

U.S. Senate Judiciary Committee, Subcommittee on the Constitution Subcommittee

Hearing on “Toxic Conservatorships: The Need for Reform”

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Written Statement of Morgan K. Whitlatch, Esq.

Legal Director, Quality Trust for Individuals with Disabilities

Senator Blumenthal, Senator Cruz, and members of the Subcommittee, thank you for inviting me to testify here today about guardianship law and options for reform. I am here in my capacity as Legal Director of Quality Trust for Individuals with Disabilities, an independent, non-profit advocacy organization in the District of Columbia that has been advancing the interests of people with intellectual and developmental disabilities since 2002. For almost two decades, Quality Trust has been addressing issues involving decision-making rights, capacity, and consent in the District and beyond, through education and training, individual legal and lay advocacy, resource development, and legislative and policy change.

Quality Trust leads the National Resource Center for Supported Decision-Making,¹ which was created in 2014 and is dedicated to advancing the decision-making rights of people with disabilities and older adults through training, information-sharing, technical assistance, research, and promotion of promising practices in Supported Decision-Making. Prior to that, in 2013, we launched the Jenny Hatch Justice Project,² following our court victory on behalf of its namesake, a woman with Down Syndrome who we represented in fighting for her right to engage in supported decision-making as an alternative to permanent plenary guardianship and who has submitted video testimony to you for review. Through this project, we provide legal advocacy and representation to assist people with disabilities, including older adults, to design and implement practical tools to support their decision-making rights; access alternatives to guardianship; and go to court to prevent, limit, or end overly restrictive guardianship. We also served under cooperative agreements with the National Council on Disability (NCD) that resulted in its two ground-breaking reports analyzing the impact of guardianship and alternatives in the lives of people with disabilities through the lens of the U.S. Constitution and federal civil

¹ www.SupportedDecisionMaking.org.

² www.JennyHatchJusticeProject.org.

rights laws. These NCD reports, issued in 2018³ and 2019,⁴ offer concrete findings and recommendations to the Administration and Congress that can inform this Subcommittee’s deliberations. Quality Trust also served as a voting delegate at the Fourth National Guardianship Summit,⁵ organized by the National Guardianship Network, which resulted in recommendations⁶ for reform to bolster and enforce not only the due process rights of people in or facing guardianship, but also people’s ability to access less-restrictive options that do not involve removing their legal right to direct their own lives.

Britney Spears’ story has shined a national and very public spotlight on the problems of guardianship and conservatorship systems and the damaging and potentially devastating impact that they can have on people’s lives. From our years working with and on behalf of hundreds of people impacted by these systems, Quality Trust knows that Ms. Spears is not alone. With that in mind, we co-led a coalition of disability justice advocates who have been working for years to advocate for alternatives to overbroad, unnecessarily restrictive, and undue guardianships.⁷ Guardianship and conservatorship are regularly imposed upon and impact adults of all ages, with different diagnoses, life experiences, and socioeconomic backgrounds. While only a rough estimate based on extrapolation because of serious gaps in data collection, it has been estimated that at least 1.3 million adults in the United States are under guardianship or conservatorship.⁸ Today, you will hear from Nicholas Clouse who will share his troubling personal experience with guardianship in Indiana, but there are many more such stories from people around the country⁹ – and it is those testimonials that are most important and the most compelling reason for why reform must happen now.

While the law varies from state to state, guardianship and conservatorship orders routinely authorize third parties to make decisions about the most personal and important choices in an individual’s life, including what kind of medical, psychiatric, or psychological treatment a person receives; how a person’s own money is spent; where a person can go; and even with

³ National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities* (March 22, 2018), available at <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives/>

⁴ National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (June 10, 2019), available at <https://ncd.gov/publications/2019/turning-rights-into-reality> .

⁵ See The Fourth National Guardianship Summit 2021 website, <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability> (including summary of summit purpose, discussion topics and issue briefs, and recommendations adopted by the summit).

⁶ Fourth National Guardianship Summit, *Recommendations Adopted by Summit Delegates* (May 2021), available at <https://tinyurl.com/4d2jkm5r>.

⁷ See Statement from Disability Justice and Supported Decision-Making Advocates: Britney Spears Spotlights the Need for Change Now, available at www.supporteddecisionmaking.org/node/489 (June 25, 2021) (signed by the National Resource Center for Supported Decision-Making, Center for Public Representation, Quality Trust for Individuals with Disabilities, The Arc of the United States, Autistic Self Advocacy Network, Burton Blatt Institute, Cardozo Bet Tzedek Legal Services, Disability Rights California, Disability Rights Texas, Disability Voices United, Georgia Advocacy Office, Indiana Disability Rights, National Disability Rights Network, and TASH).

⁸ NCD 2018 Report, *supra* note 3, at 65.

⁹ For more videos and statements on the impact of guardianship, please visit www.SupportedDecisionMaking.org.

whom a person can associate. Guardianship also can impact other fundamental rights, like the right vote and marry.¹⁰ In my almost 20 years of legal practice, I have personally seen people under guardianship denied all of the aforementioned rights and more, including being prevented from interacting with trusted family, friends, and attorneys; using their own bank accounts and personal identification cards; participating in community living and non-facility-based supports and services; engaging in meaningful and integrated employment; receiving medical treatment and palliative end-of-life care; traveling; and even accessing the telephone, mail, computers, and the internet. The power wielded by guardians is mighty, and with great power comes the risk of great abuse,¹¹ particularly given the unevenness in the rigor of court oversight of guardianship and conservatorships across the country.¹²

The NCD reports highlighted the significant due process problems with the way in which guardianship and conservatorship systems frequently operate.¹³ I have also seen such problems first-hand, over and over again. Too frequently, people facing guardianship petitions are not supported to access less-restrictive options for decision-making support; do not receive zealous representation of their expressed wishes by an attorney of their choice; are not present at the very court hearing that will determine which rights they can personally exercise; or are pressured to consent to their own incapacity in order to avoid the loss of that which they deeply value, such as family support or avoiding eviction from their homes. Many people who are subject to guardianship or conservatorship also can face legal barriers in seeking redress from the court or in having their rights restored – from not knowing they have the right to petition for termination, to not being able to access an attorney, to having to pay not only their own legal fees but those of the opposing side and other court costs; to bearing the burden of proving they are no longer “incapacitated” in a world that too frequently links that term to particular diagnoses or intellectual quotient scores.¹⁴ Ending guardianships and conservatorships, once established, frequently can be a very resource and time intensive endeavor, as Quality Trust’s representation of Ms. Hatch¹⁵ and others proved.¹⁶

¹⁰ See NCD 2018 Report, *supra* note 3, at 27-29.

¹¹ See United States Government Accountability Office, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors*, September 2010, accessed January 24, 2018, <https://www.gao.gov/assets/320/310741.pdf>; NCD 2018 Report, *supra* note 3, at 103-104.

¹² See NCD 2018 Report, *supra* note 3, at 65-70.

¹³ See NCD 2018 Report, *supra* note 3, at 85-91 and NCD 2019 report, *supra* note 4 at 37-40.

¹⁴ See American Bar Association, *Restoration of Rights in Adult Guardianship: Research & Recommendations* (2017), available at <https://tinyurl.com/yka37wvh/>.

¹⁵ Quality Trust’s representation of Jenny Hatch involved months of attorney preparation, pleadings, the retention of numerous experts, and six days of trial. See <http://www.jennyhatchjusticeproject.org/trial>

¹⁶ Other high profile guardianship termination cases supported by Quality Trust include that of Ryan King, the first D.C. resident to have his guardianship terminated in favor of Supported Decision-Making and “Dolores” (pseudonym), the first D.C. senior to have her guardianship similarly terminated. See Petula Dvorak, *Why a man with intellectual disabilities has fewer rights than a convicted felon*, WASH. POST (Sept. 21, 2015) (article on Ryan King); Amanda Morris, *Britney Spears’s Case Calls Attention to Wider Questions on Guardianship*, NY TIMES (July 10, 2021), <https://www.nytimes.com/2021/07/10/us/britney-spears-conservatorships-guardianships.html> (describing Mr. King’s almost 10 year battle to have his rights restored); Theresa Vargas, *This 87-year-old D.C. woman just made it easier for you to keep our independence*, WASH. POST, June 27, 2018,

We welcome federal scrutiny of the failures of guardianship and conservatorship systems, and we thank this subcommittee for its leadership in doing so. As highlighted in both the NCD reports, while these systems are creatures of state law, they implicate federal Constitutional rights, as well as civil rights under other federal laws, including the Americans with Disabilities Act, the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Developmental Disabilities Assistance and Bill of Rights Act, among others. In responding to this strong public outcry for change, one of the dangers we urge you to avoid is concentrating reform solely on efforts to make guardianship and conservatorship systems considered better. More attention and investment must also be placed in promoting the avoidance of guardianship and conservatorship all together, as they are over-utilized legal tools that have the effect of removing legal personhood. This means taking steps to dismantle the many pipelines to overbroad and undue guardianship – including those linked to schools,¹⁷ health care providers, adult protective services,¹⁸ and the legal profession, among others. It means promoting less restrictive and voluntary options, such as Supported Decision-Making, that advance self-determination and do not involve the courts.

Supported Decision-Making occurs when people use their family, friends, and others they trust to help them understand the choices they face, so that they can make their own decisions. Supported Decision-Making is already part of the mainstream disability rights discourse and is gaining traction for older adults as well. It has been the subject of pilots,¹⁹ state legislation and laws,²⁰ and court decisions terminating or refusing to order guardianship.²¹ It also has been endorsed by influential associations, national organizations, and federal agencies and advisory boards.²² Decades of research have found that people with disabilities who have more control

https://www.washingtonpost.com/local/this-87-year-old-dc-woman-just-made-it-easier-for-you-to-keep-your-independence/2018/06/26/92636ce6-7962-11e8-80be-6d32e182a3bc_story.html.

¹⁷ See NCD 2019 report, supra note 4, at 29-36 (identifying a school-to-guardianship pipeline, in which educators may advise parents to pursue guardianship over adult students in special education).

¹⁸ See American Bar Association Commission on Law & Aging & Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS), *The Role of Adult Protective Services (APS) in Guardianship Cases*, 1-2 (2020), available at https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-wings-action-tool-aps.pdf.

¹⁹ See Cathy Costanzo, Hon. Kris Glen, & Anna Krieger, *Supported Decision-Making: Lessons from Pilot Projects* (April 2021), <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability> (background paper prepared for the Fourth National Guardianship Summit).

²⁰ As of March 1, 2021, at least 40 states and the District of Columbia have introduced one or more pieces of legislation or resolutions specifically referring to SDM, and at least 19 of those states and the District of Columbia has passed them. See Rebekah Diller & Morgan Whitlatch, *Supported Decision-Making: Potential and Challenges for Older Persons* (April 2021), at 9-10, n. 23, available at <http://law.syr.edu/uploads/docs/academics/Diller-Whitlatch.pdf> (background paper prepared for the Fourth National Guardianship Summit). The way in which SDM has been codified in state laws varies, from formally recognizing it within enforceable legal documents, in special education for adult students, in the context of organ transplantation, and in judicial deliberations required prior to the appointment of a guardian or conservator, among others.

²¹ At least 13 states, as well as the District of Columbia, have court orders and decisions terminating or refusing to order guardianship because of supported decision-making. See *id.* at 10-11, fn. 25.

²² Tina M. Campanella & Morgan K. Whitlatch, Supported Decision-Making: U.S. Status and Trends, 32 *IMPACT* 1 (2019), <https://publications.ici.umn.edu/impact/32-1/supported-decision-making-us-status-and-trends> (noting

over their lives have improved employment and quality of life, are better problem-solvers, and are better able to avoid and resist abuse.²³ Research has also shown that older adults with self-determination have improved psychological health, including better adjustment to increased care needs.²⁴ Supported Decision-Making can be coupled with other voluntary legal tools, such as powers of attorney and advance health care directives, that also promote self-determination and autonomy.

To this end, we urge you to consider the following recommendations for federal legislation and reforms, which have been adapted from the NCD reports and the results of the Fourth National Guardianship Summit.

Invest in Promoting Access to Options Other Than Guardianship – Congress should:

- Urge the Department of Justice to issue guidance recognizing and clarifying that supported decision-making is a “reasonable modification” and nondiscriminatory method of administration that public entities and public accommodations – including courts, schools, medical professionals, banks, and others – must recognize in order to avoid disability discrimination.²⁵ It should include discussion of other legal obligations pursuant to the ADA in the context of ensuring guardianship is the last resort that is imposed only after less restrictive alternatives have been ruled out, as well as requirements that states consider including benchmarks related to SDM in their Olmstead Plans.²⁶
- Urge the Department of Justice to take the position that the degree of due process in guardianship matters should not be different for people with intellectual and

SDM’s recognition by the National Guardianship Association, the American Bar Association Commission on Law and Aging, the Arc of the United States and the American Association on Intellectual and Developmental Disabilities in 2016, the U.S. Department of Education’s Office of Special Education and Rehabilitation Services, the U.S. Social Security Advisory Board, the U.S. Senate Special Committee on Aging, and the National Council on Disability).

²³ See, e.g., Yves Lachapelle *et al.*, *The Relationship Between Quality of Life and Self-Determination: An International Study*, 49 J. INTELLECTUAL DISABILITY RESEARCH 740-44 (2005); Michael Wehmeyer & Michelle Schwartz, *Self-Determination & Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 EXCEPTIONAL CHILDREN 245-255 (1997); Michael Wehmeyer & Susan Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination*, 38 EDUCATION & TRAINING IN DEVELOPMENTAL DISABILITIES 131-44 (2003); Ishita Khemka, Linda Hickson, & Gillian Reynolds, *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*, 110 AMERICAN JOURNAL ON MENTAL RETARDATION 193-204 (2005); Laurie E. Powers *et al.*, *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education*, 25 CHILDREN & YOUTH SERVICES REVIEW 2179-2187 (2012); Shogren, *et al.*, *Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities*, 48 J. of Special Education 256-67 (2013).

²⁴ Brian P. O'Connor & Robert J. Vallerand, *The Relative Effects of Actual & Experienced Autonomy on Motivation in Nursing Home Residents*, 13 CANADIAN JOURNAL ON AGING 528-38 (1994)

²⁵ See Fourth National Guardianship Summit, adopted recommendation 3.1; *Beyond Guardianship*, *supra* n. 3, Finding and Recommendation #2, at 162-163.

²⁶ See NCD 2019 Report, *supra* note 4, at 81.

developmental disabilities simply because of their diagnosis, and issue guidance that states that have such statutes or practices are engaging in discrimination under the Americans with Disabilities Act.²⁷

- Urge the Department of Education to issue guidance to all teacher education programs and vocational rehabilitation agencies that requires them to cover the full range of decision-making options in their transition programming and instruction of accommodations for students with disabilities.²⁸
- Ensure that federally funded programs, such as those associated with the Individuals with Disabilities Education Act (IDEA) and Adult Protective Services (APS), stop being pipelines to overbroad and undue guardianship by funding technical assistance and demonstration projects on using alternatives to guardianship, as well as related education and training initiatives of educational and APS personnel.²⁹
- Establish programs that fund grants to support states in adopting Supported Decision-Making (SDM) within their policies and practices; in educating judges, attorneys, other legal professionals, service providers, and the broader public; in identifying and addressing barriers to SDM; in establishing technical assistance programs and resources; and in developing programs to provide decision-making support for people who lack pre-existing natural supports. These grants should be designed to establish, replicate, and scale up promising practices for sustainable SDM practices and models that reach diverse populations of people with disabilities and older adults, including people with communication challenges, dementia and memory loss, and mental health diagnoses, among others.³⁰
- Fund nationwide technical assistance and research to address gaps in implementing of SDM across states and populations. The Administration on Community Living recently completed a five-year grant to create the National Resource Center for Supported Decision-Making, which made significant progress in advancing the “Right to Make Choices” of people with disabilities and older adults, through training, information-sharing, technical assistance, research, and promotion of promising practices in SDM. Further funding of NRC-SDM would allow for the continuation of that progress and further innovation in the advancement of alternatives to guardianship as part of a coordinated national effort.

²⁷ See NCD 2019 Report, *supra* note 4, at 81.

²⁸ See NCD 2019 Report, *supra* note 4, at 80.

²⁹ See Fourth National Guardianship Summit Recommendation 2.1.

³⁰ See Fourth National Guardianship Summit recommendation 2.2

- Fund additional research on and dissemination of best practices in SDM through the ACL’s National Institute on Disability, Independent Living, and Rehabilitation Research (NIDLRR) program, with a focus on the populations identified above and in specific domains, such as health care and financial planning.

Enhance the Rights of Persons At Risk of or Subject to Guardianship & Promote Transparency and Accountability of Guardianship and Conservatorship Systems -- Congress should:

- Establish a Guardianship Court Improvement Program modelled on the Child Welfare Court Improvement Program to enhance the rights and well-being of adults subject to or facing guardianship by requiring implementation of consistent and meaningful data collection, improvement of oversight and accountability, avoidance of unnecessary or overbroad guardianship, and enhancement of collaboration and education among courts, agencies, and organizations that have impact on this population.³¹ This program should include establishing incentives to states to collect comprehensive data on guardianship, including the total number of people under guardianship, key demographic information, type of disability, length of guardianship, type of guardian, and type of residences. This program should also include formal guardianship diversion initiatives within the courts, so that guardianship is only considered as a last resort.
- Require States to strengthen the due process rights and protections of people at risk of or subject to guardianship, including the absolute right to an attorney to zealously represent their expressed interests (as opposed to “best interest”), the right to reasonable notice provided in their preferred language and in an understandable and accessible format; the right to participate in the proceeding; the right to contest; the right to seek termination and restoration of rights; the right to receive help in understanding and exercising these rights; and the right to the exploration of less restrictive options first. Use funding incentives to encourage states to adopt the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act, which contains many of these key protections.
- Require federal agencies, including the Social Security Administration, the American Community Survey, and the Centers for Medicare and Medicaid Services to undertake data collection efforts on guardianship, which may assist in filling in gaps in state-collected data and identify trends across benefit programs.
- Fund qualified legal service programs to provide legal assistance to individuals who are trying to have their rights restored or avoid guardianship.

³¹ See Fourth National Guardianship Summit Recommendations 6.1, 6.2, and 6.3.

Thank you for the opportunity to testify before you today. I strongly urge you to continue to coordinate with the disability rights community and people directly impacted by guardianship, so that your work is informed by practical real-life experience.