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What Do NCI Data Reveal About the Guardianship Status of People With IDD?

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The decision to place someone under guardianship is most often motivated by a desire to protect the interests of the individual with a disability, but the consequences for that individual may be profound. Research on the negative impacts 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.

This data brief explores the characteristics and outcomes of people with intellectual and developmental disabilities who have full or partial guardianship compared to those without guardianship. We also pose some starting points for examining the need for guardianship reform and the ways in which supported decision-making can be expanded and alternatives instituted. And we conclude with a description of a Missouri initiative that has helped families understand the nature and implications of guardianship and has resulted in reform legislation.

Introduction

A guardian is a person, institution, or agency appointed by a court to manage the affairs and interests of another individual. The National Guardianship Association (NGA) suggests that the most prudent use of guardianship occurs “when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence.”¹ A full guardian has plenary authority over an individual’s decisions—including crucial personal decisions such as where to live, what health care services or medical treatment to receive, as well as decisions about the person’s financial matters, benefits, real estate, and other property. A court may also grant limited guardianship that extends to specific decisions or legally binding agreements, such as signing contracts or making decisions to assure financial obligations are met, or exclusively for medical decisions.

As indicated in the description used by the NGA, guardianship is granted when evidence demonstrates that an individual lacks the capacity to make some or all important life decisions and is therefore at increased risk of harm. Such incapacity is assumed to make the individual vulnerable to risks such as financial exploitation. In reality, however, the preponderance of evidence may not always justify the removal of a person’s rights and ability to direct their own life.

Adults with intellectual and developmental disabilities (IDD)—as well as people with sensory disabilities, mental illness, traumatic brain injury, and challenges of aging—are potential subjects of guardianship. The decision to place someone under guardianship is most often motivated by a desire to protect the interests of the individual with a disability, but the consequences for that individual may be profound. For this reason, the NGA recommends guardians practice with the “highest allegiance to the person.”

When a guardian’s decision substitutes for that of the individual with IDD, the following losses may result²:

- People may not be included in conversations where important decisions are made about their lives;
- People don’t develop the skills necessary to participate in decisions (e.g., individual service plan) because they must rely on others;
- When they want to make a purchase, get married, open a bank account or enter into a legal agreement, people must ask permission;
- They are deprived of the “dignity of risk”;
- Doctors, dentists and other medical professionals may not include the person in any treatment planning.

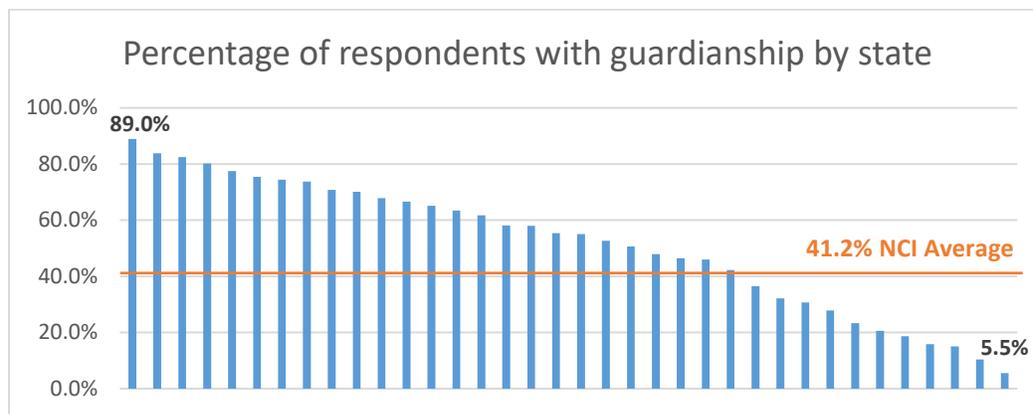
Research on the negative impact of the imposition of guardianship on the quality of life of the individual indicates:

- A person is denied the ability to be a causal agent in his/her life and often “feels helpless, hopeless, and self-critical”;³
- “Low self-esteem, passivity and feelings of inadequacy and incompetency” associated with loss of autonomy and self-determination also result in decreased functioning;⁴
- Being subject to guardianship may affect subjective well-being including physical and mental health.⁵

NCI Data on Guardianship

Use of Guardianship by State

Data from the [National Core Indicators 2017-2018 In-Person Survey \(IPS\)](#) indicate a wide range among states of individuals reported to have full or partial guardianship (or an unknown level of guardianship)—from 5.5% in one state to 89.0% in another.^a



States also vary significantly in the proportion of people who have partial guardianship and full guardianship—from 0.0% to 25.2% of respondents in partial guardianship and from 0.0% to 77.3% of respondents in full guardianship. And states range from 0.0% to 75.4% of respondents in guardianship but with a level (full or partial) that is unknown. This variation points to the need to further investigate why and how guardianship decisions are made. For those states with larger numbers of individuals under guardianship, it may suggest an uneven use of alternatives to full guardianship. Regardless of the reason, the variation itself suggests that states may want to better understand the factors that contribute to utilization rates for each type of guardianship.

Of Those With Guardianship, Who Serves as Guardian?

According to the 2017-2018 In-Person Survey, 81.3% of guardians are family members, 3.0% are friends, 11.3% are public guardians, 2.2% are nonprofit guardianship agencies, and another 1.2% are financial institutions, for-profit guardianship agencies, and “other.”

Demographics of Those With and Without Guardianship

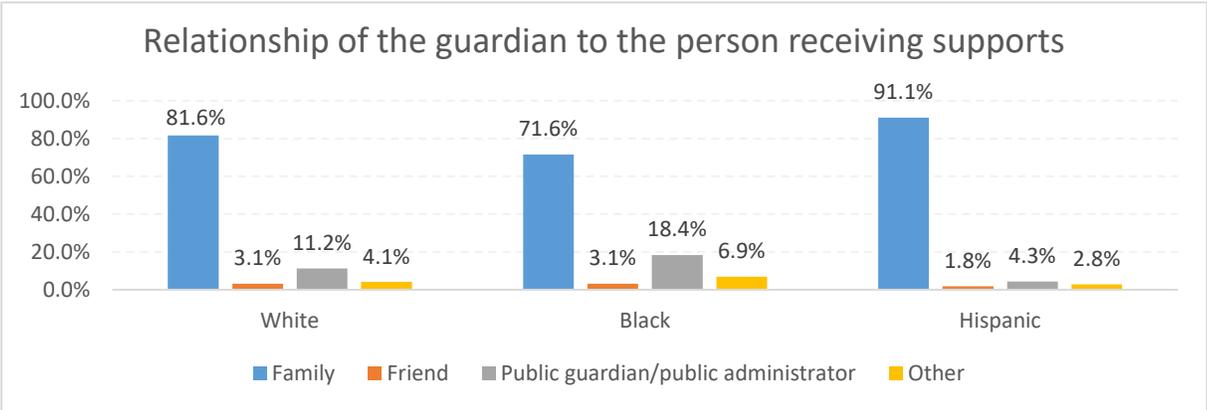
Race

According to the survey results, 14.8% of those with guardianship are Black, while 20.1% of those without guardianship are Black.

White respondents were significantly more likely to have guardianship than Black or Hispanic respondents (46.4% vs. 34.2% of Black respondents and 26.3% of Hispanic respondents).

^a All relationships shown in this data brief are significant at the $p \leq .001$ level. Data are not weighted. Total sample: 25,671 respondents from 36 states including DC. Averages are averages of cases (not averages of state averages).

Of those with guardians, Black respondents are significantly more likely to have a public guardian or public administrator as a guardian (18.4% vs. 11.2% of White respondents and 4.3% of Hispanic respondents). Hispanic respondents were significantly more likely to have a family member as a guardian (91.1% vs. 71.6% of Black respondents and 81.6% of White respondents).



ID Diagnosis

- Those with a severe or profound level of intellectual disability (ID) are significantly more likely to have a guardian than those with mild or moderate ID (56.4% vs. 37.3%).
- Those with ID on the autism spectrum are significantly more likely to have a guardian than those not on the spectrum (56.1% vs. 39.3%).
- Of those with ID and cerebral palsy, 48.2% have guardians while 41.0% of those without cerebral palsy have guardians.
- Of those with ID and a seizure disorder and/or neurological problem, 50.1% have a guardian while 39.2% of those without seizure disorder and/or neurological problem have guardians.
- 52.1% of those with Down syndrome have guardians while 41.3% of those without Down syndrome have guardians.

No ID Diagnosis

Of those without a diagnosis of ID:

- 30.0% have a guardian, while 42.6% of those with an ID diagnosis have a guardian.
- 34.0% of those on the autism spectrum have a guardian, while 27.4% of those not on the spectrum have a guardian.
- 23.1% of those with cerebral palsy have a guardian, while 32.6% of those without cerebral palsy have a guardian.
- 36.4% of those with seizure disorder and/or neurological problem have a guardian, while 27.6% of those without seizure disorder and/or neurological problem have a guardian.

Residence Type

Respondents with guardianship are significantly more likely to live in group residential facilities (31.9% vs. 28%) and less likely to live in their own home/apartment (13.3% vs. 23.9%):

	ICF/IID, nursing facility or other institutional setting	Group residential setting (e.g., group home)	Own home / apartment	Parent's or relative's home	Foster care or host home
No Guardianship	5.8%	28.0%	23.9%	38.3%	4.0%
Guardianship (limited, full, or unknown level)	5.8%	31.9%	13.3%	42.5%	6.6%

Marriage

Respondents with guardianship are significantly more likely to be single and never married than those without guardianship (97.9% vs. 93.2%).

Outcomes

Preventive Care

- Women age 40+ with guardians are significantly less likely to have had a mammogram in the past two years than those without guardianship (66.2% vs. 74.0%).
- Women 21+ with guardians are significantly less likely to have had a pap test in the past three years than those without guardianship (48.7% vs. 59.5%).

Behavior Challenges

- Respondents with guardians are significantly more likely to take medications for behavior challenges than those without guardianship (49.9% vs. 42.1%).
- Respondents with guardians are significantly more likely to have a behavior plan than those without guardianship (32.0% vs. 24.6%).

Employment

- Respondents with guardians are significantly less likely to work in a paid community job (13.8% vs. 17.7%). Of those in a paid community job, those in guardianship are significantly less likely to work in an individual job (a job in which the person works independently, with or without support; 10.0% vs. 13.1%).
- Respondents with guardians are significantly less likely to have employment as a goal in the service plan (26.0% vs. 33.2%).

Self-Direction

Respondents with guardians are significantly more likely to use a self-directed supports option than those without guardians (12.4% vs. 5.8%).

Choice

Respondents with guardians are significantly less likely to have had at least some input in choosing:

- Where to live (49.0% vs. 63.8%)
- With whom to live (38.4% vs. 52.5%)
- Their support staff (65.0% vs. 69.3%)
- Their schedule (79.9% vs. 88.1%)
- What to do in their free time (89.1% vs. 93.5%)
- What to do during the day activity (53.4% vs. 60.5%)
- What to buy with spending money (82.2% vs. 89.2%)
- Their case manager—or were aware they could change their case manager (86.8% vs. 90.4%).

Community Inclusion

Respondents with guardians are significantly more likely to have gone out for entertainment in the past month (78.6% vs. 72.7%).

Rights and Respect

- Respondents with guardians are significantly more likely to report that their mail has been opened without permission (14.0% vs. 10.2%).
- Respondents with guardians are significantly less likely to report they can be alone with visitors at home (78.9% vs. 85.2%).
- Respondents with guardians are significantly more likely to report there are rules about having visitors or friends at home (38.2% vs. 31.0%).
- Respondents with guardians are significantly less likely to report they can use the phone or internet whenever they want (88.1% vs. 91.5%).

Relationships

- Respondents with guardians are significantly more likely to report they'd like more help to contact their friends (46.2% vs. 40.5%).
- Respondents with guardians are significantly less likely to report they have other ways of communicating with friends when they cannot see them (79.5% vs. 85.5%).
- Respondents with guardians are significantly less likely to report they can go on a date when they want or are married or living with a partner (69.0% vs. 78.3%).

Summary

Respondents with guardians are less likely to:

- Live in their own homes or apartments and are more likely to live in group homes
- Be involved in making choices about their lives
- Be included in their community
- Have their rights respected
- Have community jobs or service plans with this goal
- Be supported to communicate with friends
- Be able to go on dates
- Be married

What Are the Policy Questions?

These NCI data suggest that people with guardians (limited or full guardianship) experience diminished independence and opportunities compared to those in the national sample that do not have guardians. For that reason, policymakers and administrators should consider working to ensure that the application of guardianship is carried out in a thoughtful, restrained, and just manner. States whose data show a heavy reliance on guardianship may want to examine state guardianship laws and policies to determine whether reforms are indicated. The work of the National Guardianship Association and American Bar Association provides useful information regarding more person-centered guardianship policies.

To counter the potential overuse of guardianship, states may review policies on the criteria for granting guardianship and work with their court system to educate judges on questions to ask when petitioned. For example, states may require an exploration of alternatives to guardianship prior to adjudicating a petition. An emerging alternative to guardianship is supported decision-making (SDM). The National Resource Center on Supported Decision Making (<http://www.supporteddecisionmaking.org/>) offers educational material and videos on SDM. In addition to SDM, there are other alternatives to guardianship that states can explore including medical proxies, power of attorney, special needs trust, representative payee, and advance directives.⁶ Such initiatives will require collaboration among aging advocates, the attorney general's office, the bar association and potentially legislative committees—efforts that could be informed by the state's detailed NCI results.

DD public managers may also want to work with education administrators to determine whether, at the point of transition, parents are reflexively being told to become a guardian. The National Council on Disability made the following observation:

. . . when an individual reaches the age of majority (generally 18 years of age), they are entitled to make decisions for themselves, and their parents no longer have any legal right to make decisions on their behalf or obtain confidential information unless the adult child has given permission. However, this does not mean that parents who are told by school staff that they need to seek guardianship as soon as their son or daughter with disabilities turns 18 are getting sound advice.⁷

In the following section, we describe the use of educational efforts in Missouri to help families and people with disabilities to understand the rationale and consequences of guardianship. We also describe a recent guardianship reform statute in the state.

Promising Practice

Ten years ago, the Missouri Developmental Disabilities Council (MODDC) provided a grant for a partnership project between the Missouri University Center on Excellence in Developmental Disabilities (the UCEDD at UMKC-IHD), Missouri's Protection and Advocacy (P&A) agency, and People First of Missouri to educate people with IDD, family members, and DD professionals to investigate and disseminate information on guardianship options and alternatives. The first task was to develop a tool (that eventually became known as the Stoplight Tool) to help people with IDD to determine areas where they might need decision-making support and what that support might look like. A draft training curriculum was also developed; over the course of a year, the project team went around the state collecting input on the content.

A second aspect of the project was assistance from the P&A to self-advocates who wanted their rights restored or who sought to reduce the scope of guardianship. The materials, which included videos, the Stoplight Tool, and the Resource Guide, were translated to an online learning format (flipbook) and were also housed on the Missouri Family to Family website.

The MODDC also funded a second round of training for families, people with disabilities and DD professionals a few years later, and the materials were expanded to include the populations of people within the behavioral health and aging systems. The materials were also updated to integrate the Charting the LifeCourse (CtLC) Framework.

Missouri also established the Missouri Working Interdisciplinary Network of Guardianship Stakeholders (MO-WING) group to review and reform the state guardianship statute. (The statute hadn't been updated since 1983 and contained language and concepts that had been outdated for decades.) Leadership of the group included representatives of the Missouri Developmental Disabilities Council, the UMKC Institute for Human Development, and prominent members of the Missouri Bar Association. Members included people with disabilities, parents, family members, lay guardians and conservators, service providers, AARP, NAMI, the Alzheimer's Association, MODDC, Missouri Bar Probate and Trust and Elder Law Committees, Missouri Association of County Developmental Disability Services, public administrators, social workers, nurses, psychologists, Missouri Protection and Advocacy, advocacy groups, long-term care ombudsmen, University of Missouri-Columbia Center for Health Ethics, Departments of Mental Health and Health and Senior Services, and Area Agencies on Aging.

The group met over the course of approximately five years, and their work was supported with input from judges and national experts. The recommendations of the MO-WINGS group were included in legislation (<https://www.senate.mo.gov/18info/pdf-bill/intro/SB806.pdf>) that eventually passed and was signed into law in 2018. Some of the major provisions include a delineation of the rights of the respondent/ward, priority for the appointment of a relative as guardian over a third party, factual requirements in the petition, and consideration of less-restrictive options and supported decision-making. Following the statutory changes, a symposium of stakeholders was convened in September 2018 to discuss the reforms, to articulate a vision for supported decision-making going forward, and to delineate next steps.

Conclusion

Until recently, the issue of guardianship has not been a high-priority issue in the IDD field even as values such as self-direction, independence, and choice have become more prominent. In the last few years, however, there have been significant advocacy efforts aimed at reforming the process of guardianship and advancing alternatives such as supported decision-making. Specifically:

- Two states, Texas and Delaware, have passed supported decision-making statutes that require third parties to honor supported decision-making agreements and relieve them from liability for doing so.
- The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc have developed a policy statement in support of guardianship reform and the importance of individual autonomy for people with IDD.⁸
- The American Bar Association developed guidelines to ensure that guardianship is considered a last resort.⁹
- The National Guardianship Association developed new guidelines stressing the importance of taking the individual's wishes and preferences into consideration.¹⁰
- The Administration for Community Living has funded the Quality Trust to support pilots and disseminate information about supported decision-making.

State IDD systems' guardianship policies and practices often date back to the 1990s. An analysis of the state's NCI data sorted between those with and without formal guardians may provide compelling reasons to evaluate the policies. Such work will require that the state IDD system work collaboratively with representatives of the justice and elder care systems to redesign policies to keep up with best and emerging practices.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.

We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at dhiersteiner@hsri.org

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