

TO: Maryland Senate Judicial Proceedings Committee
FROM: Bonnielin Swenor, PhD, MPH and Caroline Cerilli
DATE: February 19, 2024

RE: Maryland Senate Bill 0759 Estates and Trusts – Guardianship of the Person of a Disabled Person – Expedited Proceedings

POSITION: Oppose

We are writing as disability research scholars, disability data experts, and disability community members from the Johns Hopkins Disability Health Research Center. Our center uses data to develop evidence-based policies and create a more equitable society for people with disabilities. We are writing on our own behalf and not representing our institution.

We strongly oppose Maryland Senate Bill 0759.

All good policies must be supported by data. However, SB0759 aims to change the guardianship process without necessary evidence on the impact of guardianship on people with disabilities and our healthcare system. There is extremely limited data on the benefits of guardianship, including its efficacy in solving the problems it sets out to address and how it compares to other, less restrictive alternatives. In fact, the Fourth National Guardianship Summit calls for improved data collection on guardianship as a leading priority.¹

All action on this bill should be stopped until the impact of guardianship can be understood.

While there is not enough data on the implications of guardianship, the data we do have indicates that individuals under guardianship are more likely to face negative outcomes than those not under guardianship. Data from the National Core Indicators, a survey of adults with intellectual and developmental disabilities in the United States, shows people under guardianship are significantly less likely to receive preventative care such as mammograms and pap tests. These data also indicate that people under guardianship are less likely to work, especially independently, are less likely to be allowed private time with visitors and are more likely to have rules regarding visitors. People under guardianship are also less likely to be able to contact their friends² and are given less freedom to choose where to live and what to do during the day. Overall, these data indicate that guardianship is associated with less opportunity to make choices, which reduces an individual's quality of life.³

¹ Fourth National Guardianship Summit, "Maximizing Autonomy and Ensuring Accountability: Recommendations Adopted by Summit Delegates" (Syracuse, NY: 2021), available at https://www.americanbar.org/content/dam/aba/administrative/law_aging/2021-grd-smmt-recmndtns.pdf.

² Bradley, V. and Hiersteiner, D. "Data Brief."

³ Chambers, C.R., Wehmeyer, M.L., Saito, Y., Lida, K.M., Lee, Y., and Singh, V. "Self-determination: What do we know? Where do we go?" *Exceptionality*, 15, 3-15. (2007).

Despite the association with negative outcomes, guardianship is typically granted when petitioned for, yet rarely are rights restored. For example, from 2016 to 2021, Virginia courts appointed full guardianship or conservatorship in response to 82% of the 9,078 petitions filed and appointed limited or temporary guardianship or conservatorship to 2% of cases; fifteen percent of petitions were either withdrawn, dismissed, or judge denied.⁴ Over these six years, just ten individuals were restored to capacity.⁵ This is especially relevant for healthcare settings, where a person may only temporarily lack capacity; guardianship is an unsuitable solution during an individual’s recovery process. Guardianship has been on the rise over the past ten years, making the barriers to restoring rights an equally pressing concern.⁶

Loosening the guardianship process is not supported by the disability community or disability policy experts. The National Council on Disability (NCD), the federal agency that advises Congress and the President of the United States on disability policies, found that guardianship is “often imposed when not warranted by facts or circumstances because guardianship proceedings often operate under erroneous assumptions that people with disabilities lack the capacity to make autonomous decisions.”⁷ Several healthcare systems have updated their approach to guardianship, specifically to increase the rate at which guardianship petitions are processed. The healthcare system's financial need is not sufficient reason for this drastic measure.⁸ An individual’s experience beyond the hospital bed must be prioritized.

Instead of SB0759, alternatives, and supports for people most vulnerable to guardianship must be developed.

In 2021, the Administration for Community Living (ACL) awarded the Maryland Court of Appeals a grant to “conduct a comprehensive statewide assessment of the existing guardianship process and system to identify current strengths, weaknesses, concerns, and needs; develop a response to that assessment with interventions to address identified weaknesses, concerns, and needs; produce an evaluation aimed at measuring the quality of the assessment and the effectiveness and replicability of the interventions; and disseminate findings.”⁹ This is an excellent opportunity for our healthcare systems and courts to develop the evidence needed to improve the guardianship process in Maryland in partnership with the disability community. However, SB0759 has moved forward prior to the implementation and release of the results of this work.

⁴ “Improving Virginia’s Adult Guardian and Conservator System.” Joint Legislative Audit & Review Commission. (2021)

⁵ DiMatteo, Emily, Thompson, Vilissa, and Ahmed, Osub. “Rethinking Guardianship to Protect Disabled People’s Reproductive Rights.” Center for American Progress. (2022).

⁶ Bradley, V. and Hiersteiner, D. “National Core Indicators Data Brief” (2019), available at https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf

⁷ “Turning Rights into Reality: How Guardianship and Alternatives Impact the Autonomy of Intellectual and Developmental Disabilities.” National Council on Disability. (2019). Available at <https://www.ncd.gov/report/turning-rights-into-reality-how-guardianship-and-alternatives-impact-the-autonomy-of-people-with-intellectual-and-developmental-disabilities-1/>.

⁸ Hirschel, Alison, and Lori Smetanka. “The Use and Misuse of Guardianship.”

⁹ “New Elder Justice Grants Address APS Training, Guardianship, APS to Community Services Transitions.” Administration for Community Living. (2021). Available at <https://acl.gov/news-and-events/announcements/new-elder-justice-grants-address-aps-training-guardianship-aps>.

We urge that alternatives to guardianship be developed in partnership with people with disabilities. This should include leveraging ongoing research on supported decision-making, a tool to assist an individual without influencing their decision. Additionally, there is an urgent need to create and implement educational programs for healthcare providers and social workers on disability competent care, non-spoken forms of communication, and anti-ableism. New options for people being discharged should also be developed to bridge the gap between inpatient care and full independence, such as for individuals experiencing a mental health crisis.

We urge healthcare systems to collaborate with people with disabilities to find solutions to bed shortages that do not involve stripping away basic rights rather than pressing this bill. It is critical that the approach taken to address any healthcare resource shortages is based on evidence, leads with equity, is anti-ableist, and is not based on financial outcomes alone.

Sincerely,



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