

Bay Area Regional Advisory Committee
c/o State Council on Developmental Disabilities Bay Area Regional Office
1515 Clay Street, Ste. 803
Oakland, CA 94612

January 20, 2022

State Council on Developmental Disabilities Legislative and Public Policy Committee
c/o Bridget Kolakosky, Deputy Director, Policy and Public Affairs
3831 N. Freeway Blvd. #125
Sacramento, CA 95834

RE. Limited Conservatorship Reform Feedback and Recommendations

Legislative and Public Policy Committee Members,

The Regional Advisory Committee (RAC) for the State Council's Bay Area Region set out to review policy recommendations, gather community input, anecdotal evidence, and general feedback from the community on issues related to reform work needed in CA around limited conservatorship.¹ This work was executed by a RAC member workgroup, with support from the State Council's Regional Office.²

This RAC workgroup would like to elevate the following trends in observations and policy recommendations that have come from this work. Please consider these as you develop legislative advocacy work and focuses for the legislative cycle.

The Need for Data Tracking and Data Publication

The evaluation and reform of any system is dependent, first, on clear, consistently gathered and public data, coupled with anecdotal evidence including personal narratives. Californians report a lack of conservatorship-related data and data tracking available from counties in California, including the numbers of people in conservatorships, the status of those conservatorships, the numbers of petitions to the

¹ The workgroup reviewed policy papers, articles, op-eds, policy summaries, and testimony from US Senate hearings. Additionally, two community listening sessions were held, over Zoom, on December 20th and hosted by RAC Chair and Co-Chair, Elizabeth Grigsby and Francisco Garcia. The community listening sessions were held in English with Spanish-Interpretation and English Captioning. Forty-six people attended the listening session, and 7 people provided emailed feedback.

² The Bay Area Regional Advisory Committee (RAC) Workgroup on Limited Conservatorship Reform was led by the following RAC members: Elizabeth Grigsby, John Marble, Pam Perls, and Marla Silversmith.

courts, the numbers of conservatorship terminations, the numbers of investigations, and the trends and challenges illuminated in that data.

- California should enact higher-standard data collection for better oversight and accountability.
- California should enact consistent and publicly available internal and system-wide audits to evaluate conservatorship implementation, performance, rights monitoring, and due-process.

Need for Person-Centered and Rights Focused Education and Monitoring

Person-centered and rights focused education, monitoring, and legal services require dedicated resources for personnel, processes, and audits. California is in need of these dedicated resources. People with disabilities, their family members, and advocates express that recently enacted AB 1194 does not address all of the advocacy and legal defense needs.

- All conservatees should be entitled to counsel, should they wish to challenge their conservatorship (also known as access to universal counsel). The State Bar should adopt attorney performance standards.
- Courts should enhance the wellbeing and safety of all adults who have court-appointed conservators by implementing a comprehensive, post-appointment person-centered monitoring system.
- As a part of this comprehensive, post-appointment person-centered monitoring system, California should dedicate the court monitoring and investigation personnel in each county to ensure conservators (including corporate/professional conservators) are doing their legal duty to always act in the best interests of the conservatee.

The Need to Elevate and Strengthen Alternatives to Conservatorship, such as Supported Decision Making

Many people with disabilities, their family members, advocates, and guardians are not knowledgeable about alternatives to conservatorship, and have not been given information on these alternatives. Additionally, many people with disabilities are not informed of their rights once in a conservatorship, including the process to seek termination of their conservatorship.

- California should provide comprehensive training, education, diversion programming, and outreach programs about alternatives to conservatorship, including Supported Decision Making and Person-Centered Planning.
- This training, education, diversion programming, and outreach programming should target both people with disabilities across life-stage, as well as family members and guardians. This programming needs to include plain language, and language / cultural competencies.

People with disabilities and their family members and advocates report times when they / their family member / their advocate has been locked out of decision making when facing a medical emergency or other type of crisis. Family members and advocates report feeling the need to seek out and/or maintain a conservatorship so that their highly involved loved one's regional center and health care provider respect their loved one's wishes, as enforced or advocated for by the conservator. Family members report that they do not trust the systems in place (e.g. Department of Developmental Services, Department of Social Services, regional centers, etc.) to properly respect and care for their highly involved loved one or to protect them / their loved one from fiscal abuse and other forms of abuse. This is especially a concern when people with disabilities and their family members or advocates look ahead to a time when the advocate is incapacitated or deceased and can no longer serve as an advocate.

Family members and advocates report that the fiscal burden of obtaining a conservatorship means that this option is often not feasible for low-income families and people with disabilities.

- California should enact laws that uphold patient and service recipient rights and advocate rights. This should include strengthening the power of Supported Decision Making and other alternatives.
 - For example, federal and state agencies could recognize that supported decision making be considered as a reasonable accommodation under the Americans with Disabilities Act.
- California should ensure that people with disabilities, their family members, and advocates have access to low and no-cost resources (e.g. conservatorships and alternatives to conservatorships) to ensure their / their loved one's rights and wishes are respected and upheld in healthcare, financial services, and social service settings.

We would be pleased to provide any additional insight or information at the committee's request. We urge you to address these pressing issues at this pivotal moment in our state and nation's history when conservatorship reform and conservatee rights have been elevated to the forefront of public policy.

We would greatly appreciate your keeping our workgroup informed of what actions you pursue, so we can report back to our community.

Sincerely,

The Bay Area Regional Advisory Committee

Attachment:

Bay Area RAC's Community Feedback / Listening Session Notes on Limited Conservatorship Reform December 2021

Further Reading and Resources:

Op-ed: Cogan, S., Hadreas, A. (2021) *Spears Conservatorship Just the Tip of the Iceberg*. Daily Journal, California Lawyer. Available at:
<https://www.dailyjournal.com/articles/363398-spears-conservatorship-just-the-tip-of-the-iceberg>.

National Guardianship Network's Fourth Guardianship Summit (2021) *Maximizing Autonomy and Ensuring Accountability; Recommendations Adopted by Summit Delegates*. Available at:
http://law.syr.edu/uploads/docs/academics/Fourth_National_Guardianship_Summit_-_Adopted_Recommendations_%28May_2021%29.pdf.

Viscia, K., Hehman, H.(2008) *Developing Conservatorship Performance Standards in the California Courts: Preliminary Observations*. Office of Court Research, Administrative Office of the Courts, California. Available at:
https://www.courts.ca.gov/documents/senate_paper.pdf.

Spectrum Institute (2022) *The Route to Conservatorship Reform*. Available at:
<https://spectruminstitute.org/2022/01/the-route-to-conservatorship-reform/>.

UC Davis MIND Institute's Supported Decision-Making Page and Resources. Available at:
<https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>.

University of California, San Francisco, Office of Developmental Primary Care's Supported Healthcare Decision Making for Professionals. Available at:
https://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/Training%20Materials%20for%20Professionals%20and%20Policy%20Makers.pdf.

Kripke CC, Crisp-Cooper M, Doherty B. (2021) *Partners in Health: Implementing Supported Healthcare Decision-Making for User of Augmentative and Alternative Communication*. Regents of the University of California. Available at:

<https://odpc.ucsf.edu/advocacy/supported-health-care-decision-making/partners-in-health-implementing-supported-healthcare>.

Autistic Self-Advocacy Network's Supported Decision-Making Model Legislation. Available at:

<https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>.

Autistic Self-Advocacy Network's Transition to Adulthood Health Care Guide for Youth and Families. Available at:

<https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>.

Testimony of Clarissa C. Kripke, MD, FAAFP (2021) Senate Judiciary Committee Constitution Subcommittee Hearing on Toxic Conservatorships: The Need for Reform. Available at:

<https://www.judiciary.senate.gov/imo/media/doc/Kripke%20Testimony.pdf>.

Written statement of Zoe Brennan-Krohn, Staff Attorney, Disability Rights Program, American Civil Liberties Union (2021) Senate Judiciary Committee Constitution Subcommittee Hearing on Toxic Conservatorships: The Need for Reform. Available at:

<https://www.judiciary.senate.gov/imo/media/doc/Brennan-Krohn%20Testimony2.pdf>.