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Written Testimony to the Senate Judiciary Subcommittee on the Constitution
Ms. Marie Bergum, California Resident
Supported Decision-Making as a Less Restrictive Alternative to Conservatorship
"Toxic Conservatorships: The Need for Reform"
Hearing September 28, 2021

October 5, 2021

The Honorable Richard Blumenthal
U.S. Senate
393 Russell Senate Office Building
Washington, DC 20510

The Honorable Ted Cruz
U.S. Senate
324 Hart Senate Office Building
Washington, DC 20510

Dear Congressional Leaders:

Thank you for the opportunity to submit written testimony for the Senate Judiciary Subcommittee on the Constitution related to the hearing, "Toxic Conservatorships: The Need for Reform," held on September 28, 2021. We are grateful that the nation is taking a closer look at significant reforms and oversight of the courts, the conservatorship process - which strips fundamental human rights from people with disabilities - and the requirement of less restrictive options, like Supported Decision-Making (SDM).

Exceptional Rights Advocacy (ERA) advances people with disabilities and those who are most vulnerable, so that they are self-expressed and direct their own lives according to their unique abilities. As a disability rights advocate, I have worked with national, state and local agencies to bring education and training on Supported Decision-Making (SDM), to self-advocates, family members and professionals across community, education, healthcare and legal services for persons with developmental disabilities. I am also the parent of three joyful adult children with intellectual and developmental disabilities who practice SDM and use Augmentative and Alternative Communication (AAC).

For almost four years now, it has been my great pleasure to advocate for and support Ms. Marie Bergum, a California resident and the most persistent conservatee I have ever met. This year, she finally escaped her father as conservator and continues to practice Supported Decision-Making (SDM) with her team in a chosen residential independent living program. To learn more about Marie and her story, please see Buzzfeed: "'My Human Rights are Being Violated': Fighting A Family Conservatorship."

All persons with disabilities have the right to self-expression and choice through person centered and self determination practices. Conservatorship, called guardianship in some states, removes a clear set of rights and places people with disabilities in the control of the court system.

According to the National Council on Disability, people with disabilities under guardianship are often denied due process, determined incapacitated in hearings without sufficient scientific evidence, denied the

consideration of less restrictive alternatives[1], rarely have their rights restored and are abused or exploited in court-appointed guardianship proceedings.[2]

Access to general and individualized accommodations, services and supports – including the use of Supported Decision-Making (SDM), powers of attorney and other Less Restrictive Alternatives (LRAs) - can reduce the automatic flow of people with disabilities into a guardianship pipeline. Although IDEA does not include "conservatorship", parents of children with disabilities across the nation learn about *one "choice" only – the most restrictive option - conservatorship. By definition, one option is not a "choice."*

The federal government may act to provide greater oversight of state court systems and federally funded programs to prioritize and incentivize:

- comprehensive data collection on guardianship including information on key demographics;
- the implementation of existing probate law and new legislation that promote and ensure:
    - a reduction in the number of new conservatorships;
    - an increase in the number of conservatorships terminated through the restoration of rights;
    - better protections through due process of law;
    - access to chosen attorneys as zealous advocates for the conservatee's expressed wishes;
    - the reduction of abuse and exploitation within the probate court system through background checks and oversight of conflicts of interest;
    - proof of other less restrictive alternatives, including the use of Supported Decision-Making; and
    - access to accommodations, assistive technology, including communication devices, and support services – using scientific evidence, including self determination and person centered best practices.
- research centers, technical assistance as well as the education and training on Supported Decision-Making (SDM) best practices to families, professionals in the education, developmental and community living, healthcare and legal service fields - and to persons with disabilities.

ERA is grateful for your leadership, time and attention to these crucial, recommended reforms that pave a new pathway focused on abilities and respect for persons with disabilities.

Best,

Suzanne Bennett Francisco

Suzanne Bennett Francisco
President | CEO | Author | Speaker
Co-Chair TASH Human Rights Committee

[1] Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination (ncd.gov)
[2] Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities | NCD.gov