



Seize the Data: An Analysis of Guardianship Annual Reports

Joanne Tompkins, Heather Connors & Diane Robinson

To cite this article: Joanne Tompkins, Heather Connors & Diane Robinson (05 May 2024): Seize the Data: An Analysis of Guardianship Annual Reports, *Journal of Aging & Social Policy*, DOI: [10.1080/08959420.2024.2349494](https://doi.org/10.1080/08959420.2024.2349494)

To link to this article: <https://doi.org/10.1080/08959420.2024.2349494>



© 2024 The Author(s). Published with
license by Taylor & Francis Group, LLC.



Published online: 05 May 2024.



Submit your article to this journal 



Article views: 5



View related articles 



View Crossmark data 

Seize the Data: An Analysis of Guardianship Annual Reports

Joanne Tompkins PhD  ^a, Heather Connors PhD ^a, and Diane Robinson PhD ^b

^aThe Center for Guardianship Excellence, Andover, MA, USA; ^bNational Center for State Courts, Williamsburg, VA, USA

ABSTRACT

Courts have a legal and ethical duty to monitor adult guardianship cases to protect the rights of individuals with guardians. Aging and disability advocates have been recommending improvements to adult guardianship monitoring for decades. The aim of this study is to examine annual guardianship reporting procedures in each state. Using the National Guardianship Association's (NGA) Standards of Practice as a guide, we summarize what is missing from adult guardianship annual report forms in each state. Since 2000, the NGA Standards have been the benchmark for guiding guardianship best practices, making it a valuable tool for guardianship reporting and monitoring. Results show that most states are not collecting thorough data on adults with guardians, their guardians, or the guardian-client relationship. Additionally, many existing annual report forms may be difficult to complete due to confusing question structure and reading levels that are above the national average, especially since most adult guardians are nonprofessional guardians. Improved reporting procedures would help courts monitor guardianships more effectively, ensure that the rights of individuals with guardians are being protected, and provide meaningful data on the overall state of guardianship. Limitations and plans for future research are also discussed.

ARTICLE HISTORY

Received 8 September 2023

Accepted 13 March 2024

KEYWORDS

Aging; autonomy; conservatorship; court monitoring; disability rights; guardian reporting; guardianship; policy; supported decision-making

Introduction

Approximately 13% of all adults and 66% of adults aged 70 and older in the United States are living with a cognitive disability, such as dementia, autism, or traumatic brain injury (Centers for Disease Control and Prevention [CDC], 2023; CDC, 2023; Hale et al., 2020). This is a diverse group with varying decision-making support needs that may change over time. Someone may experience a serious injury rendering them unable to make an emergency medical decision. An older adult experiencing cognitive decline may need assistance with some or all aspects of day-to-day life. Individuals with intellectual or developmental disabilities (ID/DD) may need guidance when

CONTACT Joanne Tompkins  joanne@guardianshipcenter.org  The Center for Guardianship Excellence, 1 Elm Square, Andover, MA 01810, USA

© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

making major decisions about living arrangements, financial matters, or health care.

There are a range of decision-making support options, including guardianship – a legal arrangement in which state courts appoint individuals or entities to make decisions on behalf of adults who lack the capacity to make their own decisions. Language used in the guardianship realm differs. In many states, “guardians” are appointed to make personal or medical decisions for adults found to lack capacity. Some states refer to this role as “conservator,” but many states reserve this term for someone who only manages an individual’s financial affairs. In this paper, guardianship refers to legal authority to care for the personal and/or financial interests of another adult. Similarly, states vary in the terms used to describe persons under guardianship, including ward, protected person, and incapacitated person. None of these are particularly dignified terms, which is why this study uses client, adult, individual, or person with a guardian.

Since full guardianship strips a person of their rights, it is generally seen as a last resort after less restrictive alternatives, such as advance care planning or supported-decision making, have been explored (Karp & Wood, 2013; Nwakasi & Roberts, 2021). Regular reporting on the status of the adult with a guardian is essential, as needs can change over time and a less-restrictive alternative may be more suitable. Additionally, reporting can help courts identify if an individual is being neglected, exploited, or abused. Advance care planning, which can include designating a durable power of attorney or a health care proxy, allows an individual to choose an advocate to communicate their preferences if they become unable to do so themselves. However, most people do not plan due to a lack of time, resources, knowledge, or interest (Maller, 2013; Rao et al., 2014; Yadav et al., 2017). Supported decision-making (SDM) or self-direction, in which adults choose supporters to help them make informed decisions about their services and activities, honor individuals’ rights and autonomy and are associated with better quality of life outcomes (Bradley et al., 2021; Friedman, 2019; Jameson et al., 2015; National Core Indicators [NCI], 2019; Watson et al., 2019). Any adult can choose to engage in supported-decision making; however, not all states recognize it as a legal alternative to guardianship. While SDM laws vary by state, at the time of this writing, most states have at least proposed, and 25 states have enacted, legislation to legally recognize supported decision-making (National Resource Center for Supported Decision-Making, n.d.).

Shortcomings of current system

Courts have the vital responsibility of protecting the most vulnerable citizens, which includes adults with guardians. An estimated 85% of guardians are family members or friends and, therefore, especially in need of court guidance

(Chamberlain et al., 2018; NCD, 2019; Uekert, 2010). The processes and duties related to guardianship training, reporting, and monitoring vary by jurisdiction. This disjointed system poses challenges for guardianship oversight and monitoring.

Not all states track and report adult guardianship data, making it difficult to accurately determine the number of adults with guardians (Hurme & Robinson, 2021). Even less is known about the demographics and health of adults with guardians, characteristics of the guardian, and details about the guardian-client relationship (Chamberlain et al., 2018). The best estimate is approximately 1.3 million adults with guardians; however, this is based on a small number of states that do track and report data and the differences across states make it difficult to generalize to the entire country (National Center for State Courts [NCSC], 2018; NCI, 2019; Nwakasi & Roberts, 2021). In 2021, 35 states reported 92,117 new adult guardianship petitions; and 34 states reported 51,157 new conservatorship petitions filed (NCSC, 2018).

The AARP's Policy Institute and ABA Commission on Law and Aging (ABA COLA) conducted a national online survey that found variation across state courts in reporting, monitoring, and training (Karp & Wood, 2007). These findings were echoed in national surveys conducted by the National Center for State Courts (NCSC) in 2009 and 2020 (Hurme & Robinson, 2021; Robinson et al., 2021). A Government Accountability Office (GAO) study found that many guardians who neglected, abused, or financially exploited adults under their guardianship were not monitored after the initial appointment (United States Government Accountability Office [GAO], 2010).

Courts have always had to contend with barriers to oversight. In 1987, the Associated Press began investigating courts throughout the U.S. and published a series describing an overburdened and understaffed court system (Bayles, 1987). Decades later, state courts face the same challenges. In more recent surveys, courts throughout the U.S. report inadequate funding for guardianship training and oversight, often with no funds dedicated specifically for guardianship, placing the onus on the courts to distribute available funds for all expenses (e.g., salaries, building maintenance, various court programs) (Hurme & Robinson, 2021; Karp & Wood, 2007; Uekert, 2010). This makes it challenging for courts to invest in resources that could improve guardianship monitoring, such as training for court workers and updated technology for case management. In addition, declining budgets, including recent COVID-19-related budget cuts, place an even greater burden on courts to do so (Siripurapu & Masters, 2021).

Improving the current system

For decades, various organizations have advocated for improvements in guardianship reporting and monitoring. In 1986, participants of

a national judicial conference released a *Statement of Recommended Judicial Practices* for guardianship, including training for guardians and regular status reports about adults with guardians (Hurme & Robinson, 2021). The American Bar Association (ABA) held the first Wingspread National Guardianship Symposium in 1988, leading to the pivotal 1991 publication *Steps to Enhance Guardianship Monitoring* that outlines nine steps about the court's role and guardian's responsibilities (Hurme & Robinson, 2021).

In 1993, the National College of Probate Judges published standards for annual guardianship plans, inventories, accountings, and reports. These standards were updated in 2013 to reflect changes impacting courts, such as updated technology that allows electronic filing, an increasing number of Americans aged 65 and older, and new recommendations by various organizations, such as the ABA Commission on Law and Aging (Duizend & Uekert, 2013). Most recently, in 2021, the Fourth National Guardianship Summit – a meeting of guardians, legal professionals, and academics – developed a list of recommendations to improve guardianship. Among these are suggestions for better court monitoring systems, including regular reporting using standard forms that are easy for guardians to complete and for courts to review (Syracuse University: College of Law, 2021).

The National Guardianship Association (NGA) promulgates Standards of Practice that can be applied nationwide to accommodate these suggestions for improvement in guardianship practices. These 25 standards, detailed in a 35-page document, have been created and updated by experts in the fields of guardianship, aging, disability advocacy, and law. They cover a wide range of guardianship topics, such as obligations to the court, duties to adults with guardians, and decision-making standards (National Guardianship Association [NGA], 2022). Since 2000, these standards have been the benchmark for guiding guardianship best practices and can serve as a guide for guardianship reporting and monitoring. In addition to informing the court about issues within the guardianship on the micro-level, annual guardianship reports are an effective way to collect macro-level data on guardianship appointments. However, report forms vary across states, and sometimes within states, making it challenging to identify areas for reform. Using these NGA Standards of Practice as a guide, this study examines the annual guardianship report forms for each state, discusses which topics are missing from existing forms, and makes suggestions for improvements. Better data can improve the care provided to vulnerable adults, assure that guardians are complying with laws and standards, and help identify the need for changes to current laws and policies.

Methods

We evaluated the adult guardianship annual report forms for 43 states, including Washington DC. We limited the sample to states with a single statewide form, thus omitting eight states that, as of 2023, varied by county: Alabama, California, Georgia, Indiana, Louisiana, Missouri, Mississippi, and Tennessee. The annual report forms were downloaded from the official court website for each state and imported into NVIVO software for qualitative analyses.

Our analysis included two parts to assess content and clarity and was performed by both investigators to ensure coding consistency. First, we used the National Guardianship Association's (NGA) 25 Standards of Practice to determine which topics the annual reports should include. The NGA developed these standards to provide guidelines for guardians nationwide, regardless of differences in state laws. These standards can provide the court with a framework for creating and evaluating annual guardianship reports. The 25 standards are explained in detail in a 35-page document. For the sake of clarity and brevity, we have organized them into four broad categories, summarized in **Table 1**: (1) responsibilities; (2) decision-making; (3) laws and standards; and (4) financial and estate.

Responsibilities include initial and ongoing guardian duties. Guardians' continuing education is essential to provide the best possible person-centered care to their clients. Guardians are expected to communicate and visit clients regularly to properly assess their environment, overall health

Table 1. National Guardianship Association (NGA) standards of practice summary.

Responsibilities	Decision-making	Laws and Standards	Financial and Estate
3: Seek ongoing education about duties and laws	6: Obtain informed consent 7: Use substituted judgment or best interest when preferences cannot be determined	1: Preserve and protect Person's rights	16 and 20: Avoid conflicts of interest and self-dealing in financial matters
4: Promote social connections	8: Choose options that place the least restrictions on the Person's rights	1: Follow applicable laws and standards	17, 18, and 19: Prioritize client wishes when handling estate
5: Engage, maintain, and cooperate with service providers	9: Maximize the Person's participation in decision-making	2: Meet court requirements, including regular reporting	17, 18, and 19: Maintain asset inventory and records for court reporting
11: Maintain confidentiality	10: Identify and advocate for the Person's goals, needs, preferences, and sociocultural customs and values	21: Limit or terminate guardianship when client needs are met	22: Reasonable guardian fees must be approved by the court
12: Ensure quality living and working conditions	14 and 15: In medical treatment decisions, acquire a clear understanding, honor client's wishes, and obtain court approval as needed	23: Limit caseload to allow for effective care of each client	25: If selling practice, ensure continuity of care for Persons served; and notify clients, court, and other interested parties
13: Explain the guardian's role and the Person's rights		24: Periodic independent review of guardian	
13: Make plans for care and communication			
14 and 15: Monitor and maintain the Person's health and wellbeing.			

status, and social interactions and determine if anything can be done to improve the person's quality of life.

The category of decision-making relates to the fact that guardians must understand who their clients are to be able to make decisions on their behalf. Identifying a person's demographic characteristics can provide valuable insight into their beliefs and behaviors. Learning the person's preferences, values, and goals about their daily lives and long-term care are a vital part of advocating for someone.

The last two categories – laws and standards, and financial matters – inform the court about potential concerns or changes that should be made to the guardianship. Needs can change over time and regular assessments can help the court decide if the guardianship should be limited or terminated. The court can determine if recent legal violations or a heavy caseload interfere with the guardian's ability to provide proper care. This information can reveal potential conflicts of interest based on the nature of the guardian-client relationship or the way financial matters are handled.

We used a conceptual content analysis approach, in which textual data are matched to chosen concepts. Specifically, using NVIVO qualitative data analysis software, every annual report form question was

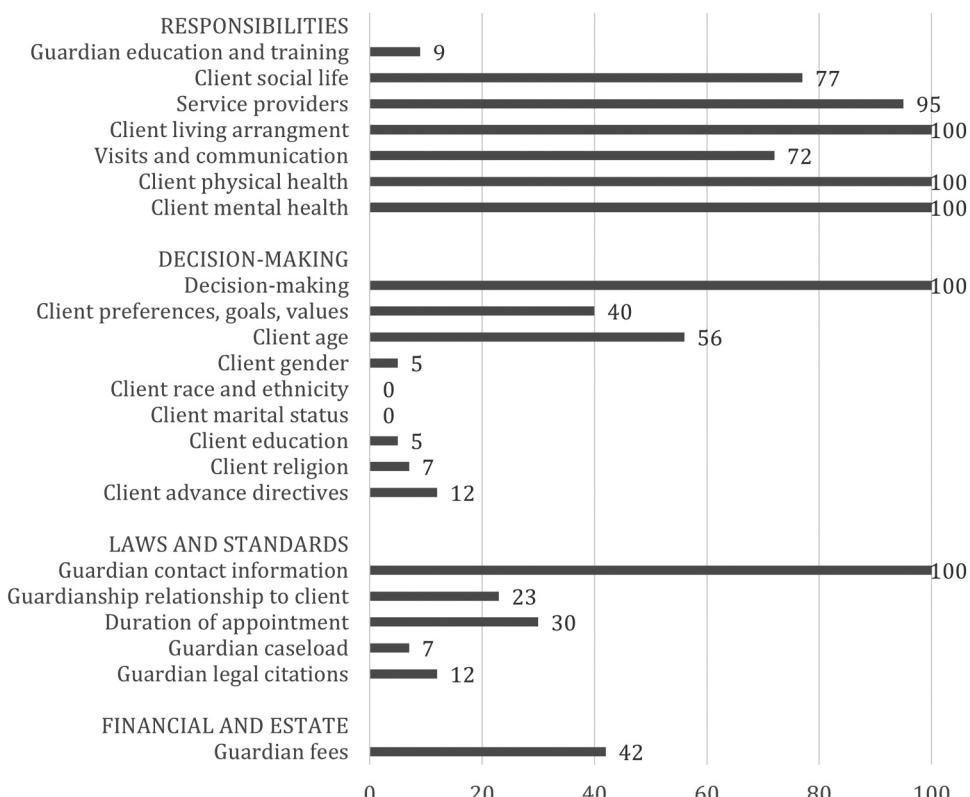


Figure 1. Percent of state forms that include questions on select guardianship topics (N = 43).

matched to one of the 25 NGA standards. For example, as shown in [Table 1](#), NGA Standard 12 under Responsibilities includes assessing the client's current living situation; therefore, any question about living arrangements was coded to this category (NGA, [2022](#)). [Figure 1](#) shows the full list of standards – or topics – and percentage of state forms that cover each topic.

In addition to analyzing what was asked, we evaluated how clearly questions were asked by noting: (a) question type – open-ended or closed-ended; (b) question structure – e.g., questions that are too vague or run-on sentences that cover multiple topics; and (c) reading level based on the Flesch-Kincaid Grade Level formula. These factors are important because better questions lead to better data. This valuable information allows the court to thoroughly evaluate the guardian's performance and assess the condition of the person with a guardian. Additionally, data can be leveraged to guide guardianship policy, such as how to allocate resources for guardianship training and court monitoring.

It is helpful to include a combination of closed-ended and open-ended questions, as there are advantages and disadvantages to both question types. Open-ended questions allow respondents to elaborate in their own words, but guardians may not provide thorough answers and these answers can be more difficult to analyze. Closed-ended questions are easier to analyze, but they limit the information guardians can provide. Therefore, we tallied the number of state forms that use only closed-ended, only open-ended, or both.

Short questions in simple language are easier to understand and answer, especially since most guardians are family members without a legal background and varying literacy skills. Long questions that cover multiple topics can be overwhelming, such as asking for a summary of the person's physical, mental, and social condition in one question. However, questions that are too broad and poorly defined can also be difficult for the guardian to understand, such as simply asking about the “condition” of the person without specifying what that means. Therefore, we tallied the number of state forms that include potentially confusing questions that ask for multiple answers in one question or are ambiguously worded.

Results

Question content

[Figure 1](#) shows the percentage of state forms that cover each of the guardianship topics.

Responsibilities

Only four states (9%) ask about the guardian's ongoing training and education.

Thirty-three states (77%) ask about the individual's social life, which includes relationships, recreational activities, school or job training, or social skills. Forty-one (95%) ask about the person's service providers, such as health-related, education, vocational, or social services.

All states ask about the individual's current living arrangements, physical health, and mental health in some way. We took a broad approach when evaluating these forms and some questions are more direct and thorough than others. For example, some specifically ask the guardian to rate the individual's mental health on a scale of poor to excellent and/or to describe their mental health status, but a question about antipsychotic medication was also tagged as a mental health question.

Thirty-one states (72%) ask about the guardian's visits or other communication with their client. Most do not distinguish between in-person visits and other types of communication. Of course, virtual visits were not as common before the COVID-19 pandemic. It is fair to assume that when a form asked about the number of visits, the guardian assumed in-person. Some state forms do include more specific language, such as "saw the ward in person," "last physical visit," or "personally observe the living conditions" (Colorado Judicial Branch, 2023; North Dakota Courts, 2022; Wisconsin Court System, 2020).

Decision-making

Every state asks the guardian about decision-making, such as describing decisions that have been made in the last year (e.g., change in residence or medical treatments) or explaining how decisions are made. Some forms include questions about whether the adult with a guardian was involved in decision-making. For example, Colorado specifically asks, "Does the ward participate in decision-making?" (Colorado Judicial Branch, 2023). New Mexico asks, "How does the Protected Person feel about the change of residence?" (New Mexico Courts, n.d.).

The main theme throughout the NGA standards is identifying and advocating for the goals, needs, and preferences for adults with guardians; however, only 17 states (40%) collect this information (NGA, 2022). Similarly, a surprisingly low number of states ask about the characteristics of adults with guardians. Twenty-four states (56%) ask for the age or date of birth. None of the reports ask about race, ethnicity, or marital status. Two states (5%) ask for the individual's gender. Two states (5%) ask about the individual's highest education level. Three states (7%) cover religion by asking about community resources, activities, or organizations, including church or religious programs.

Five states (12%) ask if the adult with a guardian has advance directives, such as a living will or health care proxy.

Laws and standards

All states collect the guardian's contact information. Ten states (23%) ask about the relationship between the guardian and their client (e.g., spouse, parent, or professional guardian). Thirteen states (30%) ask about the length of time of the guardianship appointment. Three states (7%) ask about the guardian's caseload. Five states (12%) ask whether the guardian has received any legal violations, including arrests, criminal charges, professional license revocations or suspensions, or being removed from a guardianship case.

Financial and estate

Eighteen states (42%) ask about guardian fees. The NGA standards do address managing the client's estate; however, many guardians do not handle finances. Another person, such as a conservator or representative payee, may take on this role. Therefore, this study did not examine questions about income, expenses, or assets.

Question clarity

In addition to what is asked, we examined how questions are asked. The annual report forms vary greatly in style and length, from one page with just a few general questions to 20 pages with detailed multiple-part questions (Arkansas Judiciary, *n.d.*; New Mexico Courts, *n.d.*). Most states (79%) include a combination of closed-ended and open-ended questions; however nine states only include open-ended questions.

Long compound questions, which ask guardians about multiple topics within one question, are common across states. For example, this single question asks about seven different subjects: "Provide a summary of the supported decision making, technological assistance, medical services, educational and vocational services, and other supports and services provided to the individual, as well as the Guardian's opinion as to the adequacy of the individual's care" (Maine Probate Court, *n.d.*). Other states simply ask something like, *the condition of the person is* without defining what *condition* means or providing examples. Every state form had at least one of these types of questions.

Another factor, related to question structure, is the reading level of the annual report forms. We use the Flesch-Kincaid Grade Level test – a commonly used formula that determines the reading level of text based on word and sentence length. Some experts recommend an eighth-grade reading level so that approximately 80% of people in the U.S. can

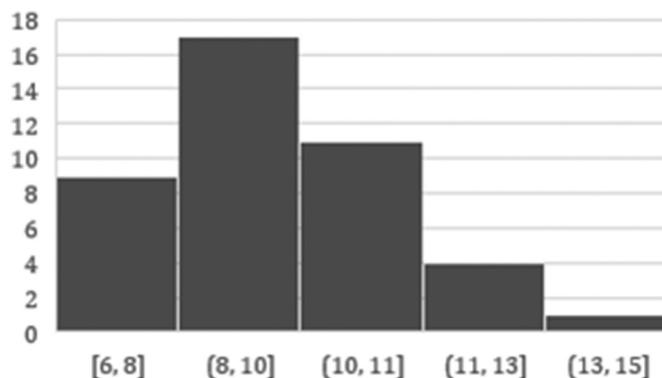


Figure 2. State form reading level distribution based on Flesch-Kincaid grade level formula.

understand it (Readable, *n.d.*). Other research suggests that about half of adults read at a sixth to seventh-grade reading level (APM Research Lab, 2022; Literacy Project, 2022). However, 65% of states in this sample are above an eighth-grade reading level. Only 21% are at a sixth or seventh-grade level. Figure 2 shows the full distribution of reading levels for this sample.

Discussion

To the best of our knowledge, this is the first study to conduct an in-depth analysis of guardianship annual report forms throughout the United States. Consistent with previous research, we find that guardianship data are not being collected regularly or thoroughly. Annual reporting should provide the court with a comprehensive overview of guardianship arrangements; however, current annual report forms leave out important data. As shown in Figure 1, the fewest number of states ask about caseload, legal violations, training, or characteristics of the adult with a guardian. For the health and safety of both guardians and adults with guardians, it is important for courts to monitor the number and difficulty of cases being managed by each guardian. Only five state forms ask about the guardian's legal violations, but this information can help courts determine if there are patterns that need to be addressed, such as having been removed from multiple guardianship cases. Continuing education updates guardians on best practices and provides opportunities to learn more about their clients' values, preferences, and goals.

Question format is just as important as question content. Most guardians are family members and some may be non-native English speakers, making long or complicated questions especially difficult to answer. For instance, many annual reports include a single open-ended question asking the guardian to describe the individual's current mental, physical, and social life. When a single question asks about multiple topics, the reader will likely need to

spend more time rereading it and could easily miss some topics or choose not to address them. Secondly, open-ended questions may not elicit the desired data. For example, this is how one guardian may answer a question about physical, mental, and social health: *His physical health is good. Mental health is fair. He sees friends weekly. Another may say, I arranged a meeting with her sister and they reconciled. It really lifted her spirits and she no longer seems depressed. Now she joins the other residents for daily activities and loves making beaded bracelets.* The first guardian fully addresses the question but with limited information. The second provides a longer response but excludes the individual's physical health. Perhaps the reader can infer that physical health is good since this individual feels better and participates in daily activities. However, guardians should be prompted to report more specific health information, such as diagnoses and medications, so the court can ensure that adults with guardians are receiving proper care and services.

Minnesota's state form provides a more effective example of assessing overall health: "For questions #3 through #5, rate the current mental, physical, and social conditions of the person subject to guardianship by choosing a number on a scale of 1 to 5 (1 = very poor, and 5 = excellent). Then give a brief explanation of why you rated the way you did" (Minnesota Judicial Branch, *n.d.*). This approach provides clear instructions for the questions that follow and separates mental, physical, and social health into separate questions. This combination of closed-ended and open-ended questions is preferred, as it allows the guardian to rate the individual's health with an explanation for the rating. Approximately 85% of guardians are family members or friends, not professional attorneys or clinicians, who may not have the experience or skills to answer these questions effectively (Chamberlain et al., 2018; NCI, 2019; Uekert, 2010). Providing more prompts for guardians, such as a poor to excellent rating scale or a list with a "check all that apply" option, can help guardians understand what is being asked and provide more thorough information. Minnesota also uses the language "person subject to guardianship," which is appreciated over less dignified alternatives.

There is an increasing demand for adult guardianship, which is not surprising given the growing number of older adults and adults with disabilities (Administration for Community Living [ACL], 2021b; Chamberlain et al., 2018; Nwakasi & Roberts, 2021; Uekert, 2010). It is difficult to know if the number of guardians is keeping up with this demand given the variation and scarcity of guardianship data. Studies consistently find that few courts maintain and report guardianship statistics (Chamberlain et al., 2018; Karp & Wood, 2007; Uekert & Duizend, 2011). Without adequate information from regular reporting, the court cannot determine if the guardian is advocating for the individual's values and if the guardianship should be modified or terminated. Some adults only need assistance with decision-making in some domains, such as medical or financial decisions, but are able to perform

daily activities independently (Peterson et al., 2021). In these cases, a limited guardianship may be the solution. Others may only require a temporary guardianship, such as in emergency situations, and later regain capacity and no longer require a guardian. Some adults with ID/DD may have been appointed a guardian once they became legal adults but have abilities that allow for a less-restrictive alternative, such as supported decision-making. This is precisely why it is essential to collect data about all aspects of a guardianship appointment over time to determine the least restrictive option that will honor individuals' autonomy and dignity.

Per the legal doctrine *parens patriae*, or “parent of the people,” the courts have a responsibility to protect vulnerable individuals (Legal Information Institute (LII), n.d.; NGA, 2022; Uekert, 2010). Courts determine an individual’s incapacity and appoint a guardian to make important decisions for that person. One could say the court is the ultimate guardian, delegating daily duties to proxies acting as guardians. Therefore, court monitoring is essential for assuring that the adult with a guardian has their needs met, that their rights are being honored, and that they are in the least restrictive environment. Fortunately, some courts do require periodic hearings, which are an opportunity to reassess the necessity of guardianship. For example, Nevada requires reviews every three years (Nevada Legislature, 2021).

The public image of guardianship has suffered due to high profile cases like Britney Spears and award-winning films like *I Care a Lot*. These cases show adults with guardians being exploited, abused, and stripped of their rights. There have been cases of abuse, such as April Parks of Nevada, on whom the *I Care a Lot* character Marla Grayson seems to be based. Parks is currently serving up to 40 years in prison for exploitation, theft, and perjury after removing hundreds of older adults from their homes, placing them in senior living facilities, and selling most of their valuable assets (Aviv, 2017; Wasser, 2019). Therefore, it is important to monitor guardians to safeguard against the real Marla Graysons of the world who pursue guardianship as a means of personal financial gain. Unfortunately, guardianship abuse and exploitation are not always documented (NCSC, 2018; Robinson et al., 2021).

Aging and disability organizations and researchers consistently advocate for improved data collection, increased monitoring, and better training for guardians and courts. More recently, the #FreeBritney movement to end Britney Spears’ conservatorship inspired politicians on both sides of the aisle to join this cause (Sprunt, 2021; United States Senate Committee on the Judiciary, n.d.; Warren & Casey, 2021). In July 2021, Senators Elizabeth Warren (D-Mass.) and Bob Casey Jr. (D-Pa.) sent a letter to the U.S. Department of Health and Human Services (HHS) requesting detailed information about the federal government’s current data collection process for guardianship and urging for improved guardianship oversight (Warren & Casey, 2021). In September 2021, Senators

Richard Blumenthal (D-Conn.) and Ted Cruz (R-Texas) held a hearing with the pun-based title “Toxic Conservatorships: The Need for Reform,” during which legal experts, disability advocates, and adults with guardians or conservators testified about the restrictions of and alternatives to guardianship (United States Senate Committee on the Judiciary, [n.d.](#)). Around the same time, another bipartisan effort came from Senators Bob Casey (D-PA) and Susan Collins (R-ME) in the form of the Guardianship Accountability Act, which would create a national database on guardianship, offer training materials, and provide more federal grants to support courts (Sprunt, [2021](#)). Even though these stories are not currently dominating the headlines, it is important to keep this momentum moving toward guardianship reform.

Courts need resources to provide proper guardianship oversight. The U.S. Department of Health and Human Services (HHS) and Administration for Community Living (ACL) are a step ahead with grant support. In 2021, seven state court systems were awarded two-year grants totaling approximately \$6 million to improve guardianship oversight (ACL, [2021a](#)). In 2022, the ACL awarded \$1,999,016 in three-year grants to Pennsylvania, Virginia, and Washington DC (ACL, [2022](#)). Ideally, these improvements will include more standardized and thorough reporting procedures, which can lead to more efficient planning and effective policies for adults with disabilities (Chamberlain et al., [2018](#)).

Coinciding with many of these efforts, The National Guardianship Network (NGN) virtually held The Fourth National Summit on Guardianship in May of 2021 at Syracuse University Law School. The Summit brought together over 100 guardians, scholars, advocates, and other stakeholders to discuss the state of guardianship and make recommendations for the future. Delegates to the Summit approved 22 recommendations, the first of which was to convene a task force to develop a Bill of Rights for persons with guardians. The task force completed the Bill of Rights in 2022 and is currently circulating it to member organizations and advocacy groups to offer instruction to guardians and those overseeing guardians.

Limitations

One important challenge not discussed in this study, which must be considered when updating reports, is the lack of technology being used by courts. Many courts do not use electronic systems for the guardianship reporting and tracking process, such as online completion of guardian reports, tracking due dates, or maintaining guardianship databases (Karp & Wood, [2007](#); Robinson et al., [2021](#); Uekert, [2010](#)). Courts are often understaffed and underfunded, but there are national efforts to improve

court procedures, such as the aforementioned ACL grant, and a pilot program by the National Center for State Courts (NCSC) to establish software systems (ACL, 2021a; Karp & Wood, 2007; NCSC, 2018; Nwakasi & Roberts, 2021; Robinson et al., 2021; Uekert, 2010). Future research should address how state courts are currently operating, what is being done to improve existing procedures, and what this means for the future of guardianship reporting.

Conclusion

Approximately 1.3 million adults and \$50 billion in assets are managed under guardianship or conservatorship; however, these numbers are likely underestimated due to inadequate reporting. Courts have a responsibility to monitor guardianship cases after the initial appointment; and annual reports are one of the few ways courts receive updated case information. This study provides an analysis of existing guardianship annual report forms, particularly focusing on what information is currently being collected and how it could be improved with the National Guardianship Association's Standards of Practice as a guide. The results show that most states are not collecting thorough and consistent data on adult guardianships. Additionally, most forms include confusing questions and high reading levels that pose challenges for guardians, most of whom are family members.

Therefore, our next step is to finalize a comprehensive annual report form that could serve as a template for all states or counties to ensure that consistent and reliable guardianship data are being collected. This template will include topics outlined by the National Guardianship Association's Standard of Practice and be written at or below an eighth-grade reading level to make it easier for family guardians and non-native English speakers to complete. It can also be modified to accommodate each state or county's needs. For example, the Massachusetts report form includes questions about a Rogers guardianship that requires court approval for the use of antipsychotic medications. This law does not apply to all states and, therefore, would not be included in all annual reports. This tool can serve multiple purposes: standardize reporting procedures to provide a better understanding of the overall state of guardianship, protect vulnerable adults with guardians, and identify the need for policy change.

Key Points

- There is a need for improved adult guardianship reporting and monitoring.
- The National Guardianship Association's Standards of Practice can improve reporting.

- Better data collection can improve guardianship arrangements and inform policy.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Joanne Tompkins PhD  <http://orcid.org/0000-0003-0569-6425>

References

Administration for Community Living (ACL). (2021a, September 28). *New elder justice grants address APS training, guardianship, APS to community services transitions*. <https://acl.gov/news-and-events/announcements/new-elder-justice-grants-address-aps-training-guardianship-aps>

Administration for Community Living (ACL). (2021b, May 25). *Projected future growth of older population*. <https://acl.gov/aging-and-disability-in-america/data-and-research/projected-future-growth-older-population>

Administration for Community Living (ACL). (2022, September 28). *Over \$2.6 million in 2022 ACL elder justice innovation grants address guardianship, opioids and substance use*. <https://acl.gov/news-and-events/announcements/over-26-million-2022-acl-elder-justice-innovation-grants-address>

APM Research Lab. (2022). *Reading the numbers: 130 million American adults have low literacy skills, but funding differs drastically by state*. Retrieved January 16, 2024, from <https://www.apmresearchlab.org/10x-adult-literacy>

Arkansas Judiciary. (n.d.). *Official probate forms*. Retrieved March 14, 2022, from <https://www.arcourts.gov/forms-and-publications/court-forms/probate-division/forms>

Aviv, R. (2017, October 2). *How the elderly lose their rights*. *The New Yorker*. <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>

Bayles, F. (1987, September 19). *Guardians of the elderly: An ailing system part I: Declared 'legally dead' by a troubled system*. The Associated Press. <https://apnews.com/article/1198f64bb05d9c1ec690035983c02f9f>

Bradley, V. J., Fenton, M. H., & Mahoney, K. J. (2021). *Self-direction: A revolution in human services*. State University of New York Press.

Centers for Disease Control and Prevention (CDC). (2023). *Disability impacts all of us*. Retrieved January 17, 2024, from <https://www.cdc.gov/ncbddd/disabilityandhealth/info-graphic-disability-impacts-all.html>

Chamberlain, S., Baik, S., & Estabrooks, C. (2018). Going it alone: A scoping review of unbefriended older adults. *Canadian Journal on Aging / La Revue canadienne du vieillissement*, 37(1), 1-11. <https://doi.org/10.1017/S0714980817000563>

Colorado Judicial Branch. (2023). *Reports and plans*. Retrieved June 12, 2023, from https://www.courts.state.co.us/Forms/Forms_List.cfm?Form_Type_ID=130

Duizend, R. V., & Uekert, B. K. (2013). *National probate court standards*. National Center for State Courts (NCSC). https://ncsc.contentdm.oclc.org/digital/collection/spcts/id/240#img_view_container

Friedman, C. (2019). Quality-of-life outcomes of older adults with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 44(4), 237–250. <https://doi.org/10.1177/1540796919879227>

Hale, J. M., Schneider, D. C., Mehta, N. K., & Myrskylä, M. (2020). Cognitive impairment in the U.S.: Lifetime risk, age at onset, and years impaired. *SSM - Population Health*, 11, 100577. <https://doi.org/10.1016/j.ssmph.2020.100577>

Hurme, S. B., & Robinson, D. (2021, 10–14). *What's working in guardianship monitoring: Challenges and best practices*. [Conference presentation]. Fourth National Guardianship Summit. <https://lawreview.syr.edu/wp-content/uploads/2022/10/8.-HURME-ROBINSON.pdf>

Jameson, J. M., Riesen, T., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities*, 40(1), 36–51. <https://doi.org/10.1177/1540796915586189>

Karp, N., & Wood, E. (2007). Guardianship monitoring: A national survey of court practices. *Stetson Law Review*, 37(1), 143–192. <https://www.stetson.edu/law/lawreview/media/document/guardianship-monitoring-a-national-survey-of-court-practices.pdf>

Karp, N., & Wood, E. (2013, August). *Choosing home for someone else: Guardian decisions on long-term services and supports*. AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/cons_prot/2013/guardian-decisions-on-ltss-report-AARP-ppi-cons-prot.pdf

Legal Information Institute (LII). (n.d.). *Parsons patriae*. Retrieved March 14, 2022, from https://www.law.cornell.edu/wex/parsons_patriae

Literacy Project. (2022). *Illiteracy by the numbers*. Retrieved January 16, 2024, from <https://literacyproj.org>

Maine Probate Court. (n.d.). *Forms*. Retrieved March 14, 2022, from <https://www.maineprobate.net/welcome/probateforms-2019/>

Maller, A. (2013, October 23). *Why aren't patients using advance directives?* Clinical Correlations. <https://www.clinicalcorrelations.org/2013/10/23/why-aren%e2%80%99t-patients-using-advance-directives/>

Minnesota Judicial Branch. (n.d.). *Court forms*. Retrieved March 14, 2022, from <https://www.mncourts.gov/getforms.aspx?c=21>

National Center for State Courts (NCSC). (2018, September). *Data quality undermines accountability in conservatorship cases*. https://www.eldersandcourts.org/__data/assets/pdf_file/0021/5844/ovc-brief-7.pdf

National Core Indicators (NCI). (2019, April). *National core indicators data brief*. https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf

National Council on Disability (NCD). (2019, June 10). *Turning rights into reality: How guardianship and alternatives impact the autonomy of people with intellectual and developmental disabilities*. https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf

National Guardianship Association (NGA). (2022). *Standards of practice*. <https://www.guardianship.org/wp-content/uploads/NGA-Standards-Final-8-22.pdf>

National Resource Center for Supported Decision-Making. (n.d.). *In your state*. Retrieved January 18, 2024, from <http://www.supporteddecisionmaking.org/in-your-state>

Nevada Legislature. (2021). *Statewide rules for guardianship*. Retrieved August 1, 2023, from <https://www.leg.state.nv.us/Division/Legal/LawLibrary/CourtRules/Guardianship.html>

New Mexico Courts. (n.d.). *Forms*. Retrieved March 14, 2022, from <https://adultguardianship.nmcourts.gov/forms/>

North Dakota Courts. (2022). *Adult Guardianship*. Retrieved June 12, 2023, from <https://www.ndcourts.gov/legal-self-help/adult-guardianship>

Nwakasi, C. C., & Roberts, A. R. (2021). Older adults under guardianship: Challenges and recommendations for improving practice. *Journal of Aging & Social Policy*, 1–17. <https://doi.org/10.1080/08959420.2021.1926198>

Peterson, A., Karlawish, J., & Largent, E. (2021). Supported decision making with people at the margins of autonomy. *The American Journal of Bioethics*, 21(11), 4–18. <https://doi.org/10.1080/15265161.2020.1863507>

Rao, J. K., Anderson, L. A., Lin, F.-C., & Laux, J. P. (2014). Completion of advance directives among U.S. consumers. *American Journal of Preventive Medicine*, 46(1), 65–70. <https://doi.org/10.1016/j.amepre.2013.09.008>

Readable. (n.d.). *Flesch reading ease and the Flesch Kincaid grade level*. Retrieved March 14, 2022, from <https://readable.com/readability/flesch-reading-ease-flesch-kincaid-grade-level/>

Robinson, D., Trescher, S., & Hamilton, M. (2021, May). *Adult guardianship monitoring: A national survey of court practices*. National Center for State Courts (NCSC). https://www.eldersandcourts.org/_data/assets/pdf_file/0035/65969/Guardianship-Monitoring-Survey-Report.pdf

Siripurapu, A., & Masters, J. (2021, March 19). *How COVID-19 is harming state and city budgets*. Council on Foreign Relations. <https://www.cfr.org/backgrounder/how-covid-19-harming-state-and-city-budgets>

Sprunt, B. (2021, September 28). *On Capitol Hill, #freebritney is just the beginning*. National Public Radio (NPR). <https://www.npr.org/2021/09/28/1041025998/on-capitol-hill-freebritney-is-just-the-beginning>

Syracuse University: College of Law. (2021). *The fourth national guardianship summit: Maximizing autonomy and ensuring accountability*. Retrieved December 1, 2022, from <http://law.syr.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-autonomy-and-accountability/>

Uekert, B. K. (2010, March 2). *Adult guardianship court data and issues: Results from an online survey*. National Center for State Courts (NCSC). <https://ncsc.contentdm.oclc.org/digital/collection/famct/id/291/>

Uekert, B. K., & Duizend, R. V. (2011). Adult guardianships: A “best guess” national estimate and the momentum for reform. *Trends in State Courts*, 107–112. <https://ncsc.contentdm.oclc.org/digital/collection/ctadmin/id/1846>

U.S. Government Accountability Office (GAO). (2010, September). *Guardianships: Cases of financial exploitation, neglect, and abuse of seniors*. <https://www.gao.gov/assets/gao-10-1046.pdf>

U.S. Senate Committee on the Judiciary. (n.d.). *Toxic conservatorships: The need for reform*. Retrieved March 14, 2022, from <https://www.judiciary.senate.gov/meetings/toxic-conservatorships-the-need-for-reform>

Warren, E., & Casey, R. P. (2021, July 1). *Letter to U.S. Department of Health and Human Services (HHS)*. <https://www.warren.senate.gov/imo/media/doc/2021.07.01%20Letter%20to%20DOJ%20and%20HHS%20re%20Conservatorship.pdf>

Wasser, F. (2019, February 25). *Guardianship system still under scrutiny—But there is progress*. Nevada Public Radio. <https://knpr.org/knpr/2019-02/guardianship-system-still-under-scrutiny-there-progress>

Watson, J., Voss, H., & Bloomer, M. J. (2019). Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling. *Research and Practice for Persons with Severe Disabilities*, 44(4), 267–279. <https://doi.org/10.1177/1540796919879701>

Wisconsin Court System. (2020). *Circuit Court forms*. Retrieved June 12, 2023, from <https://www.wicourts.gov/forms1/circuit/ccform.jsp?Category=&FormName=GN-3480&FormNumber=&StatuteCite=>

Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., Mante, A., Halpern, S. D., & Courtright, K. R. (2017). Approximately one in three us adults completes any type of advance directive for end-of-life care. *Health Affairs*, 36(7), 1244–1251. <https://doi.org/10.1377/hlthaff.2017.0175>