



Nothing about us without us!

**Written Testimony of the Autistic Self Advocacy Network  
October 5, 2021**

**For the Senate Judiciary Committee Subcommittee on the Constitution  
Hearing on Toxic Conservatorships: The Need for Reform  
September 28, 2021**

Dear Senators Blumenthal and Cruz,

On behalf of the Autistic Self Advocacy Network (ASAN), I appreciate the opportunity to provide written testimony concerning the effects of guardianship on people with intellectual and developmental disabilities, including autistic people. ASAN is a 501(c)(3) advocacy organization run by and for autistic people ourselves.

ASAN has a longstanding interest in promoting alternatives to guardianship. By taking away our right to self-determination, guardianship affects all aspects of our lives, including our rights to live in the community, exercise control over our own bodies and our own healthcare, seek employment, exercise parental rights, and even vote. It is not uncommon for guardians—especially professional guardians—to spend little or no time communicating with the people they were appointed to assist. As a result, people under guardianship often have little to no input in decisions about their own lives.

Even if a person is later released from guardianship, they may face lifelong challenges. For example, one woman we assisted was denied admission to her state bar because she had once been under guardianship.

Years of advocacy have taught us that guardianship reform is not enough. Although we support additional safeguards for guardianship, such as access to legal representation and protections against fraud and abuse, these safeguards would not change the fact that people under guardianship experience a profound loss of autonomy and face significant barriers to full community integration and participation.

Alternatives to guardianship, such as supported decision-making, enable people with disabilities to receive the support we need while maintaining our dignity and right to self-determination. The supported decision-making model enables people to choose who supports them and when. This

support could include assistance with understanding the benefits and drawbacks of available options, keeping track of expenditures, and communicating with banks, doctors, and landlords.

Supported decision-making has gained increasing recognition as an alternative to guardianship, even for people who need significant support. In 2012, a New York judge recognized that guardianship was an unnecessary deprivation of constitutional rights in situations where alternatives, such as supported decision-making, are available.<sup>1</sup> In 2013, Jenny Hatch won her petition to be freed from guardianship and to use supported decision-making instead.<sup>2</sup> Since then, numerous states have passed legislation recognizing supported decision-making.<sup>3</sup> Supported decision-making also enjoys support from most major organizations focused on disability and aging and from prominent groups of experts on guardianship.<sup>4</sup>

Nevertheless, guardianship remains extremely common. It is still extremely easy to be placed under guardianship and prohibitively difficult to escape from it. People may be placed under guardianship without ever having an opportunity to appear at an in-person hearing. Courts remain uninformed about available alternatives or may incorrectly assume that, by the time a case reaches them, all available alternatives have already been tried. Service providers also may advise families to petition for guardianship or may initiate their own guardianship petitions without first exhausting other options.

We urge Congress to promote alternatives to guardianship on a federal level. Congress should provide permanent funding for the National Resource Center for Supported Decision-Making. This valuable resource for courts, advocates, and community members, initially funded through a grant from the Administration for Community Living, is now unfunded. Congress should also ensure that federally funded programs, including special education services and adult protective services programs, do not become “pipelines” into guardianship. Grant programs could help support state pilot projects and demonstration projects to identify best practices in supported decision-making. Collecting comprehensive data on guardianship—including data on the type of guardian, the length of guardianship, the person under guardianship’s primary type of disability, and demographic information on both the guardian and the person under guardianship—will also help inform advocates and researchers.

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<sup>1</sup> Matter of Dameris L., 38 Misc.3d 570 (N.Y. Surr. Ct. 2012) (Glen, J.).

<sup>2</sup> MSN Now, *Woman with Down Syndrome Wins Freedom from Parental Guardianship* (August 3, 2013), available at [http://www.jennyhatchjusticeproject.org/2013\\_08\\_03\\_msn\\_now](http://www.jennyhatchjusticeproject.org/2013_08_03_msn_now).

<sup>3</sup> Supported Decision-Making New York, *Supported Decision-Making Laws*, available at <https://sdmny.hunter.cuny.edu/sdm-laws/>

<sup>4</sup> See, e.g., Nat’l Guardianship Network, *Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability* at 3-4 (May 2021), available at [http://law.syr.edu/uploads/docs/academics/Fourth\\_National\\_Guardianship\\_Summit\\_-\\_Adopted\\_Recommendations\\_%28May\\_2021%29.pdf](http://law.syr.edu/uploads/docs/academics/Fourth_National_Guardianship_Summit_-_Adopted_Recommendations_%28May_2021%29.pdf).

I am attaching a short set of recommendations for federal action to promote alternatives to guardianship that ASAN had previously provided to Senator Casey's office. I would appreciate the opportunity to speak to your offices in further detail. I can be reached at [scrane@autisticadvocacy.org](mailto:scrane@autisticadvocacy.org) or (202) 509-0135.

Thank you,

A handwritten signature in black ink, appearing to read 'Sam Crane', with a stylized flourish at the end.

Sam Crane, Legal Director  
Autistic Self Advocacy Network