



CONSORTIUM FOR CONSTITUENTS  
WITH DISABILITIES

**Statement for the Written Record  
from the Undersigned Members of the**

## **Consortium for Constituents with Disabilities (CCD)**

**Submitted to  
The Special Committee on Aging  
United States Senate**

**Hearing on  
Guardianships, Conservatorships, Protective Arrangements,  
and Alternatives**

**March 30, 2023**

On behalf of the undersigned members of the Consortium for Constituents with Disabilities (CCD) Rights Task Force, we thank the Special Committee on Aging for planning this hearing and for seeking public input, stories, and suggestions for reform related to guardianship, conservatorship, interdiction, and other protective arrangements (collectively referred to here as “guardianship”). CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

### **Guardianship Is a Disability Rights Issue**

We appreciate you recognizing the need to take federal action to address concerns around the overuse and abuse of guardianship. As highlighted in the 2018 and 2019 reports of the National Council on Disability (NCD), while guardianship systems are embedded in state law, they implicate critical constitutional and federal civil rights, including those under the Americans with Disabilities Act (ADA). Guardianship must be understood as a disability rights issue. Virtually every person under guardianship or at risk of guardianship either has – or is being perceived as having – a disability that substantially limits their ability to manage their own affairs, and thus is protected by federal disability rights laws.<sup>1</sup>

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<sup>1</sup> See National Council on Disability, *Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination*, 41-42 (March 2018) (hereafter, “NCD 2018 Report”), <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>; National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities*, 24-35 (June 2019), <https://ncd.gov/publications/2019/turning-rights-into-reality> (hereafter, “NCD 2019 Report”); *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157 (2010).

## Lived Experiences of People with Disabilities at Risk of or in Guardianship Warrant this Urgent Call to Action

Guardianship – particularly in its plenary form – is a severe intrusion on many adults with disabilities’ most basic right to make choices about their own lives. As recognized by this Committee in its November 2018 report on this topic, there is a long history of well-publicized stories of abuses of people under guardianship that demonstrate a continued and pressing need for widespread reforms.<sup>2</sup> As emphasized by the NCD reports, these stories are neither limited to older adults nor to allegations of financial exploitation. They include the stories of adults of varying ages and disabilities whose personal and civil rights – the rights to vote, marry, procreate, associate, travel, and live and work in the community – have also been deeply impacted. The NCD reports share stories of people with disabilities under guardianship being placed in segregated living environments, sent from competitive employment to sheltered workshops to make subminimum wage, denied control over the management of their own health and bodily autonomy, and prevented from communicating with families and friends.<sup>3</sup> Just this month, after a six-month investigation, a national news outlet released a 5-part series of articles highlighting more stories that illustrate the severe and negative impact overbroad, overly restrictive, and abusive guardianships can have on adults in all walks of life.<sup>4</sup>

### Advancing Court Improvement Initiatives Is Not Enough

We are aware of mounting interest in advancing federal legislative actions designed to promote the improvement of and funding for court guardianship systems.<sup>5</sup> We support efforts to improve guardianship processes and bolster due process protections, including ensuring access to zealous legal representation for people in guardianship or who are facing guardianship proceedings, and clear and accessible ways for terminating a guardianship. *However*, such reforms alone will not be sufficient. Such singular investment could be seen as only legitimizing a prevailing model that systematically deprives people of their decision-making rights. The federal government must simultaneously and equally invest in strategies that encourage states and territories to divert their constituents *away* from guardianship and court systems and *towards* less restrictive options, including Supported Decision-Making (described below). Such strategies will not only benefit

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<sup>2</sup> U.S. Senate Special Committee on Aging, *Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans*, at 9-10 (Nov. 2018), [https://www.aging.senate.gov/imo/media/doc/Guardianship\\_Report\\_2018\\_gloss\\_compress.pdf](https://www.aging.senate.gov/imo/media/doc/Guardianship_Report_2018_gloss_compress.pdf),

<sup>3</sup> See NCD 2018 Report, *supra* note 1, at 28-29, 63-64, 71-72, 105-106; NCD 2019 Report, *supra* note 1, at 67-68, 72.

<sup>4</sup> See Bloomberg Law, *In the Name of Protection Series*. Parts 1 to 5 (March 2023), <https://news.bloomberglaw.com/interactive/guardians-dark-side-lax-rules-open-the-vulnerable-to-abuse> (describing the experiences of Matthew Mendiola from New Mexico, who has mental health disabilities and allegedly experienced financial, personal, and physical abuses while under a private guardianship; Ruby Campos from Texas, who was placed under guardianship after she aged out of the foster care system and was denied requests to visit relatives or have her own debit card; Nicholas Clouse from Indiana, who has a history of a traumatic brain injury and was placed under a familial guardianship that impacted how he could support his own child; Kalei Bulwinkle from Georgia, a 22-year-old woman with developmental disabilities who describes the removal of her right to vote and the restrictions on her ability to drive and spend her own money; among others).

<sup>5</sup> See Summit Delegates, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability - Recommendations Adopted by Summit Delegates*, 72 Syracuse L. Rev. 29, 39-40 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/09/29-40-Preface-2.pdf> (describing recommendations relating to Congressional funding of a Guardianship Improvement Program).

people with disabilities whose rights are being unnecessarily curtailed, but also the court systems that are currently overburdened with unnecessary guardianship petitions and proceedings.<sup>6</sup>

## **Federal Initiatives to Promote Less-Restrictive Alternatives and Data Collection on Guardianship Are Key**

There are three key components that must be included in any federal legislative package seeking to address the problems associated with guardianship – namely (1) federal grants and other financial incentives to states and territories to reduce the number of unnecessary or overbroad guardianships and increase access to other options, including Supported Decision-Making; (2) investment in a long-term national technical assistance center to promote Supported Decision-Making models and to provide states and territories the support they need to advance them successfully; and (3) funding and other requirements for states and territories to collect detailed data on guardianship and report them to a national data collection entity. These three components are essential, complementary, and inseparable for a successful outcome to be achieved.

### **1. Establish Grant Programs To Incentivize States and Territories To Make the Shift to a “Supported Decision-Making First” Model**

Congress should establish grants and other financial incentives to encourage states and territories to decrease the use of guardianship and increase the use of Supported Decision-Making and other alternatives. Supported Decision-Making is an alternative to guardianship in which people with disabilities and older adults make their own decisions with the assistance of supporters they choose and trust.<sup>7</sup> It has gained widespread recognition as a best practice and as an avenue by which many people may be able to avoid overbroad and undue guardianship.<sup>8</sup> It has also been linked to the Americans with Disabilities Act, as a way in which to reasonably accommodate a person’s disability.<sup>9</sup>

This federal legislation could be modeled in part on the Transformation to Competitive Integrated Employment Act (TCIEA).<sup>10</sup> It would provide grants, resources, and technical assistance to states and territories to help them transition to a “Supported Decision-Making First” model that would include the development of guardianship diversion programs located outside the court system, the creation of innovative and far-reaching Supported Decision-Making projects, and the ultimate reduction in the number of guardianships. The funding should be long-term and nationwide, and not simply for pilot programs in a few states.

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<sup>6</sup> For example, since state legislation that would formally recognize supported decision-making was introduced in Wisconsin, the annual number of petitions to courts for guardianship decreased by almost 20 percent. See WSAW-TV, *Guardianship requests decline as knowledge of alternative legal option grows* (Aug. 2021), <https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-option-grows/>.

<sup>7</sup> See Summit Delegates, *supra* note 5, at 30 (defining Supported Decision-Making or “SDM”).

<sup>8</sup> See *id.* at 32-34 (recommending the funding of SDM projects and the mandatory consideration by courts of SDM alternatives to guardianship), 36, and 39 (recommending the provision of wide-spread training on alternatives to guardianship, including SDM). See also Center for Public Representation, *U.S. Agencies and National Organizations Promoting Supported Decision-Making*, <https://supporteddecisions.org/about-supported-decision-making/organizations-advocating-for-supported-decision-making> (last accessed Mar. 17, 2023) (includes the American Bar Association, the National Guardianship Association, the National Council on Disability, the U.S. Senate Special Committee on Aging, the Fourth National Guardianship Summit, the Uniform Law Commission, among others).

<sup>9</sup> See Summit Delegates, *supra* note 5, at 34 (recommending that SDM be recognized as a possible “reasonable accommodation under the Americans with Disabilities Act of 1990, as amended, in supporting an individual in making their own decisions and retaining their right to do so”).

<sup>10</sup> See S. 533, 118<sup>th</sup> Congress (2023-2024).

- Like the TCIEA, the legislation should adopt a tiered approach to its overall grant awarding strategy. It would first make initial five-year grants available to support states and territories meeting certain minimum requirements to become Supported Decision-Making First states, during which the infrastructure, data collection, and related processes needed to measure progress would also be built or reformed. The legislation would then provide additional on-going funding only for states and territories that can demonstrate they have met particular benchmarks for increasing the use of Supported Decision-Making and decreasing the use of guardianship.
- The state grantees should be required to use a significant portion of the funds for grants to nonprofit entities to develop and implement Supported Decision-Making initiatives that promote diversion from and termination of overbroad and undue guardianship. This should include targeted projects that seek to reach people who face barriers in accessing Supported Decision-Making, such as those who lack natural supports or who experience barriers to communication and being understood.
- Similar to the approach of the TCIEA, the legislation should require state grantees to establish an advisory council to monitor and advise the state in the process of transforming the state system into a “Supported Decision-Making First” model. The advisory council should include people with disabilities with lived experience of guardianship and alternatives; their family members; representatives of the legal services, Protection and Advocacy, and Parent Centers networks; and representatives of the state developmental disability agency, behavioral service agencies, office of aging, educational agency, and adult protection agency.

## **2. Provide Long-Term Investment in a National Technical Assistance Center to Promote Supported Decision-Making**

Similar to Title III of the TCIEA, the federal legislation should provide funding for a nonprofit entity to provide on-going and national technical assistance to “Supported Decision-Making First” grantees. The national technical assistance center would promote Supported Decision-Making, provide states with the support they need to advance it successfully, and lead development of standards, competencies, and training. The investment in the national technical assistance center should be long-term and significant, so that the center has the ability to lead the development of standards, competencies, and trainings that reach the public broadly, including people with disabilities, families, court personnel, attorneys, health care providers, adult protection agencies, and other professionals. The funding should come primarily through the Administration for Community Living (ACL), which has extensive expertise in addressing knowledge gaps through its Projects of National Significance (PNS) and other programs.<sup>11</sup>

## **3. Require Collection of Comprehensive Data on Guardianship**

Currently, there is minimal reliable data on the use of guardianship in the United States, with experts struggling even to estimate the total number of people under guardianship.<sup>12</sup> The federal legislation should incentivize states to collect comprehensive data on guardianship, including making grant funds contingent on data collection. Data should include information on the total number of people under guardianship; type of guardianship (e.g., limited or plenary; of the person

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<sup>11</sup> See Administration on Community Living, *Projects of National Significance*, available at <https://acl.gov/programs/strengthening-aging-and-disability-networks/projects-national-significance> (last visited Mar. 17, 2023).

<sup>12</sup> See NCD 2018 Report, *supra* note 1, at 65-70.

or of the property or both; permanent or temporary); key demographic information, such as age, gender identity, race, ethnicity, and primary language; type of disability; whether the person has a communication disability (*i.e.*, vision, hearing, or speech); the length of the guardianship; the type of guardian (*i.e.*, family member, friend, professional private guardian, or public agency); type of residence (*e.g.*, institution, group home, community setting); county; number of new guardianships each year; and number leaving guardianship each year, disaggregated by reason (*e.g.*, termination of guardianship or death). In addition, states should be required to collect specific information on the use of professional guardians, including the ratio of professional guardians to people under professional guardianship. Data should be reported and captured into one national data collection system, through the auspices of either the U.S. Department of Health and Human Services or the U.S. Department of Justice.

We also would support data collection efforts by federal agencies, such as the U.S. Census Bureau, the American Community Survey (ACS), Centers for Medicare and Medicaid Services (CMS), and Social Security Administration (SSA). Although such efforts may not provide a comprehensive snapshot of all people under guardianship, it may assist in filling in gaps in state-collected data and identifying trends among federal benefit program participants.

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We appreciate the opportunity to provide the Committee with our perspective on the importance of federal action to promote access to alternatives to overbroad and undue guardianship. We look forward to working with Congress and the Administration to ensure that people with disabilities do not have their rights removed unnecessarily.

If you have any questions or if we can be of any assistance, please do not hesitate to reach out to Morgan K. Whitlatch, Co-Chair, CCD Rights Task Force at 202-596-6116 or [mwhitlatch@cpr-ma.org](mailto:mwhitlatch@cpr-ma.org).

Sincerely,

Access Ready  
American Civil Liberties Union (ACLU)  
Autistic Self Advocacy Network  
Bazelon Center for Mental Health Law  
Center for Public Representation  
CommunicationFIRST  
Disability Rights Education and Defense Fund (DREDF)  
Epilepsy Foundation of America  
National Association of Councils on Developmental Disabilities (NACDD)  
National Center for Parent Leadership, Advocacy and Community Empowerment (National PLACE)  
National Health Law Program  
Quality Trust for Individuals with Disabilities  
RespectAbility  
TASH  
The Advocacy Institute  
The Arc of the United States  
World Institute on Disability