

# National Core Indicators® Data Highlight

## What Do NCI Data Tell Us About People With IDD Who Have Guardians Compared to Those Who Don't\*

**In the 2018-19 NCI In-Person Survey (IPS), 53.4% of respondents were reported to have a guardian (limited guardianship or full guardianship or unable to determine level of guardianship). The proportion of respondents with guardians varied by state and ranged from 14.6% to 86.4%. Compared to people without guardians, people with guardians are less likely to make important life decisions including where to live (46.0% vs. 68.5%), who to live with (33.8% vs. 55.5%), their daily schedule (80.1% vs. 89.8%), or what to buy with their spending money (86.7% vs. 94.1%).**

**Why does it matter?** Guardianship is broadly defined as a legal process used to protect people who are determined to be vulnerable to fraud or undue influence, but it also legally removes important rights and decision-making authority from the person. Many adults with IDD are placed under guardianship despite having the ability to make their own decisions and choices. The fact that over 53.4% of people with IDD in the IPS sample have a guardian demonstrates that a significant number of people with IDD receiving public services and supports may be constrained from making important choices in their own lives. People with guardians are not able to marry, enter contracts, get a driver's license, sign a lease, make purchases, make decisions about their own bodies and healthcare, and make other choices without the approval of a guardian. Research on the impact of guardianship indicates that it can be detrimental to the person's quality of life, causing feelings of helplessness, hopelessness, and inadequacy. Research also shows that being subject to guardianship, and the subsequent loss of autonomy and self-determination, can result in decreased functioning and can affect physical and mental health (National Council on Disability, 2018).



In January 2021, the Burton Blatt Institute at Syracuse University reported findings from the Virginia Supported Decision-Making Pilot Project. The study found that project participants engaged in supported decision-making, an alternative to guardianship, showed improved independence and decision-making skills, made more informed decisions, and had improved quality of life (Martinis & Beadnell, 2021). Despite the benefits of encouraging independent decision-making, many parents of young adults are counseled by school personnel to become guardians at the point of transition from school as part of a common "pipeline" to adult services.

**Questions to ask:** Has your state developed materials for school personnel introducing them to alternatives to guardianship? Have you developed educational materials for families on guardianship alternatives? Have you reviewed your current guardianship statutes to determine whether they are consistent with reforms suggested by the National Guardianship Association and the American Bar Association that stress exploration of less restrictive alternatives? Has your state put in place any laws to recognize supported decision-making as an alternative to guardianship? Is your Protection and Advocacy organization working with people with IDD who want to be free of guardianship? Is there a cross-disability and aging coalition to reduce the reliance on guardianship? Have there been initiatives to educate probate judges on the ways in which guardianship robs people of their self-determination and to suggest alternatives?

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\*Current events related to the singer Britney Spears and her fight to be released from guardianship (called "conservatorship" in California) have brought national attention to guardianship and how such relationships can limit the civil, legal, financial, healthcare and other life decision-making abilities of those within them.

## Want to know more?

- Alford, B., Fracht, A., Hennessy, M., & Smith, H. (2021). *How to Strengthen the Americans with Disabilities Act after 30 Years: Promoting Supported Decision-Making for Persons with Intellectual and Developmental Disabilities*. Harvard Law Review Blog. <https://blog.harvardlawreview.org/how-to-strengthen-the-americans-with-disabilities-act-after-30-years-promoting-supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities/>  
Easy read version: <https://blog.harvardlawreview.org/supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities/>
- American Bar Association. (2016). Practical tools for lawyers: Steps in supporting decision-making. Chicago, IL. [www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/practical\\_tool/](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool/)
- Center for Public Representation. *Supported Decision-Making Gives People with Disabilities a Voice*. <https://supporteddecisions.org/>
- Disability and Health Information Center (n.d.). *Missouri Guardianship: Understanding Your Options & Alternatives*. <https://health.mo.gov/shcn-secure/docs/GuardianshipInfoPack.pdf>
- Georgia Advocacy Office. Supported Decision-Making Resources. [Supported Decision-Making Resources – The Georgia Advocacy Office \(thegao.net\)](http://thegao.net)
- Martinis, J. & Beadnell, L. (2021) “I learned that I have a voice in my future” Summary, Findings, and Recommendations of The Virginia Supported Decision-Making Pilot Project retrieved from [http://www.supporteddecisionmaking.org/sites/default/files/2021\\_virginia\\_SDM\\_pilot\\_project.pdf](http://www.supporteddecisionmaking.org/sites/default/files/2021_virginia_SDM_pilot_project.pdf)
- National Council on Disability. (2018). Beyond guardianship: Toward alternatives that promote greater self-determination, Washington, D.C. [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)
- National Guardianship Association. (2017). *Position Statement on Guardianship, Surrogate Decision Making, And Supported Decision Making*. [https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision\\_Making\\_PositionStatement.pdf](https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf)
- National Guardianship Association. (2013). Standards of practice. Bellefonte, PA. <https://www.guardianship.org/standards/>
- National Resource Center for Supported Decision-Making. <http://www.supporteddecisionmaking.org/>
- UMKC Institute for Human Development. (n.d.). Missouri Guardianship Project. <https://ihd.umkc.edu/missouri-guardianship-project/>

## Videos

- Georgia Advocacy Office. John McCarty (2020). [https://www.youtube.com/channel/UCXPkGt\\_cyYyPPWFxWYB7NTQ](https://www.youtube.com/channel/UCXPkGt_cyYyPPWFxWYB7NTQ)
- Georgia Advocacy Office. *Shining a Light on the Inner Workings of Supported Decision-Making*. <https://www.youtube.com/watch?v=UXFMNguab1A>
- Guardianship requests decline as knowledge of alternative legal option grows. (Aug. 9, 2021). WSAW-TV. <https://www.wsaw.com/2021/08/10/guardianship-requests-decline-knowledge-alternative-legal-option-grows/>