


July 2023

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Recommended Citation

Hamre, Kristin and Nord, Derek (2023) "Differences Among Family and Professional Guardians: A Statewide Survey of Characteristics, Training, and Practices Related to Decision-making," *Developmental Disabilities Network Journal*: Vol. 3: Iss. 2, Article 13.

DOI: 10.59620/2694-1104.1076

Available at: <https://digitalcommons.usu.edu/ddnj/vol3/iss2/13>

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Cover Page Footnote

This study is supported by grant No. 90EJIG0007-01-00 from the Administration for Community Living, U.S. Department of Health and Human Services (DHHS). Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official Administration for Community Living or DHHS policy.

Differences Among Family and Professional Guardians: A Statewide Survey of Characteristics, Training, and Practices Related to Decision-Making

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Plain Language Summary

This study examined the differences between family and professional guardians. A total of 237 subjects serving as guardian to adults in the state of Indiana completed an online survey. Results showed group differences across race, education, diagnosis, and age of those served. Guardian types showed differences in their willingness to allow people to assist with decisions. There were also differences in their willingness to allow people to make decisions. Areas include spending money, working in the community, and treating a medical condition. Study implications for policy and practice also discussed.

Abstract

This cross-sectional study sought to examine the differences between family and professional guardians across personal and role characteristics, training received, and their inclusion of people they serve in decision making. A total of 237 subjects serving as guardian to adults in the state of Indiana completed an online survey. Results showed group differences across race and education, as well as diagnosis and age of those served. Overall, training was limited across both groups, and family guardians received significantly less training across several topics. Finally, family and professional guardians were found to significantly differ in their willingness to allow people they serve to inform and/or make decisions about spending money, working in the community, and treating a medical condition. Study implications for policy and practice are also discussed, along with recommendations about integrating values of self-determination and empowerment approaches into practice.

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Introduction

People with intellectual and developmental disabilities (IDD), people with mental health conditions, and elders are those most vulnerable to being placed under a guardianship because of cognitive impairments or incapacities experienced by these populations. These groups have long histories of facing stigma and segregation because of their conditions. For example, elders, especially in Western cultures, may be infantilized (Salari, 2005); people with mental health conditions may be viewed as dangerous and incompetent (Pescosolido et al., 2013); and people with IDD often experience low expectations and over-protection (Perske, 1972; Sanders, 2006). Subsequently, all face stigma as being unable to meaningfully contribute to their communities. These beliefs have, in many cases, resulted in a history of exclusion from their communities and families.

Guardianship is employed when a person has been adjudicated as legally incapacitated. That is, they are deemed incapable of taking care of or making decisions about their care, property, and unable to understand and enter into a legal contract. States have variable laws and procedures for guardianship and may use different terminology, such as “conservators” and “conservatorship.” Likewise, individuals under a guardianship (legally termed as “wards”) may retain certain rights based on what state they reside in. A limited or partial guardianship is one in which the court has found that there are specific areas where the individual lacks competence to make decisions, but they retain decision-making rights in other areas, while a plenary or full guardianship is one in which the court has deemed a person does not have the capacity to make any legal decisions.

A guardian may be a person, an institution, or an agency appointed by a court system to manage the affairs of another individual. This role may also be performed by a family member, a friend, or a volunteer. In these cases, guardians may be unpaid, or they may receive some reimbursement from the individual’s estate, but do not engage in guardianship to make a living.

Guardianship is typically categorized as either a guardianship of the person or of the property. When the guardian controls decisions regarding both the person and the property, it is referred to as a “plenary” or “full guardianship.” A plenary guardianship is one in which, after a court has decided incapacity, the court gives the guardian the power to exercise all legal rights and duties on behalf of an individual. In order for guardianship to occur, the adult must be adjudicated and determined to be incapacitated. A full guardian has the legal right to make decisions on behalf of the individual, including determining residence, making healthcare and medical decisions, as well as financial decisions.

Review of Literature

Research on guardianship for people with disabilities is limited. There have been a few studies reviewing state-level data describing guardianship-related issues for people with disabilities (Millar, 2008, 2009; Millar & Renzaglia, 2002; Payne-Christiansen & Sitlington, 2008) and one that used a national network of advocacy organizations to explore prevalence of

guardianship among people with disabilities, the impact of educational placement, and the presentation of information on guardianship options among other things to family members (Jameson et al., 2015). What remains unknown is whether guardians involve individuals deemed as their legal “wards” in the decision-making process. One study has examined guardians and decision-making involvement tied to evaluation of individual’s impairment and found correlations between guardian’s assessment of their ward’s competence and increases in involvement in decision-making (Ogle, 2019).

A recent report published by the National Core Indicators describes individuals with IDD experiencing a diminished quality of life, feelings of hopelessness, helplessness, and inadequacy as a result of guardianship (Bradley et al., 2019). Losing one’s autonomy may negatively impact a person’s mental and physical health. The report further found that adults who were under a guardianship were significantly less likely to have had preventative medical care in the past 2 years (i.e., mammogram, pap smear), were significantly less likely to work in a paid community job, were significantly less likely to choose where and with whom to live, and were significantly less likely to have social relationships at the frequency or level they would like. Overall, the report found that those with either or full or limited guardianship experienced diminished independence and opportunities than their counterparts without a guardian (Bradley et al., 2019).

Emerging research in the area of guardianship and people with IDD suggests that plenary guardianship has been over-utilized, and may have harmful effects such as lowered self-esteem, lower perception of self-efficacy, and the potential for abuse of privileges by appointed guardians (Jameson et al., 2015). One study found people with disabilities experienced a low and inconsistent legal threshold to lose their legal autonomy. In a review of court records in the state of Indiana, it was found that nearly all petitions for guardianship sought plenary guardianship, whereas only 1% sought limited guardianship. In many instances, the person under petition for guardianship was not present in the judicial proceeding, with written documentation on an individual’s diagnosis or level of functioning used to support a claim of incapacity. Similarly, in many cases, it was reported no evidence of incapacity was filed in court beyond the allegations in the guardianship petition, or the guardianship petition was entirely silent as to the incapacitating condition alleged overturned (Indiana Adult Guardianship State Taskforce, 2012).

Every person, regardless of ability or perceived ability, has the right to make choices for themselves. Existing law and policy recognize the rights of people with disabilities to be self-determined (Americans with Disabilities Act, 1990; Developmental Disabilities and Bill of Rights Act, 2000; *Olmstead v. L.C.*, 1999; Rehabilitation Act of 1973). Self-determination is important to a person’s quality of life and self-esteem. Indeed, people with disabilities have long advocated to obtain legal rights and protections to preserve their dignity and to be treated equally (Wehmeyer, 2005). Further, there is growing national interest in utilizing less restrictive alternatives (LRA) to guardianship in order for people to retain civil rights and to lead self-determined lives. Indiana is the eighth state in the nation to pass legislation requiring consideration of LRA to guardianship and to recognize supported-decision making agreements (Senate Enrolled Bill 380, 2019). Within a plenary guardianship, there has been a recognition of the importance of self-determination.

The recently updated National Guardianship Association's Standards of Practice highlight the importance of self-determination and involving people under guardianship in the decision-making process, even when the person is under a plenary guardianship (National Guardianship Association, 2022). Despite this, it remains unknown whether individuals under guardianship have any influence over the decisions their guardians make on their behalf.

This study sought to understand the extent guardians allowed their wards to inform or make decisions—comparing characteristics and practices of family and professional guardians. Research questions included: Do family and professional guardians have different (1) personal and professional characteristics, (2) training experiences, and (3) approaches to decisional control when supporting adults under guardianship? If so, how do they differ?

Methods

The study used a cross-sectional survey examining characteristics, training, and approach to decision making among a non-probability sample of people serving as guardians in the state of Indiana, United States. There were two distinct samples targeted for this study—professionals serving as guardians and family members serving as guardians to at least one adult in Indiana. Specific inclusion criteria required participants to be (a) age 18 years old or older, (b) currently serving as a guardian to an adult, and (c) living in the state of Indiana. Participant eligibility was confirmed through screening questions at the beginning of the survey.

For professionals, recruitment occurred via a number of professional organizations, including the Indiana State Guardianship Association, the Indiana State Bar Association, the Indianapolis Bar Association, the Volunteers Advocates for Seniors and Incapacitated Adults, the Center for Guardianship Association, the Arc of Indiana, and the Indiana Adult Guardianship Office. For family members serving in guardianship roles in Indiana, researchers contracted with Qualtrics panel services to recruit participants from various sources, including website intercept recruitment, member referrals, targeted email lists, gaming sites, customer loyalty web portals, permission-based networks, social media, among others. All surveys were completed via a web-based survey that was built utilizing the Qualtrics survey platform.

All research procedures were approved by the Indiana University Institutional Review Board. The survey began with informed consent, which outlined the anticipated length of time it would take to complete the survey (30 minutes), the principal investigator for the study, and the purpose of the study. The informed consent information indicated that participation was voluntary, and responses were anonymous. To ensure participant anonymity, documentation of consent was waived. There was no monetary or other direct incentive shared with participants for completing the survey beyond contributing to the knowledge in the field.

Instrument and Measures

The survey was field tested with a small group of guardians to assess the survey directions and useability, as well as the functioning of the online survey platform. Survey adjustments were

made based on feedback from this group, as well as legal experts with knowledge about guardianship. The survey included a series of demographic items and a section assessing the training of guardians. It also deployed a series of 5-point Likert scale items (ranging from Very Likely to Very Unlikely), which allowed guardians to rate the likelihood of allowing those they serve to inform and make important life decisions. Likert scale items were adapted from past research that identified a range of decisions on a risk continuum (Ogle, 2019). Internal consistency of the Likert scale items was assessed using Cronbach's Alpha, which suggests a high level of reliability among the items ($\alpha = .878$).

Participants Demographics

A total of 237 subjects completed surveys. One hundred sixty-seven (70.5%) of this sample served in the role of family guardian, whereas 70 (29.5%) served as professional guardians. The mean age of guardians was 46.3 years and 71% ($N = 168$) of the sample was female. Racially, 83.1% of the sample was White, 9.7% was Black, and 5.9% was Other. Educationally, 33.8% had a high school diploma; 15.2% had a trade, technical, or associate degree; and 47.7% had a bachelor's degree or higher. Two and a half percent did not have a high school diploma.

Analysis

To assess differences in family and professional guardian survey responses, a series of comparative tests were conducted. To assess subject characteristics, the populations they serve, and training, this study utilized an independent sample t test to assess differences across a single continuous measure and Pearson chi-square tests to assess differences on nominal measures. Ordinal chi-square tests, followed by Bonferroni corrected post hoc tests, were conducted to evaluate the nominal-by-ordinal variables to assess the likelihood of a guardian to allow people they support to inform and make decisions, by guardian type. Statistical tests utilized a significance level of $p < .05$ and tested a null hypothesis that statistical differences did not exist between family and professional guardians. Post-hoc tests used adjusted p values for multiple comparisons and tested a null hypothesis that family and professional guardians did not differ in their likelihood of allowing people with disabilities to inform and make decisions about their life.

Results

On average, family guardians were found to be significantly younger, averaging 43 years of age, compared to professional guardians who averaged 54.1 years, $t(233) = 5.500$, $p < .001$. As shown on Table 1, over three-quarters of family guardians identified as White, compared to 94.3% of professional guardians, a significantly higher proportion, $\chi^2(1) = 8.824$, $p = .003$. Additionally, a significantly higher proportion of family guardians self-identified as Black (12.6%) than professional guardians (2.9%), $\chi^2(1) = 5.316$, $p = .028$. Educationally, family guardians had significantly lower educational attainment compared to professionals, $\chi^2(4) = 62.251$, $p < .001$. Gender and race identified as Other were found to be statistically equal across groups.

Table 1*Comparison Tests of Guardian Characteristics by Type of Guardian (N = 237)*

Guardian	χ^2	df	Guardian type				Sig.
			Family (N = 167)		Professional (N = 70)		
			n	%	n	%	
Gender	3.543	1					†
Female			112	67.9	56	80.0	
Male			53	32.1	14	20.0	
Race							
White	8.824	1	131	78.4	66	94.3	**
Black	5.316	1	21	12.6	2	2.9	*
Other	0.715	1	9	5.4	2	2.9	
Education (%)	62.251	1					***
No HS diploma			6	3.6	0	-	
HS diploma			74	44.3	6	8.6	
Trade, Technical, or Associate			33	19.8	3	4.3	
Bachelor's			33	19.8	25	35.7	
Master's or higher			19	11.4	36	51.4	
Population Served							
Diagnosis (%)							
IDD	53.063	1	36	21.6	50	71.4	***
Physical	19.88	1	59	35.3	5	7.1	***
Mental health	1.075	1	44	26.3	14	20	
Elderly	0.391	1	62	37.1	23	32.9	
Significant health issues	3.811	1	28	16.8	5	7.1	†
Age (%)							
18-21 years	4.725	1	30	18.2	5	7.1	*
22-64 years	18.432	1	65	39.4	49	70.0	***
65+ years	0.367	1	80	48.5	37	52.9	

† < .10; * $p < .05$; ** $p < .01$, *** $p < .001$.

Regarding those served, a significantly higher proportion of family guardians supported people with physical disabilities (35.3%) and people who were 18–21 years of age (18.2%) than professionals (7.1% and 7.1%, respectively), $\chi^2(1) = 19.880$, $p < .001$ and $\chi^2(1) = 4.725$, $p = .030$, respectively). On the other hand, professional guardians served people with IDD (71.4%) and people who were 22–64 years of age (70.0%) at higher proportions than family guardians (21.6% and 39.4%, respectively), $\chi^2(1) = 53.063$, $p < .001$ and $\chi^2(1) = 18.432$, $p < .001$, respectively. The proportion of family and professional guardians supporting people with mental health diagnoses and who were elderly, had significant health issues, and were 65 years of age or older were statistically equal (see Table 1).

As shown in Table 2, the training guardians received differed by type of guardian. Overall, a significantly higher proportion of professional guardians received training on five topics compared to family guardians. Person-centered planning and supported-decision making were topics with the highest proportion, where over 50% of professionals received training. This significantly differed from family guardians, where 29.9% and 37.1% received training on these topics, respectively, $\chi^2(1) = 15.496, p < .001$ and $\chi^2(1) = 4.161, p < .05$, respectively. Similarly, significantly higher proportion of professional guardians received training on certification (18.6%), ethics (37.1%), and least restrictive environments (42.9%) than family guardians, $\chi^2(1) = 4.354, p < .05$; $\chi^2(1) = 21.288, p < .001$; and $\chi^2(1) = 14.337, p < .001$, respectively.

Table 2

Chi-Square Test of Training in the Last 12 Months by Guardianship Type (N = 237)

Training domain	χ^2	df	Guardian type				Sig.
			Family (N = 167)		Professional (N = 70)		
			n	%	n	%	
Person-centered planning	15.496	1	50	29.9	40	57.1	***
Supported-decision making	4.161	1	62	37.1	36	51.4	*
Responsibilities & duties of guardians	0.080	1	73	43.7	32	45.7	
Legal process of guardianship	0	1	43	25.7	18	25.7	
Certification of guardians	4.354	1	15	9.0	13	18.6	*
Guardianship ethics	21.288	1	19	11.4	26	37.1	***
Least restrictive environments	14.337	1	32	19.2	30	42.9	***

* $p < .05$, *** $p < .001$.

Table 3 reports responses to 12 Likert scale survey items related to guardian's self-reported likelihood of allowing people for whom they serve to either inform or make decisions across six topics. In total, four survey items were found to be significant, indicating responses differed by guardianship type. Guardians' likelihood of allowing people to make the decision to buy a television instead of paying a bill significantly differed by type, $\chi^2(1) = 5.398, p < .05$. Post-hoc contrasts found the percentage of family members (15.2%, $n = 25$) who were Very Likely to allow people to make this decision was significantly higher than professionals (1.8%, $n = 1$), whereas a significantly higher percent of professionals (29.1%, $n = 16$) were Somewhat Unlikely compared to family guardians (16.4%, $n = 24$).

Related to decisions about working in the community, guardians were found to differ significantly in their likelihood of allowing people who they support to both inform and make the decision, $\chi^2(1) = 4.944, p < .05$ and $\chi^2(1) = 17.196, p < .05$, respectively. Post-hoc tests indicated professional guardians reported they were Very Likely to allow people to inform (45.5%, $n = 25$) and make (41.8%, $n = 23$) the decision to work in the community, compared to family guardians (21.3%, $n = 35$ and 21.2%, $n = 35$, respectively). Family guardians reported a significantly higher

percent that they were Somewhat Unlikely to allow people they support to inform (11.0%, $n = 18$) and make (15.8%, $n = 26$) the decision to work in the community than professional guardians (1.8%, $n = 1$ for both items).

Table 3

Guardian Type by Decision Topic and Level of Involvement of Individual (N = 237)

How likely are you to allow the person(s) for who you are guardian to [inform/make] the following decisions?	χ^2	df	Very likely		Somewhat likely		Neither likely nor unlikely		Somewhat unlikely		Very unlikely		Sig.
			n	%	n	%	n	%	n	%	n	%	
Buy a television instead of pay a bill													
<i>Inform the decision</i>	0.643	1											
Family			28	17.1	26	15.9	36	22.0	27	16.5	47	28.7	
Professional			9	16.4	4	7.3	14	25.5	11	20.0	17	30.9	
<i>Make the decision</i>	5.398	1											*
Family			25	15.2a	20	12.1	28	17.0	27	16.4	65	39.4	
Professional			1	1.8	5	9.1	9	16.4	16	29.1b	24	43.6	
Have a romantic relationship													
<i>Inform the decision</i>	3.43	1											†
Family			39	23.9	31	19.0	44	27.0	17	10.4	32	19.6	
Professional			19	34.5	12	21.8	14	25.5	2	3.6	8	14.5	
<i>Make the decision</i>	1.448	1											
Family			38	23.0	35	21.2	33	20.0	25	15.2	34	20.6	
Professional			16	29.1	13	23.6	13	23.6	2	3.6	11	20.0	
Work in the community													
<i>Inform the decision</i>	4.944	1											*
Family			35	21.3	40	24.4	43	26.2	18	11.0a	28	17.1	
Professional			25	45.5b	10	18.2	9	16.4	1	1.8	10	18.2	
<i>Make the decision</i>	17.196	1											**
Family			35	21.2	38	23.0	36	21.8	26	15.8a	30	18.2	
Professional			23	41.8b	14	25.5	7	12.7	1	1.8	10	18.2	
Where to live													
<i>Inform the decision</i>	2.59	1											
Family			51	31.1	32	19.5	34	20.7	23	14.0	24	14.6	
Professional			24	43.6	13	23.6	7	12.7	2	3.6	9	16.4	
<i>Make the decision</i>	0.347	1											
Family			44	26.7	40	24.2	35	21.2	21	12.7	25	15.2	
Professional			13	23.6	23	41.8	5	9.1	5	9.1	9	16.4	
Treat a serious medical condition													
<i>Inform the decision</i>	0.149	1											
Family			48	29.3	35	21.3	35	21.3	20	12.2	26	15.9	
Professional			16	29.1	12	21.8	10	18.2	5	9.1	12	21.8	
<i>Make the decision</i>	7.854	1											**
Family			50	30.3a	29	17.6	32	19.4	26	15.8	28	17.0	
Professional			6	10.9	13	23.6	10	18.2	7	12.7	19	34.5b	
Sign a "do not resuscitate order"													
<i>Inform the decision</i>	0.435	1											
Family			49	29.9	35	21.3	39	23.8	18	11.0	23	14.0	
Professional			18	32.7	11	20.0	8	14.5	4	7.3	14	25.5	
<i>Make the decision</i>	3.397	1											†
Family			45	27.3	43	26.1	32	19.4	19	11.5	26	15.8	
Professional			10	18.2	14	25.5	11	20.0	4	7.3	16	29.1	

A significantly higher percentage of family guardians (30.3%, $n = 50$) were found to Very Likely to allow people they support to make the decision to treat a serious medical condition compared to professional guardians (10.9%, $n = 9$). Conversely, a significantly higher percentage of professionals (34.5%, $n = 19$) were Very Unlikely to allow the people they support to make the decisions, compared to family guardians (17.0%, $n = 18$).

Responses of eight survey items were found to be statistically the same by guardianship type. This included two items where guardian responses were found to be nearly significant at the $p < .01$ level, to allow people to inform the decision to have a romantic relationship and to make the decision to sign a “do not resuscitate order.” The insignificant items related to informing the decisions to buy a television instead of paying a bill, decide where to live, treat a serious medical condition, and sign a “do not resuscitate order.” The insignificant items related to making the decisions to have a romantic relationship and decide where to live.

Discussion

The purpose of this study was to examine differences associated with the knowledge and practices of guardians serving adults in the state of Indiana, making comparisons between those in guardianship roles as family members and those serving as professional guardians. Analyses were guided by three research questions: (1) Do family and professional guardians have different characteristics? (2) Do family and professional guardians have different training experiences? (3) Do family and professional guardians have different approaches to decisional control practices?

As the data show, those serving in guardianship roles are not a homogeneous group and family and professional guardians differ across a number personal and role characteristics. There was a disproportionately higher representation of White professional guardians, whereas there was a disproportionately higher representation of Black family guardians. A greater proportion of family members also had a high school diploma, whereas a greater proportion of professionals had a bachelor’s degree or higher. Regarding the populations guardians serve, a greater proportion of professionals served adults with IDD and people aged 22-64 than family members, respectively; whereas a greater proportion of family guardians served adults with physical disabilities and people who were 18-21 years old than professionals, respectively. The findings from this study suggest there are differences between the knowledge and practices of family guardians and professional guardians. According to data from the National Core Indicators, the majority of people serving in a guardianship role, nationally, are family members (Bradley et al., 2019). These findings align with past research that highlights the significant role that family members play in supporting their adult family members with disabilities (Braddock et al., 2013; Grossman & Magaña, 2016). We also know that many families are steered toward guardianship, many through interactions with professionals in the educational or medical system. In addition to adding to the limited research in this area and providing some contours of those serving in the role of guardian, this research has the potential to inform future work by highlighting key differences in characteristics across this role that might require focused attention, such as in intervention development or communication strategies.

Nationally, guardianship as a field has been inconsistent in its training and expectations from state to state. The National Guardianship Association has developed standards of practice, but these are not binding in state or federal courts (Kirtland, 2020). At present, no known review of state policy exists to fully understand the varied approaches nationally. However, even a cursory review of state law shows a spectrum, ranging from no training requirements for new guardians, such as in Indiana, to the required completion of a defined training program for professional guardians, such as in Illinois (Guardianship and Advocacy Act, 2018). This study adds to the dearth of research in this area by highlighting the overall lack of training across both family and professional guardians in a state that has no training requirement. This study also found large training gaps identified between family members and professionals, with significantly fewer family guardians reporting training within the past 12 months when compared to professional guardians. It is unknown why differences in training exist between family and professional guardians. Despite being actors within the judicial system, the lack of training suggests a level of informality to the role. To the extent this translates to practice remains unstudied and an important area for future research.

The concept of guardianship is variable based on a patchwork of state policy, but across all states it results in the removal of one's ability to self-direct their own life. A major finding of this study is that family and professionals appear to approach their guardianship role differently in relation to advancing self-determination by including people they serve in the decision-making process. Among the 12 different scales employed in the survey, 4 were found to differ based on guardianship type, 1 about *informing* a decision, and 3 about *making* a decision. A significantly higher percentage of family guardians reported being Very Likely to allow the people they support to decide on whether to treat a serious medical condition, while professional guardians were Very Unlikely to do so. Regarding working in the community, there were a significantly higher percentage of professional guardians who responded Very Likely to both allowing someone to inform and decide to work in the community, while family guardians reported being Very Unlikely to either allow a person to make or inform that decision. The present study shows that there are differences in how guardians approach the decision to work in the community, yet these results require contextualization because past research from a national study has suggested that individuals with IDD who had a guardian were significantly less likely to have a goal of working in the community (Nord et al., 2018). Stated differently, while one guardian group included people they serve in the decision to work in the community more regularly, guardians in general were acting as a significant barrier to community employment. Family guardians were significantly more likely to report being Very Likely to allow someone to decide on how they would use money, while professional guardians were significantly more likely to report being Somewhat Unlikely to allow this. The National Guardianship Association has laid out standards of practices that include discussions with "wards" to inform decision-making (National Guardianship Association 2022). Our data suggests that many guardians are not allowing the people they serve to inform decision-making along a number of decisional domains.

It is unknown why the differences exist between the groups, and this may be explored in future research; however, past research suggests a number of factors may be relevant. We can surmise that potential issues such as working in the community may present issues such as

inconsistency of work schedules, which, if living with a family member, may impact a family member's ability to provide supports at home. It is known that for many families, providing supports to their family member with disabilities is so consuming that they themselves leave the workforce; this is especially true of mothers (Emerson, 2003; Emerson et al., 2006; Eskow et al., 2011; Kogan et al., 2008). There is also the issue of overprotectiveness, with some families being fearful of allowing their family member a right to risk; this has long-impacted people with disabilities (Perske, 1972). With spending of money, families may be more likely to allow a person to inform how they spend money because of their closer relationship and potential ability to act as a safety net, while professionals may be more likely to approach the issue by looking solely at the finances available to the person, not accounting for the family's ability to provide additional assistance.

There is more commonality between professional and family guardians in informing decisions, while there are more differences in making decisions, with professionals more likely to exclude the person they serve in this situation. While we do not explore the reason for these differences here, there may be considerations of legal consequences and fulfillment of professional obligations to consider. While there is limited research related to guardians in this area, there is research suggesting family members and professionals approach medical decisions differently, with one study suggesting conflicts occur between physicians and the patient's substitute decision-maker in nearly two-thirds of cases (Schuster et al., 2014) and that conversations around critical care are particularly prone to conflict between professionals and family members (Breen et al., 2001; Studdert et al., 2003; Van Keer et al., 2015). While research in this area is lacking, our study showed family guardians and professional guardians approach decisions related to medical decisions differently. Future research should explore how family and professional guardians evaluate risk in decision-making and the impact on involvement of the people they are serving as guardians in decision-making. A possible consideration may be the impact of the familial relationship, where family members are able to have greater awareness of the person's wishes for treatments because of the intensity and frequency of conversations around these topics, whereas professional guardians may lack such connectedness. Additionally, organizational policies may be in place that direct and guide the practices of a professional guardian in a way that would not confine a family guardian. Again, this research does not explore why these differences exist, and future research may explore these topics in depth to understand the differences to impact policy and practices.

The recently updated National Guardianship Association Standards of Practice emphasizes the importance of self-determination and is a recognition of the importance of including people with disabilities in their life decisions (National Guardianship Association, 2022). Research examining petitions for guardianship in the state of Indiana found that in nearly all cases, a plenary guardianship is sought and granted and rarely overturned for a person to regain their decision-making rights (Indiana Adult Guardianship State Taskforce, 2012). This has been revealed to be a consistent practice nationwide, though it is difficult to attain data on guardianship because of a lack of recordkeeping, a lack of centralized data collection, and tracking systems (National Council on Disability, 2019). Self-determination is recognized as a best practice and vital for the quality of life of people with disabilities (Wehmeyer & Abery, 2013;

Wehmeyer & Schwartz, 1998). Many states are turning to legislation aimed at promoting less restrictive alternatives to guardianship. Plenary guardianship has been referred to as a “death” of a person’s civil rights; it takes a comprehensive view of incapacity, suggesting that if a person is unable to make decisions in one domain, they are unable to make decisions in all domains (Dinerstein, 2012). There is a growing recognition that guardianship should be a last resort, and that self-determination is a right that everyone should retain, even when under a guardianship (National Guardianship Association, 2022; Working Interdisciplinary Networks of Guardianship Stakeholders, 2020). At present, only 13 states have standards of practice defined in state law for guardians. These standards vary in focus, certification requisites, and type of guardian for whom they apply (National Guardianship Network, 2022). Future research would benefit from cross-state comparisons, to assess the practices of guardians to include people with disabilities decision making in states that have standards of practice to states that do not, such as in in this study.

Limitations

This study has limitations that must be noted. The data collected as part of the study came from a Qualtrics survey panel. As such, this was a non-probability sample of guardians who self-selected to participate. The data are not generalizable and may be biased by factors such as recall or self-report bias. The data were also cross-sectional; for example, participants were not asked about training prior to the previous 12 months. Future research would benefit from a representative sample to confirm these findings and make generalizations to the population. Additionally, this study does not differentiate between plenary and partial guardians and future research should explore this, which may offer valuable insights.

Conclusion

Nationally, there has been an increase in focus on the issue of guardianship, with an emphasis on the severity of the use of guardianship, and on implementing best practices to promote greater self-determination for people under guardianship. Several states have passed legislation regarding employing less restrictive alternatives to guardianship, including Indiana, and many more have brought forth such legislation. Utilization of LRAs is being advocated in order to promote empowering people with disabilities to lead self-determined lives. It is known that the rights of people with disabilities have often been minimized, leading to civil rights legislation to protect people’s rights, such as the landmark legislation the Americans with Disabilities Act. This study explored guardians, their characteristics, and their practices. This study makes several unique contributions to this area, including information on whether guardians include the people they serve in decision-making and in what domains of life. The study highlights that, while guardians have a responsibility as actors in the service system, they lack training in many cases, and are not practicing within standards of best practice in terms of promoting self-determination for the people they serve. Future research should emphasize ways to promote the empowerment of people with disabilities through policy and practice aimed at increasing self-determination for all individuals, including those under court-ordered guardianship.

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