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ASAN Recommendations for Federal Legislation on Alternatives to Guardianship

September 10, 2021

All people with disabilities have the right to self-determination. Guardianship, conservatorship, and interdiction,¹ collectively referred to here as “guardianship,” deprive people with disabilities of the right to make choices about our own lives. The Autistic Self Advocacy Network (ASAN) supports efforts to create alternatives to guardianship and protect the rights of people facing guardianship petitions and people under guardianship. Alternatives to guardianship may include supported decision-making arrangements, health care proxies, and powers of attorney.

Matters of guardianship are typically within the authority of state and local probate and family courts. However, there are several avenues in which the federal government may act to encourage alternatives to guardianship, collect comprehensive information about guardianship, and protect the rights of people under or facing guardianship.

These avenues include (1) ensuring that federally funded programs prioritize alternatives to guardianship; (2) awarding funding to states to improve access to alternatives to guardianship; (3) funding research and technical assistance on best practices for supported decision-making; and (4) collecting comprehensive data on guardianship.

Cut off guardianship pipelines through federally funded programs such as IDEA and adult protective services

School special education programs frequently serve as a “pipeline” into guardianship.² Educators may advise parents to pursue guardianship as part of the transition planning process, or parents may believe that they must secure guardianship in order to remain involved in the special education planning process after a student turns 18.

ASAN does not support reopening the substantive provisions of the IDEA, which we believe already prohibits such practices. Nevertheless, ASAN supports funding for teacher and parent training on alternatives to guardianship and use of supported decision-making in special

¹ Different states use different terms to refer to restrictions on the rights of people found to lack legal capacity. For example, California uses the term “conservatorship exclusively, whereas Louisiana uses the term “interdiction” or “continuing tutorship.” See Cal. Probate Code Sec. 1800 et seq.; La. Civ Code 362; LA Civ Code 355.

² Nat’l Council on Disability, “Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities” at 29-36 (2019), available at https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf.

education contexts. We also recommend that Congress direct the Secretary of Education to issue guidance on use of alternatives to guardianship in transition planning and that it include report language noting that the IDEA requires provision of transition planning services that maximize their opportunities for independence in adulthood.

State Adult Protective Services (APS) are also a known “pipeline” into guardianship.³ APS may respond to welfare concerns by seeking a guardianship order. The resulting guardianships can cause severe long-term consequences to affected adults.⁴ ASAN would support funding for technical assistance and demonstration projects to help APS programs use alternatives to guardianship when responding to welfare concerns.

Grants to states to implement supported decision-making (SDM) and other alternatives to guardianship

ASAN supports funding for state-level programs to improve access to SDM. Although numerous states already recognize supported decision-making as an alternative to guardianship,⁵ legal reforms alone are insufficient to ensure that everyone has meaningful access to alternatives to guardianship. Barriers may vary at the state level due to differences in state law and disability support programs.

Federal funding to support state SDM programs could support efforts to educate attorneys, judges, service providers, and the public; identify and address barriers to SDM; establish technical assistance programs and resource centers; and develop programs to provide decisionmaking support for people who lack pre-existing natural supports. States applying for grants would be required to confirm that supported decision-making is recognized, either through statute or case law, as alternative to guardianship.

Funding research and technical assistance on best practices for supported decision-making

As noted above, state-level legal reforms alone are insufficient to ensure meaningful access to alternatives to guardianship. In addition to addressing state-specific barriers, it will be necessary to provide nationwide technical assistance and address gaps in our understanding of best practices in implementation of supported decision-making - especially with respect to

³ Am. Bar Ass’n Comm. 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.

⁴ See, e.g., John Leland, *‘I’m Petitioning ... for the Return of My Life’*, N.Y. Times (Dec. 7, 2018), <https://www.nytimes.com/2018/12/07/nyregion/court-appointed-guardianship-like-prison.html> (describing a case in which Adult Protective Services was called, placing an elderly woman under guardianship who has been financially and physically exploited by her guardians and APS since placement).

⁵ See, e.g., Zachary Allen & Dari Pogach, “More States Pass Supported Decision-Making Agreement Laws,” Am. Bar Ass’n Oct. 1, 2019, available at https://www.americanbar.org/groups/law_aging/publications/bifocal/vol-41/volume-41-issue-1/where-states-stand-on-supported-decision-making/

populations such as people with significant communication challenges, memory loss, or episodic mental health concerns.

The Administration for Community Living (ACL) has extensive expertise in addressing knowledge gaps through its Projects of National Significance (PNS) and other programs.⁶ ACL recently completed a five-year grant to create the National Resource Center for Supported Decisionmaking (NRC-SDM), which made important progress toward identifying best practices⁷ and provides critical technical assistance.⁸ Although ACL has subsequently funded additional projects regarding supported decision-making, none are equally comprehensive as the NRC-SDM. We support additional ACL funding to continue operating the NRC-SDM and to support further research on best practices - with a specific focus on racial equity; developing best practices for people with significant communication, memory, mental health, and cognitive support needs; and developing best practices in specific domains such as health care and financial planning.

Collecting data on guardianship

There is minimal data on the use of guardianship in the United States; experts struggle even to estimate the total number of people under guardianship.⁹ This absence of data is a significant barrier to identifying areas of need in diverting people from guardianship.

We support incentives to states to collect comprehensive data on guardianship, such as by making grant funds contingent on data collection. Data should include information on the total number of people under guardianship; key demographic information such as gender, race, age, and primary language; type of disability; the length of the guardianship; the type of guardian (i.e. family member, friend, professional private guardian, or public agency); and type of residence. 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.

We also would support data collection efforts by federal agencies, including through 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

⁶ *Projects of National Significance*, Administration on Community Living, <https://acl.gov/programs/strengthening-aging-and-disability-networks/projects-national-significance> (last visited Aug. 25, 2021).

⁷ Administration of Community Living, “Supported Decision Making Program,” available at <https://acl.gov/programs/consumer-control/supported-decision-making-program>.

⁸ Nat’l Resource Ctr. for Supported Decision Making, *Resource Library*, <http://www.supporteddecisionmaking.org/content/resource-library> (last visited Aug. 25, 2021).

⁹ Nat’l Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities 65-70* (Mar. 22, 2018), available at https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf.

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.

Conclusion

Guardianship poses unique threats to our right to make our own decisions, access health care, and live in the community. We support a multifaceted federal legislative approach that includes improvement of services, elimination of guardianship pipelines, best practices research, and technical assistance. We look forward to working with your office on specific legislative language.