship may take away from the conservatee the authority to select a place of residence and give that power to a conservator. That is why the clerk is required to notify a proposed conservatee that an order granting the petition may give to the conservator the power to fix the residence of the proposed conservatee. (Probate Code Section 1823(b)(2).)

When a petition for a general conservatorship is filed, an order granting the petition automatically gives the care, *custody*, and control of the conservatee to the conservator. (Probate Code Section 2351(a).) Having legal custody of an individual would include the authority to fix that person's place of residence. However, the proposed conservatee (presumably through his or her attorney) can ask the court for an order allowing the power to fix the place of residence to remain with the conservatee. (Probate Code Section 2351(b).)

In a general conservatorship proceeding, there is no requirement for a determination of the proposed conservatee's capacity to make decisions regarding the place of residence. If the petition for a general conservatorship is granted without a capacity assessment being done, the default result is that the conservator is given the power to fix the conservatee's place of residence. (Probate Code Section 2352(b).)

The only way to avoid such a result in a general conservatorship proceeding is for the proposed conservatee to expressly object to the transfer of that authority. Once such an objection is made, the court would need to decide the issue of capacity to make decisions to fix the proposed conservatee's place of residence.

The attorney for a proposed conservatee can ask for an expert to be appointed to make an evaluation on this issue under Evidence Code Section 730. *(Conservatorship of Scharles* (1991) 233 Cal.App.3d 1334) But the burden to request such an assessment is on the proposed conservatee in a general conservatorship proceeding.

Just the opposite result occurs in a limited conservatorship proceeding. If a petitioner files for a limited conservatorship, then even if the order is granted, the limited conservatee retains certain enumerated rights unless the court makes a specific finding to the contrary. (Probate Code Section 2351.5.) Among the rights presumptively retained is the authority to make decisions regarding residence. (Probate Code Section 2351.5(b)(1).)

The petitioner, however, may specifically ask for this authority to be included in the limited conservatorship order. If such a request is made, then the issue of the capacity of the proposed limited conservatee to select a residence becomes an issue to be determined by the court.

Under current standard procedures, in limited conservatorship proceedings the issue of capacity to make decisions regarding residence is unlikely to receive a professional assessment other than by a regional center employee. A review of regional center practices suggests that many employees lack the qualifications and training necessary to make reliable capacity assessments of this nature.

The Legislature has recognized the importance of allowing conservatees to remain in the homes they had prior to the initiation of a conservatorship proceeding. To that end, a presumption exists that the personal residence at the time the proceeding was commenced is the appropriate placement when an order of conservatorship is granted. (Probate Code Section 2352.5)

The issue of capacity to select one's own residence – considering the constitutional rights that are at stake – has not been given the importance it deserves. In general conservatorships, the issue is generally swept under the judicial rug. Too often the issue is all but ignored. The default procedure of transferring the power to fix a person's residence occurs without any capacity assessment determination being made on this issue is inconsistent with the requirements of due process.

It is recommended that the Legislature change the law to make the retention of the right to fix one's own residence the default result in a general conservatorship proceeding, absent a specific request in the petition for the transfer of such authority. When such a request is made, a professional assessment of such capacity should be required in the new law, just as a medical capacity assessment is currently mandated before a court takes away a person's right to manage his or her own medical care.

If a survey were taken of adults as to which right was more important – the right to select one's residence or the right to make medical decisions – it is hard to say which would be given priority. People would probably say they are equally important. But current law does not treat them as such.[60]

In terms of capacity to fix a residence for adults with developmental disabilities, the default position in limited conservatorship system allows an adult to retain that right unless incapacity on that issue has been established by evidence. The problem is that a petitioner can bypass this protection for limited conservatees simply by filing a petition for a general conservatorship. Protections of this sort should not be left to the whim of a petitioner.

It is recommended that the Legislature pass a law directing judges to process any conservatorship case involving an adult with a developmental disability as a limited conservatorship proceeding even if a petitioner files for a general conservatorship.

The procedural protections afforded to proposed limited conservatees should be afforded to adults with developmental disabilities regardless of the box that someone checks in the petition. Once a court becomes aware that the proposed conservatee has developmental disabilities, substance should take precedence over form and the matter should be handled as though it were a limited conservatorship proceeding.

Education

In the context of probate conservatorship proceedings, the issue of capacity to make educational decisions arises mostly with respect to young adults who have intellectual and developmental disabilities. The impetus for parents filing a petition for conservatorship may be based partly on their desire to continue making educational decisions after their child turns 18 and becomes an adult.

Some educational decisions pertain to which school is attended or focus on which classes will be taken. Other educational decisions are financial or contractual in nature. For the latter, the issue is capacity to manage financial affairs and the criteria for evaluating such is governed by those standards. For the former, which do not necessarily involve money, a different set of criteria for determining capacity should apply.

As with all legal issues of capacity, there is a presumption that the adult student has the capacity to make educational decisions. (Probate Code Section 810.) That presumption must be overcome by evidence to the contrary.

As with many other areas of decision-making, there are constitutional considerations that come into play. The Lanterman Act declares that individuals with developmental disabilities have the same constitutional rights as everyone else. (Welfare and Institutions Code Section 4502.) Access to a public education is a constitutional right. (*Steffes v. California Interscholastic Federation* (1986)176 Cal.App.3d 739, 746.)

The Lanterman Act affirms that individuals with developmental disabilities have "the right to make choices in their own lives" and that public or private agencies receiving state funds shall respect those choices. (Welfare and Institutions Code Section 4502.1.) Most schools with special education programs receive state funds.

If a petitioner files for a limited conservatorship, an adult retains the right to make educational decisions unless there is an order transferring that decision-making authority to a conservator. Retention of educational rights is the default result unless there is a request and order to the contrary. (Probate Code Section 2351.5.)

If a petitioner attempts to bypass the protections in limited conservatorship proceedings by filing for a general conservatorship, the default result under current law is that the authority to make educational decisions is removed from the person and transferred to a conservator. This capacity-disaffirming loophole in the law should be eliminated. The rights retained by default in limited conservatorship proceedings should apply to general conservatorship proceedings when the respondent has a developmental disability.

It is recommended that the Legislature pass a law requiring a professional capacity assessment to be done if a petitioner seeks to have educational decision-making power taken from a proposed conservatee. The right to make educational decisions is too important to be adjudicated on the basis of lay opinions. If the proposed conservatee is a regional center client, the law should require an interdisciplinary team from a regional center, through an Individual Program Plan (IPP) process, to evaluate the ability of the proposed conservatee to make educational decisions.

The evaluation of capacity to make educational decisions should include an assessment of available supports and services that would enhance the ability of the proposed conservatee to make responsible educational choices. Statutes prohibiting disability discrimination require an exploration of reasonable accommodations to enhance meaningful participation in all government services, including educational services. (Government Code Section 11135; Civil Code Section 51; Welfare and Institutions Code Section 4502.1.)

As for proposed conservatees without developmental disabilities, such as seniors and other adults with cognitive disabilities, many of the same considerations should apply. There is a presumption of capacity to make educational decisions. There is a constitutional right to access to a public education. There is also a legal requirement to provide accommodations during a capacity assessment process as well as to provide accommodations to enhance an individual's capacity to make educational decisions. This requirement is part of the Americans with Disabilities Act and state laws that implement the ADA in California. These laws apply to superior courts conducting conservatorship proceedings.

For many seniors, the right to make educational decisions may be of little concern. For others, however, it maybe something they care about. When it becomes apparent to their attorney or to a judge or court investigator that educational decision-making is something of value to a proposed conservatee, an assessment should be provided so this right is retained if possible.

Furthermore, just as in the area of medical decision-making, even if a person lacks the capacity to make significant medical decisions, that should not mean that capacity to select a surrogate decision-maker is lacking.

Before a court takes away the right of someone to make educational decisions, there should be an evaluation of whether that person has the capacity to name an "educational choice proxy" to make those decisions. The mental capacity to name a proxy for these decisions would allow proposed conservatees a degree of dignity and autonomy and would eliminate the prospect of stripping them entirely of the right to direct their education. It is better that they have a say in who makes such decisions than having no say at all.

Voting

California law on the capacity of conservatees to vote has changed dramatically in the past few years, largely due to the advocacy efforts of Spectrum Institute.

When we first studied the issue in 2014, we discovered that about 90% of conservatees were having their voting rights taken away due to alleged incapacity.[61] We tackled the problem by convening a voting rights conference,[62] sponsored reform legislation,[63] and filed a complaint with the United States Department of Justice that year.[64] The following year we supported follow-up legislation that changed the criteria for capacity to vote for conservatees. As a result, almost all new conservatorship orders allow conservatees to retain the right to vote. Existing conservatorships are another matter.

Prior to 2015, the law provided that a conservatee would be disqualified from voting if a judge in a conservatorship proceeding determined that the person was not able to complete an affidavit of voter registration.[65] Some judges interpreted this to mean an individual with a disability had to complete the affidavit without assistance.[66] Partial reform occurred in 2015 due to the passage of AB1311 which clarified that someone with a disability has the right to assistance in completing an affidavit of voter registration.

The following year, SB589 was passed. It went into effect on January1, 2016. The bill created a presumption that a person has the capacity to vote regardless of his or her conservatorship status. Removing the right to vote now requires proof, by clear and convincing evidence, that a person is unable to express a desire to vote. This burden is so onerous that after the passage of SB589, we estimated that 90% of conservatees are retaining their right to vote.

However, those who had been disqualified prior to the passage of SB589 remained disqualified. Affirmative action is necessary to restore the right to vote of the estimated 32,000 conservatees who had been disenfranchised over the previous 10 years.[67] Although SB589 requires court investigators to inquire about a conservatee's desire to vote when the conservator conducts a biennial review, there is no evidence that this is routinely being done. No one is monitoring this process. In some local courts, biennial reviews are seriously backlogged.

In 2016, we advocated for voting rights restoration and encouraged all regional centers to take a pro-active approach to ensuring their clients had their right to vote restored.[68] It is unknown what action, if any, was taken in response to our request.

The state should be engaging in ongoing actions to ensure that voting rights are restored to seniors and people with disabilities who had been disqualified from voting prior to the passage of SB 589 in 2016.

It is recommended that the Legislature direct the Department of Developmental Services to require regional centers, as part of their ongoing contractual duties, to take steps to ensure that all conserved regional center clients who desire to vote

have their voting rights restored. The Legislature should also direct the Department of Aging to coordinate with the Judicial Council to survey all superior courts about their voting rights restoration practices for all other adults who have lost their voting rights in conservatorship proceedings. Most of these individuals would have been seniors.

Waiver of Rights

The federal and state constitutions provide that no person shall be deprived of life, liberty, or property without due process of law. In proceedings to establish a conservatorship of the person, the liberty of a proposed conservatee is placed at risk, while property rights are jeopardized when a conservatorship of the estate is sought. Therefore, in either situation a proposed conservatee is entitled to due process protections. (*Conservatorship of Sanderson* (1980) 106 Cal.App.3d 611.)

In addition to constitutional requirements, parties to civil cases have statutory due process rights (*In re Elizabeth T.* (1992) 9 Cal.App.4th 636, 640.) The statutory provisions enacted by the Legislature governing probate conservatorships are a starting point to determine what process a proposed conservatee is due in these proceedings.

When a petition for a probate conservatorship is filed, the clerk of the court is required to send the proposed conservatee a citation which, among other things, informs the individual of his or her procedural rights. (Probate Code Section 1823.)

Among these protections are: "[T]he right to appear at the hearing and to oppose the petition, and in the case of an alleged developmentally disabled adult, to oppose the petition in part, by objecting to any or all of the requested duties or powers of the limited conservator." (Section 1823(b)(5)) The proposed conservatee also has "[T]he right to choose and be represented by legal counsel and has the right to have legal counsel appointed by the court if unable to retain legal counsel." (Probate Code Section1823(b)(6).)

The statutory right to oppose the petition includes the constitutional right to confront and cross-examine witnesses. These due process rights apply to conservatorship proceedings even though they are civil in nature. (*In re Donald R*. (1987) 195 Cal.App.3d 703, 712.) Due process also entitles a civil litigant the right to call witnesses and present evidence. *(Elkins v. Superior Court* (2007) 41Cal.4th 1337, 1357.)

Although constitutional and statutory rights can be waived, any such waiver must be made knowingly and voluntarily. Quite fundamental is having the capacity to waive

these rights.

In juvenile dependency proceedings where custody of a child is at issue, court rules allow a parent to waive his or her right to a contested hearing, to confront and cross-examine witnesses, and to present evidence. (California Rules of Court, Rule 5.682.) After waiving these rights, the parent can admit the allegations or agree to submit the matter for a decision based on documents only. However, before accepting such waivers, the court must inquire to ensure the parent understands these rights. The court must also determine whether the waivers are knowing and voluntary. If the waivers are submitted in writing rather than made orally in open court, the waiver form must be signed by the parent and the parent's attorney.

It is noteworthy that in probate conservatorship proceedings, where significant liberty and property interests are at stake, there is no similar court rule. There is no requirement for the court to inquire personally of the proposed conservatee regarding a waiver of his or her rights. Instead, judges often accept hearsay statements of a court investigator that the proposed conservatee was advised of his or her rights and does not want an attorney, does not want to appear in court, or does not want to contest the petition for conservatorship. (Probate Code Section 1826.)

In some cases, there is no court investigator appointed and thus no court investigator report. In those situations, courts may rely on the hearsay statement of a court-appointed attorney that the proposed conservatee is waiving his or her rights and is not contesting the petition. (*San Diego County v. John L*. (2010) 48Cal.4th 131.)

In the John L. case the Supreme Court was assuming that counsel had fully informed the client of his rights, that the client understood those rights, and that the rights were knowingly and voluntarily waived. While such assumptions may have been warranted in that case, reports of negligent representation by many court-appointed attorneys in probate conservatorship proceedings cast serious doubt on the validity or reliability of such assumptions in these proceedings.

Many probate conservatorship attorneys are not properly trained about how to communicate effectively with clients who have dementia or developmental disabilities that seriously interfere with understanding and communication. Most attorneys have not received training in the ADA accommodation requirements for the use of supports and services to ensure effective communication and meaningful participation in a court proceeding. Without such training and experience, purported waivers of statutory and constitutional rights by a senior with moderate or severe dementia, or an individual with a serious intellectual or developmental disability, should be highly suspect.

It should be remembered that prior to a waiver of rights by the court, evidence has been produced that the proposed conservatee has serious problems understanding, remembering, deliberating, and/or communicating. Evidence may indicate the alleged disabilities are so serious that the court should appoint someone to take control of the individual's personal or financial decisions.

In petitions for conservatorship of the person, it is likely that a sworn medical capacity declaration has been filed indicating that the individual cannot give informed consent to any medical procedure. If that is true, then how likely is it that the individual can give an intelligent waiver of his or her constitutional rights to a trial, to confront and cross-examine witnesses, and to present evidence?

In petitions for conservatorship of the estate, facts may have been presented in the petition and supplemental materials that the individual is not able to resist undue influence. If that is true, then how likely is it that the individual can resist direct assertions or subtle hints from a family member or even a court investigator that the individual should not oppose the petition?

The Rules of Professional Conduct prohibit an attorney from settling a case or waiving the right to a hearing without express prior approval from the client. (Rule 1.2.) This rule applies to all clients, even those with diminished capacity. The Supreme Court was asked to create a separate rule for such clients but declined to do so. So an attorney must receive the express consent of a proposed conservatee before the attorney can waive the client's rights in court.

When counsel advises a court that a litigant is waiving his or her rights, the waiver should be documented to assure the court that the litigant was aware of applicable constitutional rights and knowingly and intelligently waived them. (*In re Moss* (1985) 175 Cal.App.3d 913, 926.) Such an assurance is just as vital when the litigant does not have an attorney.

A determination of whether there has been an intelligent waiver of constitutional rights depends on the circumstances of each case. (*Moss*, p. 926.) The background and experience of a litigant should be considered. Cognitive disabilities are a factor in this evaluation.

Waivers of constitutional rights must be done with sufficient awareness of relevant circumstances and likely consequences. The validity of such waivers cannot be presumed from a silent record. A waiver of rights must be based on something other than speculation.

To be truly voluntary and intelligent in a constitutional sense, a waiver is valid only if a

litigant is aware of his or her rights and the consequences of the waiver. (*In re Hop* (1981) 29 Cal.3d 82, 91.) This would include the nature of a conservatorship, its probable duration, and the conditions under which the individual will be living while under an order of conservatorship.

The failure of a proposed conservatee to affirmatively demand his or her right to an attorney or a hearing does not constitute a knowing and intelligent waiver. It would be fundamentally unfair for a judge to place on an individual perceived to have serious cognitive or communication disabilities the burden of asserting his or her rights in order to avoid an implied waiver. (*Hop*, p. 91)

It should be emphasized that Title II of the Americans with Disabilities Act and California Government Code Section 11135 require courts to ensure that litigants with significant disabilities receive the accommodations necessary to maximize effective communication and meaningful participation in a judicial proceeding. The court may delegate the implementation of this responsibility to court staff or an appointed attorney, but ultimately it is the court that is responsible for ensuring compliance with these statutory obligations.

The process of approving a waiver of rights is part of the proceeding and therefore subject to ADA requirements. The court must take reasonable steps to inquire into the process by which the waiver occurred. Who informed the litigant of his or her rights? What was said and in what words? What evidence is there that the litigant understood those rights? What evidence is there that the purported waiver was knowing and voluntary?

More fundamental is the need for an inquiry by the court as to whether the litigant even had the capacity to waive his or her rights. Unfortunately, based on the way in which waivers of rights are presently occurring in probate courts throughout the state, it appears that capacity to waive rights is assumed. Such an assumption is misplaced unless there are assurances that the waiver process was ADA-compliant and there is evidence about the method of communication that was used and the level of understanding of the litigant about those rights.

It is recommended that the Judicial Council should study the issue of capacity of conservatees and proposed conservatees to waive statutory and constitutional rights with a view toward adopting a rule for probate conservatorship proceedings similar to Rule 5.682 in juvenile dependency proceedings. The Judicial Council should consult with the Department of Aging and the Department of Developmental Services regarding the capacity of seniors with cognitive disabilities and adults of all ages with intellectual and developmental disabilities to understand the nature

of conservatorship proceedings, the consequences of an order of conservatorship, the role of and importance of an attorney in such proceedings, and the ability of such adults to withstand direct or subtle pressures to waive their rights. The Department of Fair Employment and Housing enforces Section 11135 regarding the ADA duties of public entities, including the courts, and therefore should be consulted as well.

Chapter Nine

Court Investigators and Social Workers

In addition to physicians, psychologists, and regional center staff, there are other professionals who should have a significant involvement in the capacity assessment process in conservatorship proceedings. Court investigators have a statutorily defined role. Social workers could assist the court in identifying less restrictive alternatives. Unfortunately, both types of professionals are underutilized.

Court Investigators

Investigators employed by the superior court have a statutory duty to evaluate the capacities of proposed conservatees and to file reports with the court regarding the findings of their assessment of the individual and their investigation of the case. However, what investigators should be doing in these cases and what is actually occurring are two very different matters.

The legal duties of court investigators in probate conservatorship cases are set forth in the Probate Code. The training and education requirements for court investigators have been established by statute and detailed more fully by the Judicial Council in the Rules of Court.

By law, a court investigator assigned to conservatorship cases is required to have the training or experience or both necessary to conduct the investigations mandated by the Probate Code. An investigator must also possess the skills necessary to communicate with, evaluate, and interact with persons who are subject to these proceedings. That would include communications with seniors who have cognitive disabilities and adults of all ages who have developmental disabilities. (Probate Code Section 1454.)

Court investigators have the duty to interview proposed conservatees, petitioners, and proposed conservators. They must also evaluate mental function deficits described in Section 811(a) to determine whether they significantly impair an individual's ability to understand the consequences of his or her actions. (Probate Code Section 1826.) In effect, this is a mandate for court investigators to conduct a capacity assessment evaluation.

A typical job description posted when courts recruit for the position of court investigator says the applicant should have knowledge of: assessment and analytical skills; medical

and psychiatric terms and conditions; and interviewing and investigative techniques. It also says that applicants must have a college degree in psychology, social work, or behavioral science and two years of field interviewing.[69]

Within the first year on the job, court investigators should receive 18 hours of training, including information on elder and dependent adult abuse, medical issues, assessing community resources for seniors and dependent adults, and how to effectively interview persons with cognitive or communication disabilities. (Rule 10.478(b).)

Only local superior courts know what type of training investigators have actually received. There is no transparency on this – no statewide oversight and no outside monitoring as to whether this educational requirement is being met. There are no outside evaluations of the quality of pre-employment or in-service trainings.

What statutes and court rules require and what happens in reality are two different matters.[70] Spectrum Institute released a report on limited conservatorship trainings of court investigators in the Los Angeles Superior Court and concluded that the trainings that were being done at that time should receive a failing grade.[71]

The report reviewed the caseloads of court investigators in Los Angeles and discovered that in 2014 there were only 10 investigators on staff. They were required to perform 14,000 investigations per year. This, of course, was not possible to do. As a result of budget cuts in prior years, it was also discovered that the court had stopped using court investigators altogether in limited conservatorship proceedings.

The report revealed that judges were instructing court-appointed attorneys in Los Angeles to step outside of their role as advocate and defender for proposed conservatees and to take on the additional role of de-facto court investigator. Unfortunately, these attorneys followed this instruction and filed reports disclosing client confidences and making recommendations for what they thought was in the client's best interest rather than what the client may have wanted. Even though this dual role created a conflict of interest and violated ethical principles, the attorneys did not push back. The attorneys subrogated their ethical responsibilities to carry out the directives of the court.

Spectrum Institute monitored a conservatorship oversight hearing conducted by the Senate Judiciary Committee in 2015. The presiding judge of the probate division of the Los Angeles County Superior Court testified. She painted a bleak picture in terms of overworked court investigators with unreasonably large caseloads.[72]

Although the number of investigators had been increased to 20 when this hearing occurred, staff only had time to conduct field investigations one day per week. The judge

informed the legislative panel that there were 9,200 cases to be examined each year by these 20 investigators in guardianship and conservatorship proceedings (initial interviews, annual reviews, and biennial reviews). As a result of this staffing-to-duty ratio, our report calculated that each investigator would have to conduct nine field interviews on that one day of the week when they were able to go outside of the office. This obviously was completely unrealistic.

It is recommended that the Legislature direct the Judicial Council to investigate and issue a report within three years on how the 58 superior courts are training and utilizing court investigators in conservatorship proceedings. The report should address the contents and frequency of training programs, the caseloads of each investigator, whether investigators are used in all initial conservatorship proceedings, and any backlogs or delays in conducting biennial reviews. This information can be gathered through surveys of the superior courts conducted by the Judicial Council.

It is recommended that the Legislature should direct the State Auditor, within the next year, to initiate an investigation into the policies and practices of three local superior courts regarding the training, experience, and actual practices of court investigators in connection with probate conservatorship proceedings. The audit should determine what is actually happening in these three courts. This will provide the legislative and judicial branches a hint of what is likely happening in courts throughout the state. The three courts should include one large county such as Los Angeles, one medium sized county such as San Luis Obispo, and one small county such as Yolo.

Once such information is obtained and reported, corrective action can be taken by the Judicial Council and the Legislature. This type of an investigation should not be a one-time occurrence. The Legislature should direct the Judicial Council to survey court investigator practices in three superior courts each year. A report on the findings should be issued annually to the Legislature so that further corrective action, to the extent it may be necessary, can be taken.

Some local courts may cite budget shortages for the lack of proper training, large caseloads, and failure of investigators to perform statutorily-mandated duties. Some of these duties may be attributed to reforms enacted by the Legislature in 2006 – new duties that have never been funded by the Legislature.

Some statutes pertaining to court investigator duties have a clause that excuses nonperformance. For example, Probate Code Section 1850(f) states: “A superior court shall not be required to perform any duties imposed pursuant to the amendments to this section enacted by Chapter 493 of the Statutes 2006 until the Legislature makes an appropriation identified for this purpose.”

The clause excusing investigations without proper funding does not excuse the failure of courts to ensure that investigators perform duties existing prior to 2006, including duties required by the ADA and by the constitution. As for new duties imposed by the "Omnibus Conservatorship and Guardianship Reform Act of 2006," **it is recommended** that the Legislature, Judicial Council, and Governor take steps to ensure that local courts have sufficient funding so that court investigators can comply with new mandates imposed by this law. There is no valid reason to deprive courts of this funding, considering that the Omnibus Act was passed 14 years ago.

Social Workers

An order of conservatorship may not be granted unless the court finds that conservatorship is the least restrictive alternative to protect a proposed conservatee who lacks capacity to provide for basic needs or is not capable of resisting undue influence in financial matters. (Probate Code Section 1800.3.)

If a person can manage his or her life safely with the assistance of others, a court may not impose a conservatorship. The failure to explore such an option or to make an express finding that less restrictive alternatives are not available can invalidate an order of conservatorship. (*Conservatorship of Early* (1983) 35 Cal.3d 244.)

A petitioner must produce evidence that no less restrictive alternative is available. The petition must state that alternatives to conservatorship were considered and explain why those alternatives will not work. (Probate Code Section 1821(a)(3).)

A proposed conservatee may lack the capacity to manage healthcare decisions or finances on his or her own without assistance. But with supported decision-making arrangements in place, the individual may have the capacity to handle such matters without the need for a court-supervised conservatorship.[73] In order to comply with the "least restrictive alternative" requirement of the Probate Code, there should be an investigation in each case into the availability of such supports and services and their viability for the individual in question. An assessment of capacity and the evaluation of supported decision-making options are linked.[74]

Petitioners may not have the ability or resources to explore the supportive services available in the community in which the proposed conservatee lives. They may also have personal reasons for wanting a conservatorship and not wanting other options. That is why it is important to have an assessment of capacity done by a neutral and qualified professional who fully explores supported decision-making arrangements.

Court investigators do not have the time, and often lack the expertise, to research supports

and services available in the community that would enable a proposed conservatee to survive outside of the context of a formal conservatorship. Properly trained clinical social workers are qualified not only to evaluate a proposed conservatee in terms of capacities for decision-making and managing affairs, they are also qualified to research supports and services in the local community that are available and which could make a conservatorship unnecessary.

The practice of social work applies a special knowledge of social resources and human capabilities to help people achieve more adequate, satisfying and productive lives. (Business and Professions Code Section 4996.9.) Social workers provide and make referrals for social and health services. These are exactly the types of services that may enable someone to avoid a conservatorship.

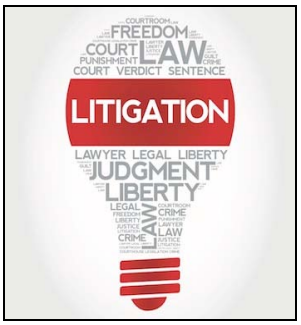
Assuming an attorney has been appointed to represent a proposed conservatee, the attorney can ask the court to appoint a social worker to make an evaluation of the viability of a supported decision-making arrangement as a less restrictive alternative to conservatorship. The court can appoint experts to assist in the evaluation of a conservatee or proposed conservatee. (*Conservatorship of Scharles* (1991) 23 Cal.App.3d 1334; Evidence Code Section 730.)

Social workers have been recognized by the Legislature as having the necessary qualifications to evaluate proposed conservatees. (Health and Safety Code Section 416.8.) Unfortunately, it appears the professional services of social workers are rarely used in conservatorship proceedings.

It is recommended that the Legislature should direct the State Bar to develop performance standards for public defenders and private attorneys who are appointed to represent seniors and people with disabilities in probate conservatorship proceedings. The standards should explain the need for attorneys to ask for Section 730 appointments of social workers for the purpose of evaluating the viability of a supported decision-making arrangements as a less restrictive alternative to a conservatorship.

Chapter Ten

Appointment of a Guardian Ad Litem and Capacity to Litigate



The Fourteenth Amendment to the United States Constitution provides that no state may deprive an individual of life, liberty, or property without due process of law. Litigation in probate courts sometimes involves potential loss of liberty, such as in a conservatorship proceeding. Other times it may involve the potential loss of property, such as litigation involving trusts or estates. In either event, a litigant in probate court whose liberty or property interests are in jeopardy is entitled to due process of law.

Due process requires fundamental fairness in civil proceedings. Thus, a litigant must be afforded an effective opportunity to defend against the loss of liberty or property, including adequate notice of the basis for the potential deprivation and an opportunity to confront adverse witnesses and to present his or her own evidence to the decision-maker. (*Goldberg v. Kelley* (1970) 397 U.S. 254, 266-270.)

The importance of the right to due process in civil proceedings was emphasized by California Supreme Court Justice Stanley Mosk in *Payne v. Superior Court* (1976) 17 Cal.3d 910, 911:

> "Few liberties in America have been more zealously guarded than the right to protect one's property in a court of law. This nation has long realized that none of our freedoms would be secure if any person could be deprived of his possessions without an opportunity to defend them 'at a meaningful time and in a meaningful manner.' (*Fuentes v. Shevin* (1972) 407 U.S. 67, 80 [32 L. Ed. 2d 556, 569-570, 92 S. Ct. 1983].)"

Citing precedents of the United States Supreme Court such as *Boddie v. Connecticut* (1971) 401 U.S. 371, Justice Mosk explained that before someone can be deprived of property interests, the individual must be afforded a *meaningful* opportunity to be heard.

California courts provide individuals with an opportunity to be heard in civil cases. This includes conservatorship proceedings and litigation involving trusts and distribution of estates. Individuals may appear with or without counsel. Once someone becomes a party to a case in probate court, the individual may make motions, file objections, and demand an evidentiary hearing on the matter in dispute. During such a hearing, the litigant may engage in various procedures, often through his or her attorney, such as confronting adverse witnesses, objecting to the admission of evidence, and presenting evidence and

witnesses in support of his or her position.

With the assistance of an attorney of choice, it is the individual litigant who controls the direction and presentation of the case. This right to litigate, however, can be taken away in a probate proceeding if the court finds the litigant is "an incapacitated person." (Probate Code Section 1003(a)(2).) In other types of civil litigation, a court may take away an individual's right to litigate if the court determines the person is "lacking legal capacity to make decisions." (Code of Civil Procedure Section 373(c).)

Thousands of cases involving seniors and other adults with actual or perceived disabilities are processed through the probate division of the Los Angeles Superior Court each year. According to the court's 2018 Annual Report, more than 3,700 conservatorship and trust cases were processed that year.[75] Since the Los Angeles court accounts for about 25% of probate cases in the state, we estimate that about 15,000 such cases would have been processed that year throughout California. Many of these cases involve seniors and adults with actual or perceived disabilities.

According to the Los Angeles County Bar Association, "Guardians ad litem ("GALs") are playing an increasingly frequent role in probate matters."[76] The increasing frequency of the use of GALs emphasizes the need for clarity in: (1) the criteria for determining incapacity to litigate; (2) the process required for assessing and adjudicating the capacity of an individual to litigate with or without the assistance of counsel; and (3) the appealability of orders authorizing and instructing a GAL.

Replacing a litigant with a GAL infringes on the constitutional right to manage one's own litigation. "Due process considerations attend an incompetency finding and the subsequent appointment of a guardian ad litem" *(Ferrelli v. River Manor Health Care Center* (2d Cir. 2003) 323 F.3d 196, 203.) "The appointment of a guardian ad litem deprives the litigant of the right to control the litigation and subjects him to possible stigmatization." (*Thomas v. Humfield* (5th Cir. 1990) 916 F.2d 1032, 1034.)

An order appointing a GAL also infringes on the First Amendment rights of a litigant. Every person has a constitutionally protected right to petition the government for redress of grievances. This is not limited to seeking redress through the legislative process. The First Amendment also protects an individual's right to have access to the courts to vindicate his or her rights.[77] Foisting a GAL on a litigant also infringes on freedom of speech because, once appointed, it is the GAL and not the litigant and his or her chosen counsel who shapes the messages delivered to the court through pleadings, presentation of evidence, motions and objections, and oral argument. Freedom of speech contemplates effective communication. (*United Farm Workers etc. Committee v. Superior Court* (1967) 254 Cal.App.2d 768, 773) Making a GAL the spokesperson for a litigant interferes with a litigant's right to control his or her own messaging, thereby rendering the communications to the court ineffective from the perspective of a litigant.

For litigants in probate court who are not indigent, the appointment of a GAL also involves the confiscation of assets. A court may order the reasonable expenses of a GAL, including compensation and attorneys fees, to be paid from the assets of the litigant for whom a GAL is appointed. (Probate Code Section 1003(c).) This could require a litigant to pay tens of thousands of dollars in fees to someone who may be using strategies objected to by the litigant or advocating for a result contrary to the litigant's wishes.

While the Legislature has enacted statutes authorizing courts to appoint a guardian ad litem to control civil litigation for someone determined to be "an incapacitated person" or "who lacks the capacity to make decisions," there are no statutes specifying the criteria or the procedures to be used in making this determination in the context of civil litigation.

This section of the report explores these substantive and procedural issues and makes recommendations for new legislation to provide direction to judges and attorneys as they grapple with these important matters.

In the context of child welfare proceedings, the Supreme Court has stated that if the trial court appoints a GAL without a parent's consent, "the record must contain substantial evidence of the parent's incompetence." (*In re James F.* (2008) 42 Cal.4th 901, 910.) The same should hold true for probate proceedings.

The Court of Appeal has ruled that due process should be followed before a litigant's right to direct his own litigation can be removed. (*In re Joann E.* (2002) 104 Cal.App 4th 347, 361.) This principle should apply to conservatorship proceedings where liberty interests are at stake or other probate proceedings where financial matters are at issue. The confiscation of a litigant's assets to pay for the compensation of a GAL and a GAL's attorney is another reason that due process should apply to proceedings where capacity to litigate is in controversy.

As to the definition of "incapacitated person," an unpublished opinion of the Court of Appeal stated: (*Buwei Shi Xi v. Gong Hau Xi (In re Estate of Yang Hua Xi)* (Aug. 19, 2019, B286213) ___ Cal.App.2d ___ [pp. 17])

> "'Incapacitated person' is not defined by Probate Code section 1003. Black's Law Dictionary defines "Incapacitated Person" as 'Someone who is impaired by an intoxicant, by mental illness or deficiency, or by physical illness or disability to the extent that personal decision-making is *impossible*.' (Black's Law Dict. (11th ed. 2019) p. 1834.)" (Emphasis added)

This standard of decision-making *impossibility* requires a very high degree of incapacity. However, because the *Buwei* decision is an unpublished California appellate opinion, its reasoning has no precedential value for anyone other than the parties to the case. (Rule 8.115, California Rules of Court.) Therefore, we must look to precedents in other states

or from federal courts on the standard to be used in evaluating the issue of incapacity to litigate. California has no rule prohibiting reference to such secondary authorities.[78]

Federal law on GAL appointments gives some guidance. Federal court rules require a court to appoint a guardian ad litem to protect a minor or incompetent person who is not represented by a guardian in a civil proceeding. (Fed. R. Civ. P. §17.)

No universally recognized measure determines a civil litigant's competency. *(Thomas v. Humfield* (5th Cir.1990) 916 F.2d 1032, 1034.) However, just because a person has mental disabilities does not mean the individual "lacks the capacity to litigate." (*Overstreet v. Hancock* (S.D. Miss., Sep. 13, 2012, CIVIL ACTION No. 2:11cv245-MTP) [pp. 1].) The legal standard for lack of capacity to litigate in federal civil proceedings is based on the standards of the domicile of the individual in question. (*Magallon v. Livingston* (5th Cir. 2006) 453 F.3d 268, 271.)

This brings us right back to the question of what standard California uses to determine an individual's capacity to litigate.[79] The answer to this question is important because the appointment of a guardian ad litem deprives an individual of an important right, namely, the right to control the litigation. This includes the power to retain counsel, hire experts and even to settle the case. (*Thomas v. Humfeld, supra*, at p. 1034.)

The issue of capacity to litigate is more fully developed in California in relation to criminal proceedings. Courts exploring or adjudicating the issue of capacity of an individual to litigate in civil proceedings could adopt some of the principles used in criminal law, including the standards and procedures outlined in statutes, court rules, and appellate decisions. Rulings of the United States Supreme Court may also be helpful.

Even though the case was decided in a criminal law context, the United States Supreme Court has defined mental competence to stand trial as a defendant's "sufficient present ability to consult with his lawyer with a reasonable degree of rational understanding" and have "a rational as well as factual understanding of the proceedings against him." (*Dusky v. United States* (1960) 362 U.S. 402.)

The stakes are so much higher in a criminal case than in ordinary civil litigation involving money damages or the administration of a trust. Felony cases also involve consequences that are more harsh than a conservatorship of the person or estate. Therefore, it would be logical for California courts to apply the *Dusky* standard when determining whether an individual in a civil case has the capacity to litigate. Since there are less onerous consequences in civil probate proceedings, it would be inappropriate to require a higher degree of capacity in this context than in a criminal law context.

The California Legislature has essentially adopted the *Dusky* standard for purposes of evaluating an individual's capacity to litigate in a criminal proceeding. Penal Code Section 1367 states: "A defendant is mentally incompetent for purposes of this chapter if,

as a result of a mental health disorder or developmental disability, the defendant is unable to understand the nature of the criminal proceedings or to assist counsel in the conduct of a defense in a rational manner." At least one California appellate decision has determined that the standard used in Section 1367 is appropriate to determine capacity to litigate in civil proceedings for litigants whose capacities are not so significant as to require the appointment of a conservator under Probate Code Section 1801. (*In Re Sarah D*. (2001) 87 Cal.App.4th 661, 667.)

This is a relatively low level of capacity. Much of the onus of this standard focuses on whether defense counsel believes the client can rationally assist in his or her own defense and communicate with counsel about substantive and strategic choices that will be made in the litigation. If a litigant's attorney believes the client has capacity to proceed, it would be a major intrusion into the attorney-client relationship for a court to sever the relationship without substantial evidence contrary to the attorney's own experience with the client.

In a civil context, the issue of a party's capacity to litigate may come to the court's attention in a variety of ways. A judge may observe behavior in the courtroom or read pleadings with information that causes a concern about the mental abilities of a party. An opposing party may present evidence suggesting incapacity. Perhaps the attorney for the party in question may advise the court that communications with the client are impossible due to a mental condition or disability. In any of these scenarios, a judge may feel obliged to inquire further into the issue of an individual's capacity to litigate.

In the criminal law context, there are two levels of inquiry. The first is when a judge has a concern about a defendant's competency that does not rise to the level of a "reasonable doubt based on substantial evidence." That amount of concern may trigger one set of procedures. Procedural formalities escalate when a judge has a reasonable doubt based on substantial evidence. Both procedural paths are explained in an Advisory Committee Comment to Rule 4.130 of the California Rules of Court.[80]

In civil cases, Evidence Code Section 730 authorizes a court to appoint an expert on its own motion to submit a report and testify on any matter as to which expert evidence may be required. The issue of capacity to litigate may be such a matter if the court has received or observed evidence concerning a party's incapacity to litigate. However, the statute does not authorize a court to compel a party to submit to a mental examination by an expert. An expert appointed under the authority of Section 730 might review documentary evidence or interview witnesses but in order to compel a mental examination of a party in a civil case, other statutory requirements must be met.[81]

Furthermore, the California Constitution protects the right of privacy of all individuals. A person is not compelled, as a condition of entering a courtroom, to discard the right of privacy. (*Vinson v Superior Court* (1987) 43 Cal.3d 833, 841-842.) The California Supreme Court has ruled that a person's mental state is protected by the constitutional

right of privacy: "If there is a quintessential zone of human privacy it is the mind. Our ability to exclude others from our mental processes is intrinsic to the human personality." (*Long Beach City Employees Ass'n v. City of Long Beach* (1986) 41 Cal.3d 937, 944.)

The normal rules of civil discovery do not apply when a party subject to a discovery order raises a constitutional objection under the right of privacy protected by Article I, Section 1 of the California Constitution. A mental exam cannot be allowed as part of a fishing expedition by an opposing party or even by the court itself.[82]

"[E]ven when discovery of private information is found directly relevant to the issues of ongoing litigation, it will not be automatically allowed; there must then be a 'careful balancing' of the 'compelling public need' for discovery against the 'fundamental right of privacy.'" (*Board of Trustees v. Superior Court of Santa Clara County* (1981) 119 Cal.App.3d 516, 525.)

California law does not specify the degree of evidence of incapacity to litigate that must exist before a court may order a party to submit to a mental examination. The constitutional right of privacy would seem to require a strong evidentiary showing of a compelling need before such an examination could be ordered. On the other hand, a litigant has the right to a fair trial and the court has a duty to ensure such. If a party truly lacks the capacity to litigate, a fair trial cannot be had. The question, therefore, is how much evidence of incapacity to litigate should be required before a court may order a party to undergo a mental exam in order to determine whether the party has such capacity.

✓ **It is recommended** that the Judicial Council direct its Probate and Mental Health Advisory Committee to review the issue of capacity to litigate, in view of the constitutional rights of privacy and due process, for the purpose of developing evidentiary and procedural standards to be used in evaluating and adjudicating the issue of capacity to litigate. The review should include an evaluation of the constitutional privacy rights that should be considered before a court may order a party to submit to a mental examination in order to determine whether such incapacity exists.

If the court believes there is reasonable doubt based on substantial evidence of incapacity to litigate, then due process requires the court to give notice to the party of the court's concern and to provide a meaningful opportunity to be heard on the matter. This issue would generally arise when the court on its own motion or on request of another party is considering the appointment of a GAL to litigate on behalf of a party who lacks the capacity to litigate for himself or herself even with the assistance of counsel.

When the issue of appointing a GAL arises, the court has two issues to determine. One is substantive and the other is procedural. The substantive issue is what level of incapacity must exist to deprive an individual of the right to control and direct litigation and to communicate to the court through retained counsel. The procedural issue involves the

methods to be used in making this substantive determination.

As explained above, the Legislature has not defined incapacity to litigate in either the Probate Code or the Code of Civil Procedure. California probate case law does not offer assistance. It is therefore necessary to turn to federal and state civil cases[83] and to California criminal cases which have significant discussions on standards to determine the capacity to litigate.

✓ **It is recommended** that the Legislature enact a statute defining the standard to be used by courts in determining the issue of capacity to litigate in civil cases. The statute should state: "For purposes of Probate Code Section 1003 and Code of Civil Procedure Section 373, a party lacks the legal capacity to make decisions in civil litigation, thus authorizing the appointment of a guardian ad litem, when a mental health disorder or developmental disability renders the party unable to understand the nature or consequences of the proceedings or to assist counsel in the conduct of the litigation in a rational manner."

The adoption of such a law would provide clarity to judges and attorneys on the substantive part of capacity to litigate. Clarification is also needed with respect to the procedural part of this matter.

California case law recognizes that a litigant must be afforded due process before a court appoints a GAL due to an individual's lack of capacity to litigate. However, those cases talk about an informal procedure.[84] In contrast, federal courts have ruled that the United States Constitution requires more than a proforma inquiry. Some cases indicate that when a litigant objects to appointment of a GAL, an evidentiary hearing is required.[85]

An individual has a protected liberty interest in pursuing a lawsuit as a principal. (*Thomas v. Humfeld, supra,* at pp. 1033-1034.) A declaration of incompetence stigmatizes a person's good name, honor, and integrity and deprives the individual of the power to control the lawsuit. Therefore, the federal constitution requires an evidentiary hearing before such a huge intrusion into a person's liberty interests can occur.

A person whose capacity to litigate is challenged must be given notice, an opportunity to review and rebut the allegations of incapacity, and to introduce written and testimonial evidence on the issue. (*Thomas, supra*.)

✓ **It is recommended** that the Legislature enact a statute requiring that before a GAL may be appointed in civil litigation over a party's objection, the party must be given notice of the right to an evidentiary hearing at which the party may contest evidence of alleged incapacity, cross examine witnesses, and present evidence to the court on the matter.

Once a GAL is appointed in a civil case, the GAL takes control of the litigation, thereby

rendering the party to be little more than a bystander or observer. While California law may allow the party to appeal from an order appointing a GAL, statutory and case law are ambiguous as to whether the order is immediately appealable or only after a final judgment is rendered.[86]

✓ **It is recommended** that the Legislature enact a statute clarifying that an order appointing a GAL may be appealed from immediately. The law should require the court to notify the party who has been adjudicated to lack the capacity of the right to an immediate appeal from this determination. Since a GAL can make decisions affecting the financial interests and personal rights of a party, it would be unjust to require the party to wait to appeal until a final judgment is entered in the matter. Irreparable harm could be done between the time a GAL is appointed and a final judgment is entered, often many months or even years after the GAL's appointment. One of those harms would be the payment of compensation to the GAL and his or her attorney from the assets of the litigant prior to an appellate court ruling on the validity of the GAL appointment in the trial court. Further harm could also occur as a result of the inevitable delays, often years, in having an appeal decided.

Conclusion

Assessments of capacities and alternatives should be the very foundation of probate conservatorship proceedings. In addition to information provided by family members and friends of a proposed conservatee, judges should have solid professional evaluations of an individual's capacity to make decisions in all major areas of life. These evaluations should conform to constitutional requirements, nondiscrimination mandates, and best practices suggested by professional associations.

Unfortunately, these standards and practices are not occurring in many, if not most, conservatorship proceedings in California. The conservatorship system is mostly running on auto pilot, with the default being a rush to judgment without the benefit of professional assessments of capacities and alternatives. Supported decision-making options are all but ignored.

This report is intended to attract the attention of the elected and appointed officials who are in charge of all three branches of government. There is much that the Chief Justice, Governor, and Legislature can do to improve the conservatorship system, including the capacity assessment process.

The need for improvement is real. The question is whether these officials have the will to listen, learn, and make a commitment to create the necessary changes in policy and practice outlined in this report. Time will tell.

Endnotes

1. Subsequent investigations into individual cases not involving people with developmental disabilities have only reinforced my belief that the probate conservatorship is badly broken, mostly because of the lack of accountability for judges and appointed attorneys. The case of David, a former producer with National Public Radio who suffered communication disabilities due to a medical illness, revealed voting rights violations as well as financial exploitation of him by the San Diego County Superior Court. https://spectruminstitute.org/votingrights/ The case of Theresa, a retired FBI employee in her 80s with mild cognitive challenges due to aging, revealed myriad abuses by the judge, appointed attorney, and petitioner in the Los Angeles County Superior Court. https://disabilityandabuse.org/theresa-letter-to-cap.pdf The abuses in these cases were consistent with reports I have received for several years from family members involved in conservatorship cases and attorneys who practice in the probate courts in California. Alameda County Supervisor Nate Miley is working with a group of such family members to explore ways to prevent conservatorship proceedings from abusing and exploiting seniors and people with disabilities. https://spectruminstitute.org/path/ A recent federal lawsuit filed by a grandchild of Walt Disney provides another example of how judges in California are abusing their power and denying due process to persons perceived to have disabilities. The lawsuit alleges that Judge David Cowan and the Los Angeles Superior Court violated Brad's right to due process by summarily appointing a guardian ad litem to take control of the litigation and replace Brad in settlement negotiations, thus depriving Brad of the right to control his own litigation and interfering with Brad's ongoing relationship with his own attorneys. This order was made on the basis of assumptions and prejudice rather than evidence. Without conducting a hearing, the judge entered this order because he perceived Brad had "limited intellectual abilities." Not only did this violate Brad's right to an evidentiary hearing as a matter of due process, it also violated the Americans with Disabilities Act which prohibits a state official from discriminating against someone because of a *perceived* disability. https://www.ocregister.com/2020/03/22/walt-disneys-grandson-locked-in-legal-battle-for-personal-freedom-millions-in-inheritance/ I am very familiar with the cases of David, Theresa, and Brad since I researched each of their cases thoroughly and became familiar with the oppressive practices of the judges in their cases.

2. "Justice Denied: How California's Limited Conservatorship System is Failing to Protect the Rights of People with Developmental Disabilities," a pre-conference report (May 9, 214) https://disabilityandabuse.org/conferences/justice-denied.pdf; "Voting Rights: How California's Limited Conservatorship System is Violating the Voting Rights of People with Developmental Disabilities," a pre-conference report (June 20, 2014) https://disabilityandabuse.org/doj/ex-24-pre-conference-report.pdf; "Strategic Guide for Court-Appointed Attorneys in Limited Conservatorship Cases," a report on how to represent clients in conservatorship proceedings (September 1, 2014) https://disabilityandabuse.org/strategic-guide.pdf; "A Missed Opportunity," a report on deficiencies in a training program for court-appointed attorneys (September 20, 2014)

https://disabilityandabuse.org/pvp-training/; "Limited Conservatorship Trainings of Probate Investigators," a report documenting poor training programs (December 11, 2014) https://disabilityandabuse.org/training/investigator-training-report.pdf "Gregory's Law: A Bill to Reaffirm "Next Friend" Advocacy for People with Disabilities," a report on the need for legislation to affirm standing for a third party to file an appeal for conservatees who are unable to do so (January 20, 2015) https://disabilityandabuse.org/gregory-law/; "Limited Conservatorships: Systematic Denial of Access to Justice," a report to the Senate Judiciary Committee (March 24, 2015) https://spectruminstitute.org/judiciary-report.pdf; "Proposals to Modify the California Rules of Court: Qualifications, Continuing Education Requirements, and Performance Standards for Court-Appointed Attorneys in Limited Conservatorship Proceedings," a report to the Judicial Council of California (May 1, 2015) https://spectruminstitute.org/attorney-proposals/; "Elusive Justice – False Advocacy," a report submitted to the United States Department of Justice (June 1, 2015) https://spectruminstitute.org/elusive/report.pdf; "Efficiency vs. Justice: The deliberate bypass of legal protections has denied many limited conservatees access to justice in violation of Title II of the ADA," a report to the United States Department of Justice (August 17, 2015) https://spectruminstitute.org/amicus/efficiency-vs-justice.pdf; "Regional Center Conservatorship Assessments: The Need for Guidance and Oversight from the Department of Developmental Services," a report to the Department of Developmental Services and the Health and Human Services Agency (April 6, 2017) https://disabilityandabuse.org/dds.pdf; "The Domino Effect: Judicial Control of Legal Services," a report to the California Supreme Court (September 24, 2018) https://spectruminstitute.org/ethics/ "Administrative Steps to Improve California's Probate Conservatorship System," a report to the Chief Justice (November 12, 2018) https://spectruminstitute.org/steps/administrative-steps.pdf; "ADA Compliance," a report to the Judicial Council (September 24, 2019) https://spectruminstitute.org/ada-compliance.pdf; "A Call to Action," a report to Disability Rights California (October 3, 2019) https://disabilityandabuse.org/drc-report.pdf; "Proposals to Use FEHC Authority to Protect the Civil Rights of People with Disabilities in Conservatorship Proceedings," a report to the Fair Employment and Housing Council (October 23, 2019) https://spectruminstitute.org/fehc.pdf;

3. Complaint to the U.S. Department of Justice for systematic voting rights violations by the Los Angeles Superior Court against people with disabilities involved in conservatorship proceedings (July 10, 2014) https://disabilityandabuse.org/doj/complaint.pdf; Amendment to voting rights complaint (August 23, 2016) https://spectruminstitute.org/votingrights/doj-amended-complaint.pdf ; Complaint to Los Angeles County for ADA violations in connection with its funding for the court-appointed counsel program for conservatees (June 9, 2015) https://spectruminstitute.org/lacounty/ Complaint to the U. S. Department of Justice for ADA violations by the Los Angeles County Superior Court in connection with the operation of its court-appointed attorney program. (June 26, 2015)

https://spectruminstitute.org/doj/full-class-complaint.pdf ; Complaint to the U.S. Department of Justice for ADA violations in the conservatorship case of Gregory D. (June 26, 2015) https://spectruminstitute.org/elusive/gregory-full-complaint.pdf; Complaint to the Sacramento County Superior Court for violating the ADA by not appointing attorneys to represent people with cognitive disabilities in conservatorship proceedings (August 16, 2018) https://spectruminstitute.org/Sacramento/; Pre-Complaint Inquiry to the Department of Fair Employment and Housing regarding violations by the Sacramento County Superior Court (August 16, 2018) https://spectruminstitute.org/Sacramento/dfeh-inquiry-letter.pdf

4. "Disability and the Law" includes a collection of more than 20 commentaries published over the past few years by the Daily Journal legal newspaper about the conservatorship system. https://disabilityandabuse.org/dj-compendium.pdf Many other commentaries and essays are listed in a Digital Law Library on Guardianship and Disability Rights. https://spectruminstitute.org/library/

5. Amicus Curiae Brief of Spectrum Institute, Conservatorship of O.B., California Supreme Court, Case No. S254938. https://disabilityandabuse.org/amicus-brief-final.pdf

6. Materials and commentaries were submitted to workgroup members over the course of many months on the following topics: Global and National Views; UN Convention on the Rights of People with Disabilities; World Congress Updates; ABA/APA Assessment Handbook for Psychologists; ABA/APA Assessment Handbook for Lawyers; ABA Assessment Handbook for Judges; Supreme Court Brief and Judicial Council Report; ADA, Capacity Assessments, and Less Restrictive Alternatives; The Role of Supported Decision-Making in the Capacity Assessment Process; Regional Centers and the Capacity Assessment Process; State Laws Relevant to the Capacity Assessment Process; Capacity to Consent to Sexual Activity; Capacity to Consent to Marriage; Capacity to Make Social Decisions; Capacity to Make Medical Decisions; Capacity to Make Financial Decisions; Capacity to Make Decisions on Residence; Capacity to Make Educational Decisions; Capacity to Retain Voting Rights; Capacity to Waive Constitutional and Statutory Rights; Capacity Assessments by Court Investigators; and Social Worker Role in Supported Decision-Making. https://spectruminstitute.org/capacity/readings.htm

7. Kristin Booth Glen, "Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond," 44 *Columbia Human Rights Law Review* 93 (2012)

8. "Better Protection for Our Most Vulnerable Adults: Is It Time to Reform the Conservatorship Process?", Report of Assembly Judiciary Committee (2005) https://ajud.assembly.ca.gov/sites/ajud.assembly.ca.gov/files/reports/1205%20Conservatorship%20background.pdf

9. This quote is taken from legislative findings contained in subdivision (g) of Section 2 of Assembly Bill 1363, known as the "Omnibus Conservatorship and Guardianship Reform Act of 2006." Many of the necessary reforms have never been

implemented due to the failure of the Legislature to fund them.

10. Unlike mental health conservatorships where there are limitations on who may initiate such a proceeding, virtually anyone can file a petition for a probate conservatorship proceeding against anyone else. In a considerable number of cases, persons targeted by the petition are not represented by counsel and are unable to properly defend themselves. When attorneys are appointed, they are generally selected and their fees are authorized by the same judges or same courts before whom the attorneys appear – thus creating an incentive for the attorneys to please the judges rather than vigorously advocate for and defend the proposed conservatees they are supposed to represent. Although a court investigator should screen each case, they often are not involved at all. Mental health experts are seldom involved to assess the various areas of capacity that are at issue, other than a perfunctory evaluation for medical decision-making capacity. Social workers are not used to evaluate less restrictive alternatives even though are supposed to be ruled out. Jury trials are almost nonexistent. Genuine court trials, with production of witnesses and documentary evidence seldom occur. Appeals by conservatees are rare. The system simply does not operate as intended when it was created. The system and the judges and attorneys who run it are unaccountable.

11. "Losing It in California: Conservatorships and the Social Organization of Aging," 73 Wash. Univ. Law Quarterly 1501, 1512 (1995).

12. Rothke, Demakis, and Amsbaugh, "State Statutes Regarding the Role of Psychologists in Performing Capacity Evaluations for Guardianship Determinations," 50 Professional Psychology: Research and Practice 228, 229 (2019).

13. Joann Lublin, "Trailblazing Bench: California High Court Often Points the Way for Judges Elsewhere," Wall Street Journal, 20 July 1972.

14. André Bzdera, "Supported Decision-Making Replaces Adult Guardianship in Austria," (2019) https://spectruminstitute.org/capacity/update-on-austria.pdf

15. Ibid.

16. World Congress on Adult Guardianship, Excerpts from Papers, Spectrum Institute (2019) https://spectruminstitute.org/capacity/third-installment.pdf (Papers submitted by delegates from: Argentina, Australia, Canada, England, Wales, Germany, Hong Kong, Ireland, Netherlands, Scotland, Switzerland, Taiwan, United Kingdom)

17. "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination," National Council on Disability (2018) https://disabilityandabuse.org/ncd-report.pdf

18. "Autonomy, Decision-Making Supports, and Guardianship Joint Position Statement of AAIDD and The Arc" (2016) https://disabilityandabuse.org/joint-policy-statement.pdf

19. Resolution approved by the ABA House of Delegates on August 14, 2017. https://www.americanbar.org/content/dam/aba/administrative/law_aging/supported-decision-making-resolution-final.pdf

20. Under a grant from ACL, the ABA Commission on Law and Aging coordinates and provides technical assistance to establish and enhance state-operated WINGS agencies. https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_wings%20action%20tools_court%20assessments.pdf

21. The document was the work product of a task force consisting of representatives from the National College of Probate Judges, the National Association for Court Management, the American College of Trust and Estate Counsel, the ABA Section on Real Property, Trust, and Estate Law, and the National Center for State Courts. https://ncsc.contentdm.oclc.org/digital/collection/spcts/id/240/

22. "Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists," American Bar Association/American Psychological Association, Assessment of Capacity in Older Adults Project Working Group (2008) https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf Key excerpts from the handbook were sent to members of our Capacity Assessment Workgroup. https://spectruminstitute.org/capacity/fourth-installment.pdf

23. A report published by the Probate and Mental Health Advisory Committee of the California Judicial Council in 2018 found the Supreme Court's action to be instructive to lawyers who are appointed to represent clients in conservatorship proceedings. The committee observed that it had not found any support "for the proposition that a trial court, having created an attorney-client relationship [by appointing counsel] has the authority to modify the terms of that relationship – including ethical duties or standards of representation – set forth by the Legislature in statute . . . or by the Supreme Court in the California Rules of Court . . . and the California Rules of Professional Conduct. . . It is perhaps worth noting in this context that of the 70 new or amended rules of professional conduct for which the State Bar requested Supreme Court approval in 2017, the Court declined to approve only one: proposed rule 1.14, regarding a lawyer's obligations in representation of clients with diminished capacity." (SPR18-33 (Guardianship and Conservatorship: Court Appointed Counsel) https://www.courts.ca.gov/documents/W19-08.pdf

24. Excerpts most relevant to conservatorships are found on the website of Spectrum Institute. https://spectruminstitute.org/capacity/aba-guidebook-judges-excerpts.pdf The full text is online. https://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf

25. Of the 10 statewide court rules pertaining to conservatorships, none of them focus on pre-adjudication proceedings to determine whether a conservatorship should be established or on the process for assessing capacity. They primarily involve post-adjudication matters. This is a glaring omission. Judges need guidance on pre-

adjudication procedures to help them comply with statutory and constitutional mandates.

26. Spectrum Institute filed an administrative records request with the Judicial Council seeking access to all training materials used by the Council, including CJER, to educate judges on capacity assessments and adjudications. The topics covered in the materials were barely adequate. No mention was made of international developments and trends. Constitutional requirements were barely referenced. The application of the ADA to conservatorship proceedings and the capacity assessment process was not mentioned.

27. The medical portion of the presentation focused on the science of aging, the aging brain, and components of capacity. It also addressed diseases of the brain, manifestations of mild cognitive impairment, and various types of dementia. Focus was also placed on a screening test for cognitive impairment. Physical, sensory, and psychological changes associated with aging were discussed. The legal portion of the presentation discussed the presumption of capacity and limits of the presumption. Attendees were reminded that capacity should be viewed as a sliding scale. Probate Code Section 810-813 dealing with capacity determination were addressed as was GC-335 – the capacity declaration form. Criminal law considerations involving the insanity defense were also included in the presentation. Legal requirements for testamentary and contractual capacity were discussed as was capacity to marry. Elder abuse was addressed as were legal definitions of undue influence and medical evaluations for such.

28. Leslie Saltzman, "Rethinking Guardianship (Again): Substituted Decision-Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," (2010) 81 University of Colorado Law Review 157.
https://spectruminstitute.org/olmstead-ADA-and-LRA.pdf

29. The ADA website of the United States government explains: "On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity." While Olmstead specifically dealt with institutionalization versus community integration, the same principles would apply to unnecessary restrictions on the right of individuals to make their own decisions and the need to provide reasonable accommodations to enable them to retain as many decision-making rights as feasible.
https://www.ada.gov/olmstead/olmstead_about.htm

30. "ADA Compliance: A Request to the California Judicial Council to Clarify the *Sua Sponte* Obligations of Courts to Ensure Access to Justice," Spectrum Institute (2019).
https://spectruminstitute.org/ada-compliance.pdf

31. See: "The ADA and Guardianship Courts: Excerpts from DOJ and HHS Joint Guidance to Courts in Child Welfare Proceedings, with Comments on their Application to Adult Guardianship Proceedings," A Commentary by Spectrum Institute (2018) https://disabilityandabuse.org/doj-hhs-ada-guidance-to-courts.pdf Also see: "ADA Guidance from the United States Department of Justice is Instructive to Participants in Maryland's Guardianship System," A Commentary by Spectrum Institute (2018). https://disabilityandabuse.org/doj-guidance-and-maryland.pdf

32. Spectrum Institute submitted written recommendations to the Council regarding its proposed regulations. https://spectruminstitute.org/fehc-11135-recommendations.pdf An addendum was also ssubmitted.
https://spectruminstitute.org/fehc-regs-11135-addendum.pdf

33. A pre-complaint inquiry was filed by Spectrum Institute with DFEH for alleged ADA violations by the Sacramento County Superior Court. When the department declined to open a director's investigation into the matter, an appeal was filed to challenge that decision. https://spectruminstitute.org/Sacramento/dfeh-appeal.pdf The appeal was denied. However, subsequently the director affirmed that the department would accept and investigate complaints from third parties for ongoing violations of the ADA and Section 11135, including violations in court proceedings.

34. See: Letter from Spectrum Institute to the executive director of the State Bar dated October 1, 2019. https://disabilityandabuse.org/state-bar-ada-request.pdf

35. I made a presentation on safe and legal supported decision-making as an alternative to guardianship and conservatorship at the World Congress on Adult Guardianship in 2018. https://spectruminstitute.org/sdm-materials.pdf Other delegates to this conference submitted papers and made presentations about the strides being made in their nations to promote and use alternatives to guardianship whenever feasible.

36. Thomas F. Coleman, "Supported Decision-Making: My Transformation from a Curious Skeptic to an Enthusiastic Advocate," Spectrum Institute (2016) https://spectruminstitute.org/sdm/sdm-essay.pdf; Thomas F. Coleman, "Supported Decision-Making: A Critical Analysis," Spectrum Institute (2016) https://spectruminstitute.org/sdm/sdm-essay.pdf

37. The need to explore supported decision-making in guardianship proceedings as a matter of due process was explained in a relatively recent New York court decision. (*In re Hytham M.D.* (N.Y. Surr. Ct. 2016) 41 N.Y.S. 719) Since conservatorship proceedings in California place fundamental liberties at risk, proposed conservatees are entitled to due process in these proceedings. (*Conservatorship of Sanderson* (1980) 106 Cal.App.3d 611)

38. Saltzman, "Rethinking Guardianship," endnote 27, supra. Excerpt from article: "Building on the reasoning in the Supreme Court's decision in Olmstead v. L.C.527 U.S. 581 (1999), and subsequent decisions interpreting the Americans with Disabilities Act's integration mandate, this Article argues that by limiting an individual's right to make his

or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the Act's mandate to provide services in the most integrated and least restrictive manner. After discussing why recent reforms of state guardianship laws have proven inadequate, this Article conceptualizes guardianship as a form of disability-based discrimination and argues that Olmstead and the integration mandate are legitimately applied to the guardianship context. Therefore, the article argues that courts must seriously explore and use less restrictive alternatives to guardianship (conservatorship) when they are available and viable." Thus, the inclusion of supported decision-making options as a way to enable proposed conservatees to make some or all of their own decisions, would be a required component of a capacity assessment process in a conservatorship proceeding.

39. Principles of supported decision-making already exist in California law. Whether these principles will translate into SDM being used more frequently depends on whether attorneys for proposed conservatees investigate alternatives to conservatorship, ask judges to appoint social workers to help identify available supports and services, demand IPP reviews by regional centers to explore such options, and press for evidentiary hearings if judges are reluctant to dismiss a conservatorship petition due to the availability of less restrictive alternatives. https://spectruminstitute.org/it-already-exists.pdf

40. Evidence Code Section 730; *Conservatorship of Scharles* (1991) 233 Cal.App.3d 1334.

41. It is within the purview of the Judicial Council to conduct such a survey. Article VI, Section 6(d) of the California Constitution states: "To improve the administration of justice the council shall survey judicial business and make recommendations to the courts, make recommendations annually to the Governor and Legislature, adopt rules for court administration, practice and procedure, and perform other functions prescribed by statute."

42. "Regional Center Conservatorship Assessments: The Need for Guidance and Oversight from the Department of Developmental Services," A report from Spectrum Institute to DDS and the Health and Human Services Agency (2017) https://spectruminstitute.org/capacity/dds-report.pdf

43. Barbara Imle, "Exploring Regional Centers, Limited Conservatorship Policies, and Implications for Adults with Intellectual or Developmental Disabilities," California State University Thesis (2016) https://spectruminstitute.org/capacity/6-imle-thesis.pdf; Answers to survey questions. https://spectruminstitute.org/capacity/3-survey-imle.pdf

44. "Expanding the Role of Regional Centers in Limited Conservatorship Proceedings," Spectrum Institute (2014) https://spectruminstitute.org/capacity/1-regional-center-role.pdf "Individual Program Plan (IPP) for Limited Conservatorships: An Essential Advocacy Tool for Court-Appointed Attorneys," Spectrum Institute https://spectruminstitute.org/capacity/ipp-by-pvp.pdf

45. See: recommendations to the Legislature (pp. 29, 39); recommendations to DDS (p. 39); recommendations to the Judicial Council (p. 39)

46. Assembly Bill 1363 was introduced in the Legislature in response to articles published in the Los Angeles Times in 2005 exposing abuses occurring within the probate conservatorship system. In reaction to these stories, the Chief Justice convened a Conservatorship Task Force and the Legislature held public hearings. A consensus emerged for the Legislature to enact an Omnibus Conservatorship and Guardianship Reform Act. However, as the costs associated with these reforms were examined, some provisions in the bill were stricken. Among the abandoned reforms was the creation of an Office of Conservatorship Ombudsman within the Department of Aging. http://leginfo.ca.gov/pub/05-06/bill/asm/ab_1351-1400/ab_1363_bill_20060607_amended_sen.html

47. Presentation by Thomas F. Coleman, Judicial Council Meeting, Sacramento, January 17, 2020. https://disabilityandabuse.org/spectrum-institute-materials-1-17-20.pdf

48. Thomas F. Coleman, "We County What We Care About," Daily Journal, October 20, 2019. https://disabilityandabuse.org/spectrum-institute-materials-1-17-20.pdf

49. The report is found on the State Bar's website. https://www.calbar.ca.gov/Portals/0/documents/ethics/Indigent_Defense_Guidelines_2006.pdf

50. "The Domino Effect: Judicial Control of Legal Services," A Report to the California Supreme Court (2018) https://spectruminstitute.org/ethics/supreme-court-letter.pdf; Amicus Brief of Spectrum Institute, Conservatorship of O.B., California Supreme Court (2019) https://disabilityandabuse.org/amicus-brief-final.pdf

51. More information about assessments of medical decision-making capacity is found in a report to the Capacity Assessment Workgroup titled "Capacity to Make Medical Decisions," https://spectruminstitute.org/capacity/capacity-medical-decisions.pdf

52. The opinion of the California Court of Appeal was filed on February 18, 2020. It reversed an order of conservatorship because the judge never once laid eyes on the proposed conservatee in court. Spectrum Institute was instrumental in having appellate attorney Gerald Miller appointed for the young autistic woman whose rights were violated by the judge. Miller joined with Lisa MacCarley, counsel for the woman's mother, in arguing for a reversal because the mandate of Probate Code section 1825 was not followed. The opinion is online at: https://disabilityandabuse.org/AE-opinion.pdf

53. Moye, Sabatino, and Brendel, "Evaluation of the Capacity to Appoint a Healthcare Proxy," 21 Am J. Geriatr Psychiatry 326 (2013) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4859336/

54. The right to marry is not absolute. Sometimes courts are required to balance the freedom to marry against the need for society to protect a vulnerable adults from abuse or exploitation. ""Case Tests Limits of Right to Marry," Daily Journal, Feb. 1, 2018.

https://disabilityandabuse.org/limits-on-right-to-marry.pdf For a thoughtful ruling balancing these competing interests, see: Conservatorship of Ryan Morris, Court Ruling on Petition to Remove Sean Spicer as Conservator of Ryan Morris, May 17, 2019. https://disabilityandabuse.org/sykes-order.pdf

55. "Evaluation of the Capacity to Marry," Journal of the American Academy of Psychiatry and the Law (2017)

56. Interview of Judge Michael Levanas with Thomas F. Coleman, February 18, 2014.

57. Sexual decision-making capacity is explored in detail from a national perspective in a report titled "Capacity to Consent to Sex: Legal Standards & Best Practices for Adult Protective Services." https://spectruminstitute.org/aps-capacity-sex.pdf

58. "The state has competing interests to respect the privacy and sexual rights of its citizens on the one hand and to protect persons whose intellectual disabilities make them vulnerable to sexual predation on the other. As this case demonstrates, however, states and judges have yet to reach consensus on the point at which protection should override sexual freedom. Forensic clinicians involved in these cases should therefore be mindful of local legal standards, if they exist, and of the relevant literature on this complex subject." Comment on *North Dakota v. Mosbrucker* (N.D. 2008) 758 N.W.2d 663, in "Capacity to Consent to Sexual Acts: Understanding the Nature of Sexual Conduct" J Am Acad Psychiatry Law 38:3:417-420 (September 2010) http://www.jaapl.org/content/38/3/417.full

59. A review of court records in a sample of limited conservatorship cases in the Los Angeles County Superior Court indicates that social rights are routinely being taken away from adults with developmental disabilities. "Searching for Clues: Putting Together Pieces of the Limited Conservatorship Puzzle by Examining Court Records," Spectrum Institute (2014) https://disabilityandabuse.org/conferences/searching-court-records.pdf Unfortunately, court-appointed attorneys are surrendering rather than defending their client's right to make social decisions. Attorneys should be advocating for their client's right to make social decisions. "Social Rights Advocacy for Adults with Autism: Forced Socialization of Conservatees is Never Acceptable," Spectrum Institute (2014) https://spectruminstitute.org/social-rights-advocacy.pdf

60. The decision about where a conservatee should reside is, in many cases, fraught with potential conflicts of interest. Selling a house or residence in California, where housing prices are high, can result in substantial work and compensation to the conservator. Thus, the conservator may have a financial interest in selling the conservatee's residence in order to generate more work and fees for the conservator. Further, the emotional consequences of selling a residence and the personal effects of the conservatee can be devastating or at least emotionally wrenching for the conservatee. According to scientific research, moving from one residence to another ranks very high on the list of things that

can cause emotional problems. Moving is ranked right up there with divorce when it comes to anxiety and stress.

61. Memo from Spectrum Institute to the United States Department of Justice, July 31, 2014. https://disabilityandabuse.org/doj/follow-up-research.pdf

62. "Voting Rights: How California's Limited Conservatorship System is Violating the Voting Rights of People with Developmental Disabilities," pre-conference report, June 20, 2014. https://disabilityandabuse.org/doj/ex-24-pre-conference-report.pdf

63. Assembly Committee on Elections and Redistricting, Report on AB 1311, August 27, 2014. https://spectruminstitute.org/ab1311-analysis.pdf

64. Complaint filed by Spectrum Institute with the United States Department of Justice, Juy 10, 2014. https://disabilityandabuse.org/doj/index.htm

65. See a side-by-side comparison of California law with federal voting rights laws. https://disabilityandabuse.org/doj/fed-state-comparison.pdf

66. "Yes, Your Honor, That is How it Works," a commentary on the need for AB 1311. https://disabilityandabuse.org/ab1311-becomes-law.pdf

67. "California Judges May Have Banned 32,000 People with Disabilities from Voting," a commentary on the need for voting rights restoration efforts after the passage of SB 589. https://spectruminstitute.org/32-thousand-estimate.pdf

68. Webpage for the Voting Rights Restoration Project of Spectrum Institute. https://spectruminstitute.org/restore-voting-rights/

69. Court investigator job description posted by San Luis Obispo County Superior Court. https://spectruminstitute.org/capacity/investigator-job-description.pdf

70. Through an administrative records request filed in 2014, Spectrum Institute inquired into the training that court investigators were receiving in the Los Angeles County Superior Court. Information and documents were ultimately provided, but very reluctantly. We discovered that the training mandates of Rule 10.478 were not being met. Staff training meetings for 2013 and 2014 were reviewed. None of the staff training meetings focused on adults with developmental disabilities or on limited conservatorships. None discussed abuse of adults with developmental disabilities. None addressed how to interview adults with developmental disabilities. The training manual, which had not been updated in 14 years, was reviewed. It contained no information about various types of developmental disabilities and how they could affect cognition, communication, or emotions. There was nothing in it about abuse of adults with developmental disabilities. The questionnaire form that is supposed to be used by court investigators in their interviews and evaluations was reviewed. There was nothing in it about the types of disabilities the proposed conservatee has or about the capacity the

proposed conservatee has for decision-making in any of the several areas the court may rule on other than the issue of capacity to make medical decisions. Online videos used for training investigators were viewed. None focused on limited conservatorships or proposed conservatees with developmental disabilities. One did address the issue of undue influence of elderly adults.

71. "Limited Conservatorship Trainings of Probate Investigators by the Los Angeles Superior Court," Spectrum Institute, December 11, 2014. https://spectruminstitute.org/capacity/investigator-training-report.pdf

72. "Disturbing Details Revealed at Legislative Hearing on the Ability of California Courts to Protect Vulnerable Adults," Spectrum Institute, Mach 27, 2015. https://spectruminstitute.org/capacity/backlog-for-court-investigators.pdf

73. See memo to members of the Capacity Assessment Workgroup. https://spectruminstitute.org/capacity/sdm-and-capacity-assessments.pdf

74. Browning, Bigby, and Douglas, "Supported Decision-Making: Understanding How Its Conceptual Link to Legal Capacity is Influencing the Development of Practice," Research and Practice in Intellectual and Developmental Disabilities (2014) https://www.tandfonline.com/doi/abs/10.1080/23297018.2014.902726

75. "2018 Annual Report," Los Angeles County Superior Court, p. 29. (https://spectruminstitute.org/2017-18-probate-filings.pdf)

76. "Guardian ad Litem Mandatory Training," Website Announcement, Los Angeles County Bar Association, Feb. 6, 2018. (https://spectruminstitute.org/lacba-program.pdf)

77. "The right to petition the government for redress of grievances is protected by both the federal and state Constitutions. (U.S. Const., 1st Amend.; Cal. Const., art. I, § 3.)" (*Vargas v. City of Salinas* (2011) 200 Cal.App.4th 1331, 1342 (*Vargas*).) "[T]he right to petition extends to all departments of the Government. The right of access to the courts is indeed but one aspect of the right of petition. [Citations.]" (*California Motor Transport Co. v. Trucking Unlimited* (1972) 404 U.S. 508, 510 (*California Motor Transport*).) "The right includes the right to petition the executive or legislative branches directly." (*Vargas*, *supra*, 200 Cal.App.4th at p. 1342.)

78. "Citation to Unpublished Cases: A Brief Comparison of Federal And California Practices," McManis Faulkner Blog, November 29, 2018. https://www.mcmanislaw.com/blog/2018/citation-to-unpublished-cases-a-brief-comparison-of-federal-and-california-practices

79. Standards for determining capacity to litigate vary from state to state. In Colorado, for example, appointment of a GAL is not appropriate for a person with a mental disability, if the person "understands the nature and significance of the proceeding, is able to make decisions in her own behalf, and has the ability to communicate with and act on

the advice of counsel." *(People in Interest of M. M.* (Colo. 1986) 726 P.2d 1108, 1120.) Alabama law suggests a different standard, namely, whether there is sufficient evidence in the record showing that the litigant "is mentally impaired to the extent that he cannot understand the nature and effect of this litigation." (*United States v. 9607 Lee Rd. 72* (M.D. Ala. 2012) 915 F. Supp. 2d 1270, 1272.)

80. The Advisory Committee comment explains: "The case law interpreting Penal Code section 1367 et seq. established a procedure for judges to follow in cases where there is a concern whether the defendant is legally competent to stand trial, but the concern does not necessarily rise to the level of a reasonable doubt based on substantial evidence. Before finding a reasonable doubt as to the defendant's competency to stand trial and initiating competency proceedings under Penal Code section 1368 et seq., the court may appoint an expert to assist the court in determining whether such a reasonable doubt exists. As noted in *People v. Visciotti* (1992) 2 Cal.4th 1, 34-36, the court may appoint an expert when it is concerned about the mental competency of the defendant, but the concern does not rise to the level of a reasonable doubt, based on substantial evidence, required by Penal Code section 1367 et seq. Should the results of this examination present substantial evidence of mental incompetency, the court must initiate competency proceedings under (b)."

81. Any party may obtain discovery by means of a mental examination of another party whose mental condition is in controversy in the legal proceeding. (Code Civ. Proc., § 2032.020(a).) A motion for a mental exam may only be granted for good cause. (Code Civ. Proc., § 2032.320.) In order to obtain such an order, there must be a demonstration of specific facts justifying the discovery. (Weil & Brown, California Practice Guide, Civil Procedure Before Trial, Chap. 8, section 8:1557, p. 81-16.) These statutes, however, do not authorize a court to order a mental examination on its own motion. Furthermore, for a party's mental condition to be "in controversy," the condition must be "'directly involved in some material element of the cause of action or defense.'" *Id.* at 448 (citation omitted). When the pleadings have not put a party's mental condition at issue, it must be affirmatively shown that the party's mental condition "'is really and genuinely in controversy and that good cause exists for ordering each particular examination.'" *Brooks v. Brown*, 744 S.W.2d 881, 882 (Mo. App. 1988) (quoting *Schlagenhauf v. Holder*, 379 U.S. 104, 118 (1964)). The rule requires a "greater showing of need than relevancy." *Id.*

82. "Your Client's Privacy is Not a Myth: How to Protect Your Client's Privacy – And Your Case – In Discovery," Law Office of Jeremy Pasternak. https://pasternaklaw.com/publications/your-clients-privacy-is-not-a-myth-how-to-protect-your-clients-privacy-and-your-case-in-discovery/

83. Citing *In re Jessica G.* (2001) 93 Cal.App. 4th 1180, 1186, one federal court ruled that a party lacks the capacity to litigate if he or she does not have the ability to understand the nature or consequences of the proceeding, or is unable to assist counsel in the preparation of the case. (*AT&T Mobility, LLC v. Yeager* (E.D. Cal. 2015) 143 F. Supp. 3d 1042, 1050)

84. Especially in situations where a litigant's assets will be confiscated by the court to pay for the fees of a GAL and the GAL's attorney, an informal hearing would not cut the muster for due process purposes. The loss of thousands of dollars in assets should require a formal evidentiary hearing to determine whether the triggering factor, i.e., incapacity to litigate, is supported by substantial evidence.

85. These two approaches can be reconciled. An informal interaction between the court and a litigant would be sufficient when the process satisfies the court that a GAL is not needed because the individual understands the nature of the proceedings and potential consequences and has the ability to cooperate with counsel. However, if the result of such an inquiry is a tentative decision by the court to appoint a GAL over the party's objection, then a formal evidentiary hearing should occur at which evidence is presented, witnesses testify, resulting in a finding based on substantial admissible evidence.

86. In the context of a juvenile dependency proceeding, one appellate decision states that an order appointing a GAL can be challenged in an appeal from a final judgment in the matter. *(In re Joann E*. (2002) 104 Cal.App.4th 347.) One problem with this procedure is that if the GAL order is reversed, it undoes the entire case and requires the parties to start litigating from scratch. This is not an effective way to preserve judicial resources. Nor it is fair to the parties who may have expended months or even years in trial court litigation and considerable financial resources spent in the process. Making a GAL order immediately appealable makes more sense. In fact, such an order already may be immediately appealable but statutes and case law are somewhat ambiguous on this point. Spectrum Institute filed an amicus curiae letter with the California Supreme Court on this issue in April 2020, asking the court to grant review to clarify the matter. *(Lund v. First Republic Trust Company*, California Supreme Court, Case No. S261165.) https://disabilityandabuse.org/S261158.pdf

Recommendations

(Per Official or Agency)

Chief Justice

It is recommended that the Chief Justice, in coordination with the Judicial Council, convene a Task Force on Alternatives to Conservatorship. The Task Force should investigate how judges who process probate conservatorship cases throughout the state are complying with statutory and constitutional requirements that alternatives to conservatorship be seriously considered. The Chief Justice should direct the presiding judges in all 58 counties to cooperate with this investigation. The Task Force should issue a report to the Judicial Council and the Legislature within one year of its first meeting. (p. 45)

Judicial Council

It is recommended that the Judicial Council direct its Center for Judicial Education and Research to include the Convention on the Rights of Persons with Disabilities, especially sections 12, 13, and 16, into all training programs and materials for judicial officers and court personnel regarding probate conservatorship proceedings or the assessment of capacity in any legal context. (p.13)

It is recommended that the Judicial Council convene an ongoing WINGS agency to advance each of these action items in California for the purpose of improving the capacity assessment process used in probate conservatorship proceedings. WINGS is a Working Interdisciplinary Network of Guardianship Stakeholders. (p. 20)

It is recommended that the Judicial Council direct its Probate and Mental Health Advisory Committee to review current policies and practices for capacity assessments regarding all areas of decision-making involved in probate conservatorship proceedings. The committee should determine whether any new court rules or statutes should be enacted to make current policies and practices conform to the letter and spirit of Standard 3.3.9 of the National Probate Court Standards, due process, and requirements under the ADA. (p. 22)

It is recommended that the Rules of Court be amended to require a full day of training on conservatorship issues before a judicial officer is allowed to hear and decide such cases. The amendment should specify the issues to be covered in such a training, including the requirements of due process, best practices specified in the ABA/APA Handbook for Psychologists, and the *sua sponte* duties of courts to litigants

with cognitive and other disabilities under Title II of the ADA. The Rules of Court should also be amended to require that judges hearing and deciding probate conservatorship cases must participate in a half-day training program each year. These annual refresher courses should focus on recent developments in conservatorship law in California, nationally, and around the world. (p. 38)

It is recommended that the Judicial Council direct the Center for Judicial Education and Research (CJER) and the Probate and Mental Health Institute (PMHI) to expand their trainings on capacity assessments and conservatorships to include the following legal topics: constitutional considerations in capacity assessment and adjudications and the application of the ADA to the capacity assessment process. The use of interdisciplinary teams should be included in the clinical aspect of trainings, with special emphasis on the use of social workers and service providers in identifying supports and services that may enhance or strengthen a person's functional abilities to make a conservatorship unnecessary. An intensive training should be developed on capacity assessments and alternatives to conservatorship for adults with intellectual and developmental disabilities. (p. 38)

It is recommended that the Judicial Council adopt rules pertaining to pre-adjudication conservatorship proceedings. Judges need specific guidance on what they should do to comply with due process and what they must do, sua sponte, under the Americans with Disabilities Act (ADA) to afford proposed conservatees access to justice in these proceedings. Access to justice is required not only inside the courtroom but also in ancillary services such as capacity assessments and investigations by court investigators. The absence of guidance in state court rules leaves too much room for errors and abuses of discretion by judges at the local level. (p. 38)

It is recommended that the Judicial Council revise Rule 1.100 and its educational materials to clarify that more is required than merely responding to requests for accommodations. The rule and materials should specify that courts have a duty on their own motion to initiate an interactive process to determine what accommodations to provide when judges or court staff become aware that a litigant, witness, or other participant may require an accommodation to maximize effective communication and meaningful participation in the proceeding. This clarification is especially important for conservatorship proceedings where judges and court staff are informed from the start that a proposed conservatee has, or is perceived to have, one or more serious disabling conditions that impair cognitive or communication functions. (p. 40)

It is recommended that the Judicial Council direct staff to study the Department of Justice (DOJ) guidance memos on court responsibilities in criminal and child welfare proceedings and to prepare educational materials for judges and court

staff about analogous duties in probate conservatorship and other mental health proceedings. The current void in education and training on these issues should be filled without delay. (p. 41)

It is recommended that the Judicial Council conduct a survey of all 58 superior courts to inquire into: (1) the number of new probate conservatorship proceedings that were filed in the previous three years; (2) the number of times experts were appointed in these cases; (3) the number of IPP reviews the court requested or ordered from regional centers; (4) any procedures the court has in place for evaluating less restrictive alternatives; and (5) an explanation as to why such appointments or IPP reviews are not ordered more frequently. (p. 45)

It is recommended that the Judicial Council should create, and the Legislature should fund, an Office of Conservatorship Research and Planning within the Judicial Branch. There is no statewide administrative accountability within the judicial branch with respect to conservatorship proceedings. The Chief Justice and Judicial Council do not even know how many seniors and people with disabilities are living under an order of conservatorship in California. These vulnerable adults are supposed to be under the "protection" of the superior courts. The superior courts are part of a unified statewide judicial system. Therefore, the safety and well-being of these protectees are the responsibility of the State of California via the Judicial Branch. But how much protecting is actually occurring when the Chief Justice and the Judicial Council do not know what the 58 superior courts are doing in these cases, much less how many seniors and people with disabilities are living under orders of conservatorship? (p. 56)

It is recommended that the Judicial Council require the following information to be provided by a physician or psychologist executing a Capacity Declaration Form: (p. 62)

1) Name of the person who scheduled the appointment;
2) Name and relationship of the person who paid the evaluator's fees;
3) Prior contact of the evaluator with petitioners, proposed conservators, or their attorneys;
4) Names and relationships of any individuals present during the evaluation;
5) Extent of prior medical relationship of the evaluator with the person evaluated;
6) What ADA assessment was done prior to the evaluation to determine what supports and services might be necessary to ensure effective communication by the person evaluated and meaningful participation of that person in the evaluation process;
7) Training and experience of the evaluator to interact with and evaluate people with developmental disabilities or seniors with dementia or other adults with cognitive issues;

8) Amount of time that was spent during the evaluation process;
9) Names of persons other than the respondent who were interviewed;
10) Documents that were reviewed;
11) List of all medications the person evaluated has been taking prior to and at the time of the evaluation and whether those medications might have side effects that could affect the performance of the person during the evaluation;
12) Whether the effects of the medications were ruled out as a source of incapacity; and
13) Whether the respondent is suffering from depression and whether such depression was ruled out at the source of some or all of the incapacity;
14) Whether the individual has had a comprehensive physical examination that might rule out physical problems that could be causing cognitive decline or confusion.

It is also recommended that, since judges are so pressed for time, the addendum should contain a short and concise narrative about the practitioner's opinion and the basis for the opinion. It should also state the degree of certainty underlying the practitioner's opinion that there is no form of medical treatment for which the conservatee has the capacity to give informed consent. Is the opinion supported by reasonable suspicion, probable cause, preponderance of evidence, or clear and convincing evidence? The practitioner should know the definition for each degree of proof. (p. 63)

It is recommended that if a practitioner declares that an individual is unable to attend a hearing or hearings due to medical inability, the form should ask the practitioner to describe the specific reasons for that medical inability. To comply with the ADA, there should also be an opinion about whether personal presence would be possible if certain supports or services were provided by the court to the individual. If the practitioner is unsure of this, the practitioner should recommend that an ADA needs assessment be done by a qualified professional to make this determination. (p. 64)

It is also recommended that the capacity declaration form should ask the practitioner to render an opinion on the individuals's capacity to waive the right to attend court hearings. The practitioner should evaluate the individual's ability to understand the consequences of the proceedings, the benefit to the individual of personal presence, and the value to the court of having the individual at the hearing and the ability to make an informed decision on waiving the right to be present in court. An informed waiver of being personally present would require an understanding of these matters. (p. 64)

It is recommended that if a proposed conservatee has executed a medical power of attorney or health care directive prior to the initiation of the conservatorship proceedings, Form GC-335 should ask the practitioner to assess whether, in his or her professional opinion, the individual had the capacity to execute the document at

the time it was signed. Such previously executed documents should not be ignored or lightly dismissed as they often are. If such capacity existed at the time a document was signed, it should be honored and medical decision-making authority should not be delegated to a conservator. (p. 65)

It is recommended that the Judicial Council include the issues of social decision-making capacity and constitutional rights in conservatorship training programs for judges. These issues should also be included in mandatory training programs for court-appointed attorneys in conservatorship proceedings. (p. 82)

It is recommended that the Judicial Council study the issue of capacity of conservatees and proposed conservatees to waive statutory and constitutional rights with a view toward adopting a rule for probate conservatorship proceedings similar to Rule 5.682 in juvenile dependency proceedings. The Judicial Council should consult with the Department of Aging and the Department of Developmental Services regarding the capacity of seniors with cognitive disabilities and adults of all ages with intellectual and developmental disabilities to understand the nature of conservatorship proceedings, the consequences of an order of conservatorship, the role of and importance of an attorney in such proceedings, and the ability of such adults to withstand direct or subtle pressures to waive their rights. The Department of Fair Employment and Housing enforces Section 11135 regarding the ADA duties of public entities, including the courts, and therefore should be consulted as well. (p. 92)

Supreme Court

The State Bar is an arm of the Supreme Court. That court has been apprised of myriad systemic deficiencies in probate conservatorship proceedings. **It is therefore recommended** that the Chief Justice should put this recommendation on the administrative agenda of the Supreme Court. The justices should direct the State Bar to initiate and conduct a study looking into the manner in which legal services are currently being provided in probate conservatorship proceedings and what should be done to improve these services. Without such a proactive measure, it is likely that the status quo of deficient legal services for seniors and people with disabilities will continue to be the norm. (p. 57)

State Bar

It is recommended that the California State Bar develop a new rule regarding the professional duties of attorneys representing clients in conservatorship proceedings or other litigation where the legal capacity of the client is at issue. In addition to clearly stating that lawyers have the same ethical and professional duties to these clients as they do to all clients, comments to the rule should offer guidance

regarding investigative, advocacy, and defense activities and provide examples of what attorneys should and should not do. (p. 30)

It is recommended that the State Bar reach out to and work with disability rights organizations to identify specific topics, references, and resources that should be mentioned in any trainings authorized by the State Bar for credit under its mandatory continuing education program. The quality of new trainings programs on these topics should not be left to chance. (p. 42)

It is recommended that the Legislature should direct the State Bar to develop performance standards for public defenders and private attorneys who are appointed to represent seniors and people with disabilities in probate conservatorship proceedings. The standards should explain the need for attorneys to ask for Section 730 appointments of social workers for the purpose of evaluating the viability of a supported decision-making arrangements as a less restrictive alternative to a conservatorship. (p. 97)

MCLE Providers

It is recommended that training programs for attorneys who represent proposed conservatees should reference the APA/ABA Handbook for Psychologists and urge the attorneys to become familiar with the best practices it offers. As competent advocates for proposed conservatees, these attorneys should question any expert who offers an opinion on capacity about the procedures and standards they used, whether they are familiar with the handbook, and whether the expert used or deviated from any of the suggested practices. (p. 27)

Superior Courts

It is recommended that if a superior court has a list of experts qualified for appointments in conservatorship proceedings or for capacity assessments in other proceedings, the court should require a professional to disclose whether he or she has received specialized training in capacity assessments and whether the methodology used in the evaluation conforms to the best practices suggested by the APA/ABA psychologists handbook for the evaluation process. (p. 28)

Governor

It is recommended that the Legislature authorize funding for a Governor's Commission on Alternatives to Conservatorship. The purpose of the commission would be to review international trends in reforming guardianship and conservatorship systems with a view to developing improvements and alternatives to the

conservatorship system in California. The commission should be housed in the executive branch since it plays little or no role in conservatorship proceedings and therefore would not have a real or apparent conflict of interest that could hinder an honest and thorough consideration of moving away from the status quo of the current conservatorship system. Commissioners would be appointed by the Governor, Legislature, and Chief Justice. The commission would be staffed by the Department of Aging and the Department of Developmental Disabilities. It would take testimony from scholars, advocates, service providers, and most importantly from persons who have participated in conservatorship proceedings, including seniors and people with disabilities. The commission would submit a report and recommendations to the Governor, Legislature, and Chief Justice within two years of its first meeting. Without a properly funded study, conservatorship reform may remain perpetually stagnant and elusive. (p. 17)

It is recommended that all three branches of government work together to review the current process used for evaluating the capacities of proposed conservatees with intellectual and developmental disabilities and investigating the feasibility of alternatives to conservatorship. The Governor should take the lead by convening a task force to determine what increases in funding would be required to ensure that regional centers have adequate resources to conduct such assessments and that DDS has sufficient resources to provide the necessary direction to, and oversight of, regional centers to assure quality and uniformity throughout the state. (p. 47)

DDS

It is recommended that the Department of Developmental Services include in its contracts with regional centers a clause requiring that an Individual Program Plan (IPP) review process be conducted for clients who are proposed conservatees in probate conservatorship proceedings and include a line item in the regional center's budget to provide funding for such reviews. (p. 45)

It is also recommended that the Department of Developmental Services establish criteria for determining the training and experience required for regional center staff or medical or mental health professionals to be considered qualified to conduct assessments of capacity to consent to marriage. (p. 75)

It is recommended that the Department of Developmental Services (DDS) amend the regulations it has adopted on client's rights to clarify the right of adults with developmental disabilities to exercise their freedom of association. Section 50510 of Title 17 of the California Code of Regulations should be amended to specify that such adults have the right to make choices to associate or not with anyone and to have those choices respected and implemented. (p. 80)

It is recommended that DDS add the italicized phrase to Section 50510(a)(6) so that it states: "A right to social interaction and participation in community activities, *including the right to associate with specific individuals or not to associate with them.*" The regulation should be abundantly clear that the right to social interaction includes the constitutional right to freedom of association. (p. 81)

It is recommended that the Legislature direct the Department of Developmental Services to require regional centers, as part of their ongoing contractual duties, to take steps to ensure that all conserved regional center clients who desire to vote have their voting rights restored. The Legislature should also direct the Department of Aging to coordinate with the Judicial Council to survey all superior courts about their voting rights restoration practices for all other adults who have lost their voting rights in conservatorship proceedings. Most of these individuals would have been seniors. (p. 87-88)

DFEH / FEHC

It is recommended that the Fair Employment and Housing Council (FEHC) include in its new regulations a specific section on the application of the ADA and Section 11135 to court proceedings, including and especially conservatorship and other mental health proceedings. (p. 42)

It is recommended that the Fair Employment and Housing Department develop educational materials on the application of the ADA and Government Code Section 11135 to court proceedings, with special guidance to judges, court staff, and public defenders and other attorneys appointed to represent conservatees and proposed conservatees. The department should notify the State Bar, local bar associations, presiding judges of all 58 superior courts, Center for Judicial Education and Research, California Judges Association, and Public Defenders Association, that such materials are available online. (p. 42)

ARCA

It is recommended that the Association of Regional Center Agencies develop guidelines for evaluations of the capacity of clients to consent to marriage. The guidelines should be developed in consultation with psychological and medical professionals as well as the Client's Rights Office of Disability Rights California. (p. 75)

Legislature

It is recommended that the chairpersons of the Assembly and Senate judiciary committees direct all staff members to become acquainted with the Convention

on the Rights of Persons with Disabilities, especially sections 12, 13, and 16, so that any proposed legislation coming before those committees for approval can be evaluated by legislators and staff with these principles in mind. (p. 13)

It is recommended that legislators in California review the representation agreement statute in Austria. The Legislature should pass a bill giving adults with cognitive or mental disabilities a method of selecting someone to make medical decisions and conduct ordinary financial transactions for them. Powers of attorney should be made available to adults who lack the capacity to contract but who nonetheless can understand in general terms the concept of appointing another person to make such decisions on their behalf. The lack of capacity to contract should not be used as a barrier to receiving the benefits of a simplified power of attorney. (p. 16)

It is recommended that the Legislature authorize funding for a Governor's Commission on Alternatives to Conservatorship. The purpose of the commission would be to review international trends in reforming guardianship and conservatorship systems with a view to developing improvements and alternatives to the conservatorship system in California. The commission should be housed in the executive branch since it plays little or no role in conservatorship proceedings and therefore would not have a real or apparent conflict of interest that could hinder an honest and thorough consideration of moving away from the status quo of the current conservatorship system. Commissioners would be appointed by the Governor, Legislature, and Chief Justice. The commission would be staffed by the Department of Aging and the Department of Developmental Disabilities. It would take testimony from scholars, advocates, service providers, and most importantly from persons who have participated in conservatorship proceedings, including seniors and people with disabilities and their family members. The commission would submit a report and recommendations to the Governor, Legislature, and Chief Justice within two years of its first meeting. Without a properly funded study such as this, conservatorship reform may remain perpetually elusive. (p. 17)

It is recommended that the Legislature enact a law requiring courts to inform conservatees or proposed conservatees of their right to request the appointment of an interdisciplinary team to evaluate relevant areas of the individual's capacity, with or without ancillary supports and services, prior to the court limiting any area of the individual's decision-making authority. As contemplated by this statute, an interdisciplinary team should include a physician, licensed mental health professional, and social worker or regional center case worker. In many nations, interdisciplinary teams are a standard procedure for determining whether a guardianship or conservatorship is needed or whether a supported decision-making arrangement would be sufficient to protect the individual, while at the same time respecting his or her right to self-determination. It is time for California to modernize its antiquated capacity assessment process and to bring its procedures into conformity with international trends. (p. 23)

It is recommended that the Legislature enact a law stating that, absent exceptional circumstances, courts shall only appoint experts to conduct capacity assessments in conservatorship proceedings if they have received specialized education or training on capacity evaluations within five years of the date of the appointment. If a court appoints an expert without such training, the court should be required to state on the record the reason for doing so. Since capacity assessments should be essential to a court's decision in a conservatorship proceeding, professionals without training in capacity assessments should not be appointed to conduct such evaluations. While the initial training of a professional regarding the capacity assessment process could have been many years before the date of appointment, the professional should have more current training to ensure that he or she has been educated on new developments, improvements, or recent trends in the capacity evaluation process. (p. 28)

It is recommended that the Legislature enact a statute declaring that regional center reports must be filed in all cases involving proposed conservatees with developmental disabilities and attorneys must be appointed in all such cases regardless of whether petitioners have filed for a general or a limited conservatorship. Judges should always receive regional center reports in conservatorship proceedings involving proposed conservatees with developmental disabilities. The report should be reviewed by the court prior to any adjudication on issues of capacity. Proposed conservatees should always have an attorney appointed to ensure they receive due process, have access to justice as required by the ADA, and receive the benefit of a thorough capacity assessment – one that includes the serious exploration of less restrictive alternatives. (p. 33)

It is recommended that the Assembly Committee on Aging and Long Term Care hold hearings to inquire into amending state law to entitle proposed conservatees to have an interdisciplinary assessment of capacities and alternatives. Just as adults with developmental disabilities are entitled to an IPP review for such purposes, seniors and other adults with disabilities should have access to a similar process. The committee should ask the Department of Aging to develop a report outlining procedures that may be available under existing law and recommendations for legislation that may be needed to make interdisciplinary assessments readily available to proposed conservatees. Judges will make better and more reliable decisions on issues of capacity and alternatives to conservatorship if they have the benefit of the opinions of a multidisciplinary team of professionals. (p. 34)

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COVID-19 is 10 times deadlier for people with Down syndrome, raising calls for early vaccination

By Meredith Wadman Dec. 15, 2020 , 5:00 PM

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When the COVID-19 pandemic descended last winter, Catherine Ross was filled with dread. Her 36-year-old sister, Amanda Ross, has Down syndrome (DS), which makes her especially vulnerable to respiratory viruses. Amanda Ross had been hospitalized repeatedly with pneumonia. In 2017, she ended up on a ventilator and nearly died.

In April, she was back on a ventilator. She lives in a group home in Somers, New York and had been diagnosed with COVID-19 on 31 March. The doctor told her close-knit family that, given her history, they needed to prepare for the worst. "It shook us," Catherine Ross says. Her sister and others with DS, also known as trisomy 21, "are dealing with a stacked deck against them in terms of dealing with the virus," she says.

Among groups at higher risk of dying from COVID-19, such as people with diabetes, people with DS stand out: If infected, they are five times more likely to be hospitalized and 10 times more likely to die than the general population, according to a large U.K. study published in October. Other recent studies back up the high risk.

Researchers suspect background immune abnormalities, combined with extra copies of key genes in people with DS—who have three copies of chromosome 21 rather than the usual two—make them more vulnerable to severe COVID-19. "This is a vulnerable population that may need protective policies put in place," says Julia Hippisley-Cox, a clinical epidemiologist at the University of Oxford's medical school and senior author on the U.K. study.

On 2 December, the United Kingdom's Joint Committee on Vaccination and Immunisation recommended prioritizing people with DS for speedy vaccination. But the more than 200,000 Americans with DS so far are not slated for early vaccination. Nor has the U.S. Centers for Disease Control and Prevention (CDC) included DS in its list of conditions it says boost the risk for severe COVID-19.

Hippisley-Cox and her colleagues analyzed a database of 8.26 million people in the United Kingdom for their paper, published in the *Annals of Internal Medicine*. The extraordinary risk they found emerged even after they corrected for many other factors including obesity, heart disease, diabetes, and living in a group home. Another recent preprint that includes findings from a large international survey found that people with DS hospitalized with COVID-19 who

are 40 and older bear most of the increased risk, with a mortality of 51% versus 7% for those under 40. “At about the age of 40, things are getting really bad … [with] a mortality rate comparable with those older than 80 in the general population,” says first author Anke Huels, a biostatistician at the Rollins School of Public Health at Emory University.

Experts say the typical anatomy of people with trisomy 21, including large tongues, small jaws, and relatively large tonsils and adenoids, along with lax throat muscle tone, helps explain their higher rate of respiratory infections in general. But genetics may also make them particularly susceptible to SARS-CoV-2, the pandemic coronavirus. They have three copies of a gene on chromosome 21, *TMPRSS2*, which codes for an enzyme that the virus hijacks to help it enter human cells. The TMPRSS2 enzyme cleaves the spike protein that studs the virus’ surface, launching a series of steps that allows the virus to invade the host cell.

Cells from people with DS typically express 1.6 times more *TMPRSS2* than those from people without the condition, according to an analysis posted as a preprint in June by Mara Dierssen, a systems biologist at the Centre for Genomic Regulation in Barcelona, Spain, and her postdoc Ilario De Toma. “Down syndrome individuals might be more susceptible to infection due to triplication of *TMPRSS2*,” Dierssen says.

Immune system abnormalities likely add additional risk, experts say. In people with DS, T cells don’t develop properly, and levels of circulating B cells are low. So are levels of a key protein that prevents immune cells from attacking the body’s own tissues. In contrast, levels of potent, inflammation-inducing signalling proteins are high, contributing to a state of chronic inflammation even in the absence of infection.

“The cells of people with Down syndrome are constantly fighting a viral infection that does not exist,” says Joaquin Espinosa, a genomicist at the University of Colorado’s Linda Crnic Institute for Down Syndrome. That reflects a revved-up immune system that may tip people with trisomy 21 into the hyperinflammatory state that typifies severe and fatal COVID-19, he suggests.

His group showed in 2016 that the interferon response, a first line of defense against viruses, is constantly activated in DS. Four genes for crucial interferon receptors are located on chromosome 21, likely leading to an “overdose” of receptors and thus of interferon activity, he says, noting there’s plenty of interferon available to bind to those receptors. In August, a team led by geneticist Jean-Laurent Casanova of Rockefeller University buttressed this hypothesis with a paper showing that certain white blood cells from DS patients display extra interferon receptors on their surfaces.

A **powerful interferon response** may be helpful early in the course of COVID-19 infection. But the elevated interferon activity seen in people with DS isn’t necessarily protective. Chronic background stimulation can make interferon receptors unresponsive to still more stimulation, says Louise Malle, an M.D./Ph.D. candidate at the Icahn School of Medicine at Mount Sinai. She was lead author on yet another recent study in New York City hospitals that found that patients with DS were on average 10 years younger and had significantly more severe COVID-19 than age-matched controls. Interferon hyperactivity may feed the immune storm that can turn COVID-19 fatal 1 week or more after symptoms appear, adds Andre Strydom, an expert in the neurobiology of DS at King’s College London who was senior author on the preprint.

The picture is complicated and not fully understood, Strydom says. But, he adds, “What is clear … is that the immune differences in people with Down syndrome probably do put them at a disadvantage for fighting infection with COVID-19. And for the consequences.”

Public health experts in some countries agree. Within days of the *Annals* publication, the United Kingdom’s chief medical officers added people with DS to a list of “clinically extremely vulnerable” people who should be shielded from exposure.

The international Trisomy 21 Research Society has since issued a pointed statement strongly calling for people with DS, especially those 40 and over, to be prioritized for early vaccination. In the United States, however, a panel advising CDC on vaccine prioritization has not yet defined the medically vulnerable groups that may be included in a second wave of vaccinations. Despite the new studies, a CDC spokesperson said: “At this time, there is not enough evidence to determine if adults with Down syndrome are at increased risk of severe illness from COVID-19.” They added that the agency’s list of those at risk for severe COVID-19 “is not exhaustive and … may not include every condition,” and noted that CDC can update its list as the science evolves.

Because the prognosis for older COVID-19 patients with DS can be so poor, they should have high priority for monoclonal antibody treatments, which are in short supply says Beau Ances, a neurologist at Washington University in St. Louis who takes care of patients with DS. “A 40-year-old with Down syndrome who develops COVID-19 … that’s the kind of individual that physicians should be thinking about for early antibody treatment,” he says.

Physicians should also consider a drug called baricitinib, Espinosa says, because it blocks a signaling pathway essential to the interferon response. In a study described last month in *Cell Reports*, his group showed it prevented otherwise-lethal immune hypersensitivity in mice with trisomy 21. That suggests baricitinib could help tame an out-of-control immune response in DS patients with COVID-19, he says. The Food and Drug Administration last month authorized baricitinib, in combination with remdesivir, for emergency use in hospitalized, severely ill COVID-19 patients.

Amanda Ross managed to survive her infection. After 6 days, she was able to come off the ventilator, and 6 days after that she was discharged. She’s now back in her group home. “I can’t begin to tell you how grateful we are to have her still,” Catherine Ross says. But she still worries for her sister and others with DS in the group home. For all of them, she says, the increased severity of COVID-19 “is all the more reason why they need to be considered for vaccination right behind the front-line workers.”

Mental Health Project

Purpose. The purpose of the Mental Health Project of Spectrum Institute is to promote improved access to mental health therapy for adults with intellectual and developmental disabilities.

Focus. The project focuses on the role of guardians, conservators, and care providers as mental health therapy fiduciaries for this special needs population.

Mission. The mission of the project is to educate these fiduciaries about their duty to take the necessary steps to implement the right of adults with intellectual and developmental disabilities to have prompt access to the necessary and appropriate mental health therapies they need.

Methods. The project accomplishes its mission through research, education, and advocacy. In addition to working with mental health fiduciaries, it also reaches out to primary care physicians who are often the gatekeepers to mental health services, and to psychologists, psychiatrists, social workers, and other licensed mental health professionals.

Legal Principles

The constitution protects the right of adults to make their own medical decisions. (*Cruzon v. Missouri* (1990) 497 U.S. 261, 262; *Thor v. Superior Court* (1993) 5 Cal.4th 725, 731)

People with developmental disabilities have the right to full participation in society and to equal access to health care services. (ADA Section 12101; Wash. Rev. Codes Section 71A-10.030)

When courts give the power to make health care decisions to guardians or conservators, these fiduciaries should be proactive. They have a duty to become aware of the need for, and to arrange for, appropriate mental health treatment for adults under their care. (Daily Journal Commentary)

There are a wide range of mental health therapy options available for people with intellectual and developmental disabilities, including therapies to treat trauma, depression, anxiety, and PTSD. ("Intellectual and Developmental Disabilities: A Bibliography on Trauma and Therapy" [Part One: Books] [Part Two: Articles and Other Resources])

Individuals with intellectual and developmental disabilities have a right to prompt medical care and treatment. (Cal. Welf. & Instit. Code Section 4502(b)(4)) Failure to provide such care is neglect.

Additional qualified professionals are needed to provide therapy for individuals with intellectual and developmental disabilities. Those already working in this field should improve their skills with in-service training. Trauma-informed therapy should be included in all training programs.

Care providers who deprive necessary health care services to dependent adults in their custody or care commit dependent adult abuse. (Wash. Rev. Codes Section 74.34.020(16)) Medical care includes mental health therapy. Deliberate indifference to medical and mental health needs is unconstitutional. (*Doty v. County of Larsen* (9th Cir. 1994) 37 F.3d 540, 546)

People without disabilities have access to a full range of mental health therapies. It is disability discrimination for guardians, conservators, or other care providers to deprive individuals with disabilities access to a full range of mental health therapy options. (*Federal Law:* Americans with Disabilities Act; *State Law:* Cal. Gov. Code Section 11135; Wash. Rev. Codes Section 49.60.030)

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From: BestLife: The CDC Just Confirmed This Disorder Could Put You at Risk of Severe COVID

By Zachary Mack
January 1, 2021

Note reformatted: images removed for brevity, and because they were stock images that added no information. In addition, many of the links included are for further information about covid and it's concerns, not about DS specifically.

The CDC Just Confirmed This Disorder Could Put You at Risk of Severe COVID

Since the beginning of the pandemic, the U.S. Centers for Disease Control and Prevention (CDC) has kept a list of underlying conditions that put patients at a high risk of developing severe COVID-19. And while many complications specified have been included since day one, the agency has taken the opportunity to add certain conditions to the list as more information has become available. Now, **the CDC has confirmed that anyone who has Down syndrome should be included among potential patients at risk for severe COVID.** Read on to see what recommendations the agency has for those affected, and for more on what determines how sick you'll get, check out This One Thing Could Determine If Your COVID Case Will Be Severe or Mild.

In an update posted on Dec. 23, the top infectious disease agency announced that it had amended its "living document" of conditions and disorders that lead to severe COVID to include Down syndrome. The CDC recommends speaking to your healthcare provider to "discuss your individual level of risk based on your condition, medical history, your treatment, and the level of transmission in your community," if you or someone you care for is affected.

The addition to the list comes after an October report, published in the journal *Annals of Internal Medicine*, where researchers found that people with Down syndrome were 10 times more likely to die of severe COVID than patients without the disorder, including adjustments for other risk factors. At the time of the study's publication, the authors of the report pointed out that those with the condition were "a group that is not currently strategically protected," despite showing a fourfold increase in hospitalizations amongst them, CNN reports.

"[Down syndrome] is associated with immune dysfunction, congenital heart failure, and pulmonary pathology and, given its prevalence, may be a relevant albeit unconfirmed risk factor for severe COVID-19," the researchers concluded.

For those affected by the update or with any concerns, the CDC recommends you contact your healthcare provider should any symptoms or issues arise, or after possible exposure to COVID-19. Read on to see which other conditions the agency considers high risk, and for more on what your symptoms could be telling you, consider The Earliest Signs You Have COVID, According to Johns Hopkins.

1
Heart disease

As a disease that causes dangerous inflammation, the CDC warns that any type of preexisting heart condition may put you at a higher risk of severe COVID-19. The agency says that heart failure, coronary artery disease, cardiomyopathies, and pulmonary hypertension are considered to be the most concerning ailments, specifically. And for an update on how to keep yourself safe, check out If You Don't Have This in Your Home, You're at Higher Risk for COVID.

2
Obesity

According to the CDC, obesity is a high-risk factor for severe COVID-19. Research has found that people who are considered obese—which is defined by the agency as someone with a body mass index, or BMI, of 30 or higher—have a higher likelihood of being hospitalized after they've been infected with the coronavirus than those who are not. And for more on safety guideline mistakes you could be making, check out If You're Not Doing This, Your Mask Won't Protect You, Study Says.

3
Diabetes

People with type-2 diabetes have been considered among the highest risk for severe cases of COVID-19 since early in the pandemic, according to the CDC and medical experts around the world. In fact, a French study published in May highlighted the level of severity individuals with the condition face when infected with coronavirus, finding that 10 percent of patients with diabetes who were hospitalized for severe COVID-19 died within a week of being admitted. And for more regular COVID news delivered right to your inbox, sign up for our daily newsletter.

4
Age

usted its recommendations to broaden its guidance on how age plays into your risk of severe COVID-19, but the agency maintains that it is still very much a factor. "CDC now warns that among adults, risk increases steadily as you age, and it's not just those over the age of 65 who are at increased risk for severe illness," their site warns. And for more on what puts you at risk when it comes to the coronavirus, check out If You Have This Blood Type, You're at a High Risk of Severe COVID.