


Guardianship and the Potential of Supported Decision Making With Individuals with Disabilities

Research and Practice for Persons
with Severe Disabilities
1–16
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**J. Matt Jameson¹, Tim Riesen², Shamby Polychronis³,
Barbara Trader⁴, Susan Mizner⁵, Jonathan Martinis⁶, and Dohn Hoyle⁷**

Abstract

Guardianship is a complicated legal concept, which is further complicated by differences from state to state in the framing and implementation of distinctly different forms. Few professionals explain the long-term consequences of obtaining guardianship or provide the range of alternatives available to support an adult with disabilities. This study reports descriptive data from a national survey on guardianship and people with disabilities. The results indicate that regardless of who provides information about guardianship, and regardless of disability classification, full guardianship is consistently discussed most frequently while other options are rarely discussed. We describe implications for practice and provide recommendations. Specifically, supported decision making is described as one potential alternative to legal guardianship that, according to these data, is the least frequently discussed with parents, but which has the potential to avoid many of the legal and social pitfalls that guardianship presents. Limitations and current research needs are described.

Keywords

guardianship, supported decision making, individuals with disabilities

There is growing recognition that overreliance on formal systems of substituted decision making (i.e., guardianship) can hinder or prevent inclusion, self-determination, and community integration, in conflict with the intent of the Americans With Disabilities Act (ADA; 1990) and other federal laws (Salzman, 2010). Research has repeatedly found that people who exercise greater self-determination, those with more control over their lives, have greater independence and quality of life. For example, two recent studies have found that young adults who took part in transition programs designed to increase self-determination experienced better employment outcomes, became more independent, and experienced more community integration (Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). Wehmeyer and Schwartz (1998) also found that young adults with greater self-determination skills were more likely to want to live independently, manage their money, and be employed.

¹University of Utah, Salt Lake City, USA

²Utah State University, Salt Lake City, USA

³Westminster College, Salt Lake City, UT, USA

⁴TASH, Washington, DC, USA

⁵American Civil Liberties Union – Disability Rights Program

⁶Quality Trust for Individuals With Disabilities, Washington, DC, USA

⁷The ARC Michigan, Lansing, MI, USA

Corresponding Author:

J. Matt Jameson, University of Utah, 1721 Campus Center Drive, SAEC 2296, Salt Lake City, UT 84105, USA.

Email: matt.jameson@utah.edu

Other researchers have found that adults with disabilities who exercised higher levels of self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and be promoted more frequently in their employment positions (Wehmeyer & Palmer, 2003). McGlashing-Johnson, Agran, and Sitlington (2003) investigated the effects of the Self-Determined Learning Model of Instruction on student-selected work skills for transition-aged students with moderate to severe disabilities. The students learned to set their own goals, developed an action plan, implemented the plan, and adjusted their goals and plans as needed. All students made progress or met their goals. The results provide additional support for self-determination instruction for transition-aged youth with moderate to severe disabilities.

Unfortunately, guardianship, by definition, alters the opportunities for an individual with disabilities to make independent choices and exercise self-determination skills (Millar, 2007). This formal system of substituted decision making can remove the opportunity to make a variety of choices about their lives and removes many of the rights the rest of us enjoy. It must be emphasized that we do not believe that instruction in self-determination skills is a prerequisite for either individual self-determination, making choices, or for avoiding guardianship. However, there is an extensive literature base supporting self-determination instruction and improved outcomes for individuals with disabilities, and it is clear, as Millar (2007) highlighted, there is a disconnect between supporting self-determination and current guardianship practices.

Before any further discussion of guardianship, it is important to define several terms and note the limitations of the definitions. As laws defining this phenomenon are determined by states, descriptive terms can be different or inconsistently applied. There are also different levels of decision-making authority, which can complicate understanding. The following definitions are offered to clarify these differences and were used in the survey design for clarity.

Definitions

What Is Guardianship?

A guardianship (or “conservatorship”) is a legal process by which a court appoints an individual or organization to make decisions on behalf of an individual after finding that the person is unable to make some or all decisions for himself or herself, and there are no less restrictive alternatives available (Quality Trust for Individuals With Disabilities, 2013). Guardianship is legally founded on the principle of “*parens patriae*” or parent of the state in which the state has the power to intervene on behalf of those who must be protected and cared for (Karp & Wood, 2007). This process is governed by individual state law in which a court appoints someone (a guardian) to have authority over the decisions for another (a ward or respondent) who has been determined either totally or partially incompetent or lacking capacity (Millar, 2007). Guardianship is commonly divided in two basic forms: limited or partial guardianship and plenary guardianship. A “limited or partial guardianship” is one in which the court has found that there are only specific areas in which an adult does not have the capacity or competence to make decisions. For example, an individual may be under a “limited or partial guardianship” for entering into legal contracts or making decisions about finances, but the individual retains the right to make decisions in all other areas. A “plenary guardianship” or “full guardianship” is one in which the court has decided that a person does not have the capacity to make “legal” decisions.

Although this may seem quite extreme, plenary guardianships are much more common than limited guardianships for individuals with disabilities. For example, Millar and Renzaglia (2002) examined 221 court files in Michigan and found that full guardians for individuals with intellectual disability were appointed in more than 54% of the cases. The study also noted that the distinction between full and partial guardianship was minimal. Another study (Teaster, Wood, Lawrence, & Schmidt, 2007) found that courts awarded limited or partial guardianship in only 10% of the public guardianship cases examined. Still another found that plenary guardianships were ordered in more than 87% of cases reviewed (Lisi, Burns, & Lussenden, 1994).

More recently, Payne-Christiansen and Sitlington (2008) conducted a qualitative study of transition and guardianship. They found that planning for guardianship was separated from the transition planning process

and that full guardianship had become the default option for every student with an intellectual disability in the educational program they examined. Both of these findings have implications for individuals with disabilities and their ability, and others' perceptions of their capacity, to live a self-determined life. One obvious consequence of the appointment of even a partial or limited guardian is the removal of rights from the person. (Hence, the undoing of a guardianship is called restoration of rights.) Another potential consequence is the stigmatization and value judgments imposed on the person found incompetent or incapacitated. At its core, guardianship is too often sought based on the assumption of a lack of "capacity" and can be seen as a restrictive form of adult support (Millar, 2014).

What Is Supported Decision Making?

Supported decision making incorporates a range of models, all of which allow the individual with a disability to retain the final say in her or his life. Under supported decision-making models, adults with disabilities, as all of us do, get help in making decisions, but they retain control over who provides that help, and what the ultimate decisions will be. Supported decision-making models for adults with disabilities can range from highly structured forms such as micro-boards to simple informal consultation with appropriate individuals (Martinis, Blanck, & Gonzalez, 2015). In general, it is an individualized process where people with disabilities use trusted friends, family members, or professionals to give them the help they want and need to understand the situations they face and so they can make their own decisions (Blanck & Martinis, 2015; Quality Trust for Individuals With Disabilities, 2013). Most adults with disabilities are able to enter into an agreement for supported decision making even if the law would not otherwise recognize them as having the "capacity" to enter into a contract.

A supported decision-making agreement is not a contract so much as it is an authorization. The adult authorizes another to be the person to advise and consult with them. If at some point that relationship does not work, the adult can choose another person to serve in that role. Salzman (2010) described supported decision-making models as having four primary characteristics: (a) The individual retains legal decision-making authority, (b) the relationship is freely entered into and can be terminated at will, (c) the individual actively participates in decision making, and (d) decisions made with support are generally legally enforceable.

There has been some criticism of supported decision-making models (e.g., Kohn & Blumenthal, 2014; Kohn, Blumenthal, & Campbell, 2013) because there has been little published empirical validation in terms of process or outcomes. However, this same criticism could be made regarding the formalized decision-making processes and outcomes of current legal guardianship practices. We could not identify any research to support the positive outcomes of guardianship and people with disabilities. In fact, Moye et al. (2007) found that, in some states, guardianship cases were made with nearly two thirds of the written evidence being illegible, descriptions of functional deficits were often missing, information about the individual's key values and preferences was almost never provided, and individuals were rarely present at the guardianship hearings. Millar (2003) in a review of 221 court files found similar issues with the guardianship process. Often, the decision was based primarily on a disability label, and the evidence used to prove a lack of capacity was unclear. There is simply a lack of research regarding the process and outcomes of any form of guardianship or less restrictive alternatives. Without any evidence base to support guardianship, it seems there is a responsibility to default to systems of support that are less restrictive options.

Concerns About the Use of Guardianship

Research has consistently shown that people with disabilities who exercise greater self-determination have improved employment and quality of life, are better problem solvers, and are better able to resist and avoid abuse (Khemka, Hickson, & Reynolds, 2005; Schur, Kruse, & Blanck, 2013; Wehmeyer & Schwartz, 1998). Nevertheless, the estimated number of adults under partial or total guardianship in the United States has tripled from 0.5 to 1.5 million since 1995 (Reynolds, 2002; Schmidt & Winsor, 1995; Uekert & Van Duizend, 2011). Guardianship can result in the loss of people's right to make decisions affecting their lives,

which in turn can negatively affect their quality of life. As famously stated by Representative Claude Pepper (1987),

The typical ward has fewer rights than the typical convicted felon . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. (p. 1)

People placed under guardianship may experience “low self-esteem, passivity, and feelings of inadequacy and incompetency” that “set up expectancies of failure . . . [and] diminish subsequent performance” (Winick, 1995, p. 15). For example, Millar (2009) found that students without guardians had more Individual Education Program (IEP) objectives focused on promoting and supporting self-determination. There were also differences in the number and quality of objectives related to employment, transportation, and self-care.

Parents may seek to become their child’s guardian on someone else’s recommendation or with the belief that they need to do so to protect their child or be able to provide long-term support. Few people providing this advice understand the far-reaching consequences of imposing guardianship on an individual. Millar (2007) found that the majority of students, parents, and special education teachers in her study said that they perceived that they exhibited or promoted self-determination, but that they did not recognize the disconnect between self-determination and guardianship, and most critically, the participants had very little understanding of the implications of guardianship or its alternatives. Compounding the issue, the transition planning process for young people with disabilities nearing adulthood can default to guardianship, without training on, or discussion of, the many preferable approaches available. In fact, some of the only published literature regarding guardianship and people with disabilities not only recommends health and social workers to advocate for full guardianship of people with disabilities but also presents a process where the professional can influence the process (Downes, 1992).

In another example, the practice of transferring rights seems to have become embedded in the transition process of IEP online computer support systems. In some IEP software programs used for IEPs to support millions of public school students with disabilities, information relating to guardianship is included in transition process forms (i.e., an age of majority form) and does not offer alternatives to full or partial guardianship to parents, and as previously described, the differences between full and partial guardianship for individuals with disabilities are often indistinguishable (Millar, 2007). Although the evidence indicates that the transition process seems to default to guardianship, parents and professionals are often unaware of the long-term consequences of imposing guardianship on a child or adult. For example,

- What if the only long-term option once parents are deceased is for the “ward” to be appointed a guardian by the court, who may be a stranger to the person or even be a company?
- What if the appointed guardian does not care if the person is happy and only considers “best interests” as they perceive it? In many states, guardians are not even required to know or ever meet their “ward.”
- What if the person wants to determine where and with whom to live?
- What is the impact of guardianship on the individual who wants to have his or her own business? Who wants to get married and take on other adult responsibilities?

Other long-term implications of guardianship are seldom discussed and often not considered. For example, undoing of guardianship is unlikely, very difficult, and seldom occurs. Second, a person whose parents are appointed guardian will likely outlive those parents by a full generation (30-35 years). Guardianship also outlives the parents: After the death of the parent, a new guardian will be appointed. Therefore, it is possible that a total stranger will ultimately become the person’s guardian, even if the family has planned for successors. Fundamentally changing the nature of their relationship with their child is not what parents typically envision or seek. Yet, by becoming a guardian, they are inviting the government, in the form of the court, into their relationship with their child. From that point forward, parents will need to report to the court to continue in that role. The court is now potentially the most powerful party in this three-way relationship.

Advocates, parents, and adults with disabilities question the use of guardianship—especially as a legal model of first resort. Many believe that to recognize and respect the right of people with disabilities to be self-determined in their own lives, alternatives to guardianship need to be better developed and used. Both law and policy already encourage self-determination and community integration (e.g., ADA, 1990; Developmental Disabilities and Bill of Rights Act, 2000; *Olmstead v. L.C.*, 1999; Rehabilitation Act of 1973). Admittedly, too little is known about supported decision-making outcomes, but even its critics agree that supported decision making has the potential to be a less restrictive alternative to the current structure of guardianship (Kohn & Blumenthal, 2014; Kohn et al., 2013).

This study attempts to capture a current snapshot of guardianship and people with disabilities. It is framed around four primary research questions.

Research Question 1: What is the prevalence of guardianship among people with disabilities?

Research Question 2: What information was presented to respondents on the range of adult support options for people with disabilities?

Research Question 3: What influence did the disability label have related to what guardianship alternatives were discussed?

Research Question 4: Did educational placement have any impact on guardianship recommendations?

To date, the authors could only identify four data-based articles (i.e., Millar, 2008, 2009; Millar & Renzaglia, 2002; Payne-Christiansen & Sitlington, 2008) that have described guardianship-related issues for people with disabilities, and none has looked beyond a state level at guardianship issues relating to individuals with disabilities.

Method

Respondents

The study was conducted with the support of the TASH Human Rights Committee and the Alliance to Prevent Restraint, Aversive Interventions, and Seclusion (APRAIS). APRAIS is a collaboration among 31 advocacy organizations primarily focused on the elimination of restraint and seclusion in schools, but whose collective and individual member organizations all have a stake in issues relating to guardianship. We used convenience sampling to identify participants for the survey. Specifically, target participants for the study were parents and guardians of individuals with disabilities or individuals with disabilities who were affiliated with the myriad organizations that comprise APRAIS. We used methods similar to the survey conducted by Westling, Trader, Smith, and Marshall (2010) of the use of restraint and seclusion and its impact on students with disabilities. In this study, all participants were either (a) contacted by an advocacy organization by email with a request to participate in the study, (b) saw a notice of the study on an APRAIS member's organization website, or (c) learned about the study because information was forwarded to them by email from someone aware of it. Like many online surveys, the total number of potential participants who were aware of the survey cannot be accurately determined. However, on the basis of the Westling et al. article, and membership in the APRAIS organizations and the potential for emails to have been forwarded to various other stakeholders regarding this survey, the authors estimate that between 10,000 and 20,000 individuals may have been aware of the survey. This represents a fraction of the 1.5 million Americans who have guardians, although it is unclear how many of these individuals have a disability. Before beginning the questionnaire, participants were informed in an introductory webpage that their responses would be anonymous. The online survey tool did not store any identifying information that could be linked to any single or set of responses. The survey had respondents from 48 states, the District of Columbia, and several respondents who were not in the United States. A total of 2,051 respondents started the survey, and 1,225 respondents completed the entire survey.

Survey Design

We developed a 13-item web-based survey that was hosted by Qualtrics, a commercial web-based survey research program. The survey questions were provided by the TASH human rights committee and several

guardianship advocates. Prior to distributing the survey, each author reviewed the survey for language use, organization, clarity, and relevance, and provided suggestions to improve the content and design of the survey. Suggestions and comments regarding survey content were incorporated into a final survey. We also incorporated Qualtrics skip logic into the final design of the survey. Skip logic is a survey design feature that allows the online survey to send respondents to future points or to the end of the survey based on predetermined question conditions. For example, if a respondent indicated that he or she was under 18, the survey skipped to a confirmation page, and then to the closing page of the survey. Similarly, if a respondent indicated that guardianship or conservatorship was not recommended, the survey skipped forward to questions about special education services and skipped all questions relating to who recommended guardianship or what kind was recommended. As can be seen in Table 1, some of the questions offered multiple choices and allowed the respondent to check one or more of the choices from a list. Other questions allowed for open-ended responses and numbers for ages. Some questions allowed respondents to both check several boxes and enter open-ended information under an "other" category. Qualtrics also allowed us to look at a single response as a filter for responses to other questions. For example, we could look at a single disability category and see what guardianship recommendations were made to individuals with the specified categorical label. Finally, we used the Flesch–Kincaid Grade Level Formula (<http://www.readability-score.com>) to determine reading level and accessibility of the survey. The survey cover letter was written at just over a sixth-grade reading level, and the questions were written at between seventh- and eighth-grade reading levels.

To access the survey, respondents were asked to click on a uniform resource locator (URL) provided in an email or posted on a website. When respondents accessed the survey, they were directed to a letter of information page that described (a) the reason for the survey, (b) how the survey worked, (c) right to refuse to participate, (d) contact information, and (e) confidentiality information. Finally, the Qualtrics data collected were stored on multiple secure data servers to ensure protection and security that exceed Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) requirements. The only way to access results was to use a username and password protected portal.

Data Collection

When the final form of the survey was completed and pilot tested, a URL was emailed to all of the APRAIS member organizations by the fourth author. As in Westling et al. (2010), the survey was accessed by respondents through the URL link that was embedded in the email sent to them by their APRAIS organization or by going to the organization's website and clicking on the URL. It is likely that APRAIS member organizations forwarded the email announcement of the survey or the URL link to other parents or to parent or advocacy organizations to seek a greater number of responses. Thus, as noted previously, the respondents (who were not able to be identified by their responses) likely included persons beyond the individual affiliates of the APRAIS member organizations.

Data Analysis

All the data collected were descriptive including the number and percentage of different responses to an item or numbers entered in response to specific questions, as shown in Table 1. We also analyzed the types of guardianship recommendations based on who first recommended guardianship (Figure 1), Individuals with Disabilities Education Act (IDEA) disability category (Figure 2), and the amount of time an individual received educational services in inclusive settings (Figure 3). Interobserver agreement (IOA) was conducted on 32% of the coded responses (Questions 5, 8, 9, 10). Two of the authors independently coded open-ended answers for common themes. After creating a common coding system for each response based on recurring categories of responses, two authors independently coded the responses. IOA was calculated by dividing the total number of agreements by the number of agreements possible and multiplying by 100. IOA was more than 92% for the four questions that included open-ended responses.

Table 1. Questionnaire Items and Responses.

Questionnaire items	Response options	Response	Percentage
1. Which best describes you?	Person with a disability	156	13
	Parent	1,069	87
	Total	1,225	
2. Are you or the person you are answering for above 18?	Yes	1,119	91
	No	106	9
	Total	1,225	
3. Do you or the person you are answering for have a court-appointed guardian?	Yes	447	37
	No	754	63
	Total	1,201	
4. Was guardianship or conservatorship recommended to you?	Yes	282	37
	No	472	63
	Total	754	
5. Who first suggested guardianship or conservatorship to you? (suggested options)	School personnel	173	*
	Adult or social service personnel	155	*
	Attorney	99	*
	Medical professional	85	*
	Family friend or family member	156	*
	Life insurance agent or salesperson	3	*
	Special needs trust/financial advisor	72	*
	Judge or other court personnel	21	*
	Other (please specify)	195	*
	Total answering question	726	
6. Did the recommendation include information about (check all that apply):	Alternatives to guardianship and what those alternatives could be	216	*
	Full guardianship	439	*
	Limited guardianship	287	*
	Power of attorney	205	*
	Supported decision making	140	*
7. If guardian was appointed, at what age was the appointment made?	Total answering question	568	
	M	21.5	
	Mode	18	
	Median	18	
	Range	88	
8. Did you receive any training or education related to guardianship?	Total answering question	501	
	Yes	302	42
	No	421	58
9. Briefly describe the training or education you received related to guardianship in the space below. [OK]	Total	723	
	Total	308	
10. Who provided the training or education related to guardianship?	School personnel	3	1
	Adult or social service personnel	28	9
	Attorney	96	31
	Medical professional	1	0
	Friend or family member	9	3
	Life insurance agent	0	0
	Special needs trust/financial advisor	13	4
	Judge or other court personnel	30	10
	Other	125	41
Total	305		

(continued)

Table 1. (continued)

Questionnaire items	Response options	Response	Percentage
11. Did you or your child receive special education services?	Yes	979	82
	No	222	18
	Total	1,201	
12. Under which Individuals with Disabilities Education Act (IDEA) category of disability was special education provided?	Autism	355	*
	Deaf-blindness	14	*
	Deafness	7	*
	Developmental delay	272	*
	Emotional disturbance	75	*
	Hearing impairment	33	*
	Intellectual disability	397	*
	Multiple disability	188	*
	Orthopedic impairment	72	*
	Other health impairment	151	*
	Specific learning disability	69	*
	Speech and language impairment	205	*
	Traumatic brain injury	25	*
	Visual impairment, including blindness	54	*
Did not receive special education services	5	*	
Total	979		
13. Where did you/your child receive the majority of their education services?	In the general education/ community-based setting for more than 80% of the time	376	38
	In the general education/ community-based setting for more than 60% of the time	124	13
	In the general education/ community-based setting for more than 40% of the time	81	8
	In the general education/ community-based setting for less than 40% of the time	101	10
	In the general education/ community-based setting for less than 20% of the time	297	30
	Total	979	

Note. Asterisk indicates percentage was not calculated as respondents could select multiple response items.

Results

A total of 2,051 respondents started the survey, and 1,225 respondents completed the entire survey. Discussion will be limited to the completed surveys. One hundred fifty-six (13%) individuals reported that they were a person with a disability, and 1,069 (87%) individuals reported that they were a parent of a person with a disability. A total of 1,119 (91%) respondents indicated they were above 18, and 106 (9%) indicated they were below 18. If a respondent indicated he or she was under the age of 18, the survey automatically skipped to a confirmation question. All but 24 of these 106 responses were changed, and the individual confirmed he or she was above the age of 18 and redirected to Question 3. Respondents who were not above 18 ($n = 24$) were directed to the closing page of the survey and could not complete a survey.

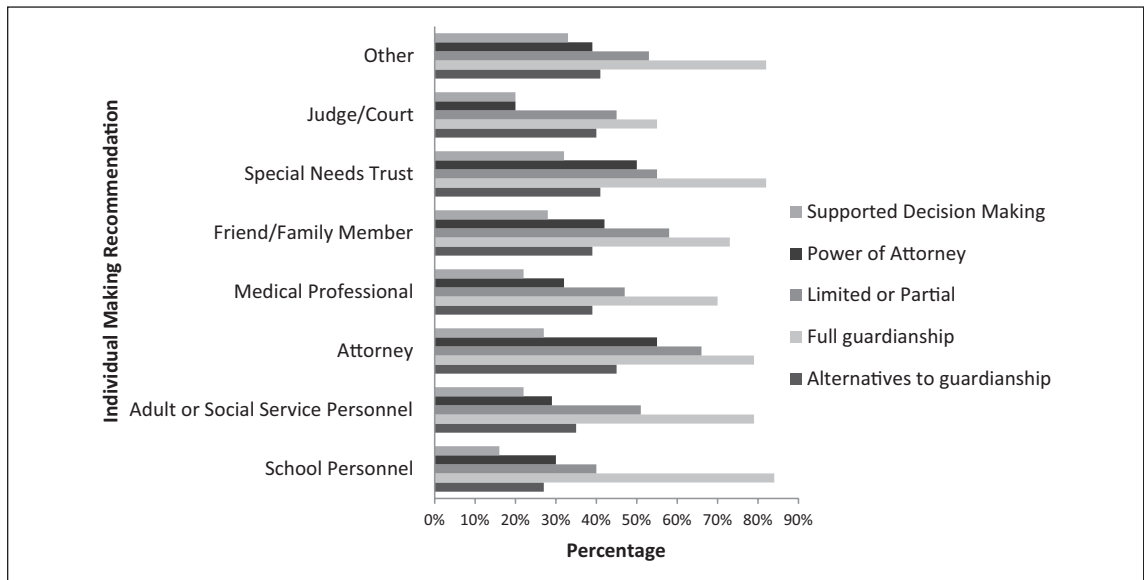


Figure 1. Guardianship recommendations by who first recommended guardianship.

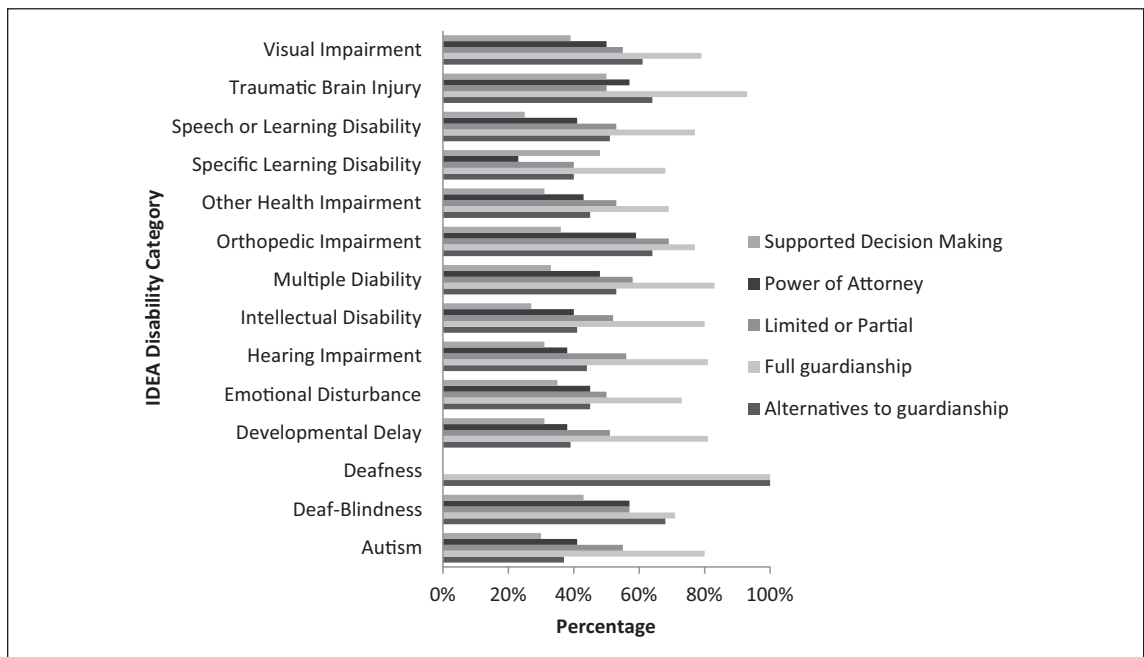


Figure 2. Guardianship recommendations based on IDEA disability category.

in accordance with the Institutional Review Board (IRB) approval. This resulted in a total of 1,201 surveys that included answers to all the questions.

When asked about whether the respondent or the person they were answering for had court-appointed guardianship, 447 (37%) indicated that they or the person they were answering for had a court-appointed guardian and 754 (63%) indicated that they or the person they were answering for did not have a court-appointed guardian. Respondents who indicated that they did not have a court-appointed guardian were

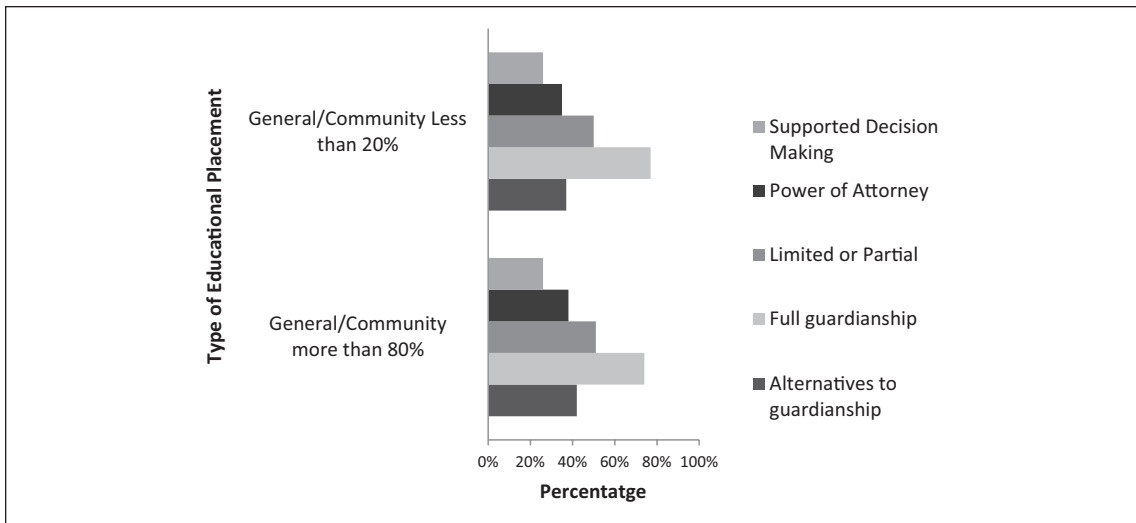


Figure 3. Guardianship recommendations by education placement.

asked to indicate whether guardianship was recommended to them. A total of 282 (37%) respondents indicated guardianship was recommended and 472 (63%) indicated it was not recommended. Respondents were also asked to indicate who first suggested guardianship/conservatorship and were provided with a list of suggested options from which they could select multiple options (so no percentages were calculated). One hundred seventy-three respondents indicated school personnel, 155 indicated adult or social service personnel, 99 indicated an attorney, 85 indicated a medical professional, 156 indicated a family friend or family member, 3 indicated a life insurance or sales agency, 72 indicated a special needs trust/financial advisor, 21 indicated a judge or other court personnel, and 195 indicated other individuals/entities. Selection of “other” allowed respondents to include a brief text response to explain who first suggested guardianship/conservatorship. The 195 “other” responses were coded, and 3 respondents indicated the suggestion came from a friend, 8 indicated an attorney or other court personnel made the suggestion, 26 indicated a disability advocate made the initial recommendation, 102 respondents reported coming to the decision on their own, 10 indicated health/medical professionals made the recommendation, 15 came from adult service agencies, 12 from parent groups, 2 indicated that it was fraud and no recommendation was made (e.g., “they filed behind our backs”), 2 indicated the initial recommendation came from education professionals, and there were 15 responses that were not coded as the answer did not fit the question (e.g., illegible typing, symbols).

We also examined the types of guardianship recommendation filtered by individuals who first suggest guardianship. As can be seen in Figure 1, the most common recommendation was full guardianship and the least common was supported decision making. In fact, there is a consistent pattern of the most restrictive form of guardianship being discussed the most frequently. For example, school personnel discussed full guardianship 84% of the time compared with 16% discussing supported decision making. Similarly, adult service personnel recommended full guardianship 79% of the time compared with 22% for supported decision making. As further data will illustrate, this was a consistent pattern: It does not matter who was making the recommendation, full guardianship was the most commonly discussed alternative, whereas supported decision and other less restrictive alternatives to guardianship were consistently the least discussed options.

We asked respondents to indicate what type of information was included in a specific guardianship recommendation. For this question, we provided a list of choices from which respondents could select multiple answers. Two hundred sixteen respondents indicated that alternatives to guardianship were discussed, 439 indicated full guardianship was discussed, 287 indicated limited guardianship was discussed, 205 indicated power of attorney was discussed, and 140 indicated supported decision was discussed. The average age of guardianship appointment was 21.5, the median and mode was 18, and the range was 88 ($r = 1-89$). Despite the wide range, the vast majority of the guardianship appointments were made at age 18.

A total of 302 respondents (42%) reported that they received training related to guardianship, and 421 (58%) reported that they did not receive training related to guardianship. Respondents who received training were asked to briefly describe the training or education they received. There were 308 initial responses to this question. Three respondents answered the question but did not enter a legible text response. The remaining 305 responses were coded according to the respondent description of the training or education; 5 (2%) answered they received school-related training; 96 (31%) indicated a combination of legal advice, advocacy organizations, and self-study; 72 (24%) responded they received legal information from a legal professional (e.g., attorney or court personnel); and 42 (14%) indicated their training consisted of an advocacy organization presentation or workshop. Forty-eight (16%) of the respondents indicated that they attended workshops or trainings, but it was unclear as to who was providing the training. Seventeen (6%) indicated they had arrived at the decision by themselves and what they had learned by themselves (e.g., self-taught through brochures, videos, books, online research). One (0.01%) respondent indicated he or she received training on medical aspects of guardianship, 2 (0.01%) indicated that they got information from their parents, and 5 (1%) indicated that they did not receive any training or were not interested in training. Seventeen (6%) additional responses could not be coded as they were not accurate answers to the question (e.g., descriptions of the guardianship process). What became clear as we analyzed these data was that it was impossible to identify with any certainty the actual content of the information or training based on the responses as most participants reported where or from whom they received training but did not describe what the content of the training consisted of.

Respondents were also asked to indicate who provided the guardianship training or education, if they received any. Three (1%) individuals indicated school personnel, 28 (9%) indicated adult or social service personnel, 96 (31%) indicated an attorney, 1 (0%) indicated a medical professional, 9 (3%) indicated friend or family member, 0 (0%) indicated life insurance agent or salesperson, 13 (4%) indicated special needs trust/financial advisor, 30 (10%) indicated judge or other court personnel, and 125 (41%) indicated other. The 125 other responses were reviewed, coded, and divided into response categories. Based on the review, 19 (5%) responses were classified as "other" because of response ambiguity; for example, the respondent listed a person's name, unknown abbreviation, or vague response such as "none." Of the remaining 106 responses, 34 (32%) respondents indicated an advocacy organization provided training, 23 (22%) indicated they received training from multiple sources (i.e., attorney, advocacy groups, self-study), 15 (14%) indicated they independently researched information about guardianship, 13 (12%) indicated adult or social service personnel provided training, 8 (7%) respondents indicated they received training from a workshop/conference, 5 (5%) indicated they received training by a state agency, 5 (5%) indicated they received training from an attorney, and 3 (3%) indicated school personnel provide training.

We asked respondents to indicate whether they or their child received special education and related services. A total of 979 respondents (82%) indicated either they or their child received special education services and 222 (18%) did not. We asked respondents who indicated they received special education and related services to identify the IDEA category under which special education was provided. Respondents could select multiple items. Of the 979 responses, the most common IDEA categories in which special education was provided were autism ($n = 355$), developmental delay ($n = 272$), intellectual disability ($n = 397$), and speech and language impairment ($n = 205$). We also examined guardianship recommendation filtered by these IDEA disability categories. As indicated in Figure 2, the most common recommendation across all disability categories was full guardianship and the least common recommendation was supported decision making.

Respondents were also asked to indicate whether they or their child received the majority of the education services in inclusive settings. Three hundred seventy-six (38%) indicated that they or the person they were answering for received services in general education/community-based settings for more than 80% of the day, and 297 (30%) indicated they received services in general education/community settings for less than 20% of the day. We examined guardianship recommendations filtered by these extremes of educational placement and did not find any substantial differences in recommendation based on an individual's educational placement. As can be seen in Figure 3, full guardianship was most commonly recommended, and supported decision making was the least common recommendation regardless of educational placement.

Discussion

This study attempted to address four basic research questions.

Research Question 1: What is the prevalence of guardianship among people with disabilities?

Research Question 2: What information was presented to respondents on the range of adult support options for people with disabilities?

Research Question 3: What influence did the disability label have related to what guardianship alternatives were discussed?

Research Question 4: Did educational placement have any impact on guardianship recommendations?

In response to the first research question, these data clearly indicate that individuals with disabilities are much more likely to have court-appointed plenary guardians than their peers without disabilities. In fact 37% of the respondents indicated they had/or were legal guardians, a rate only seen in guardianship literature related to the elderly. Data related to what information was presented to individuals/parents on the range of adult support options for people with disabilities suggest that full guardianship was the most commonly recommended option for individuals before, at, and after age of 18, whereas supported decision making was the least common recommendation. These data show that school personnel, adult or social service personnel, or attorneys first suggest guardianship in more than 50% of the cases. But, the data related to information provided during guardianship recommendations also suggest that it does not matter who provides the education and training, full guardianship was the most commonly discussed option and supported decision making the least. In addition, almost 60% of the respondents indicated that they had received no training or education related to guardianship. Respondents who did receive training were asked to describe what training they did have; the bulk of the responses indicated that what education/training they did receive came from legal professionals.

It was surprising that school personnel are not often identified as being involved in the training and education relation to guardianship. This is especially troubling given the mean and mode age of guardianship was shown to be at age 18 (school age) for individuals with disabilities in transition programs. Even when pulled out of the "combination" category, schools were only identified 12 times in the 305 responses as being a source of any information or education relating to guardianship in the transition process despite being identified as frequently being the professionals who initiate guardianship discussions. This is also surprising given IDEA 20 U.S.C. § 1400 (2004) requires that 1 year prior to a student with a disability reaching the age of majority, the IEP must include a statement that the student was informed of any rights that transfer to the student when he or she reached age of majority. As described, school personnel are identified as a primary source of an initial recommendation. In light of these data, it is troubling that schools are rarely identified as providing students or parents education or training relating to guardianship at this point.

In analyzing the data, it appears that when the child is approaching the age of 18, the school IEP process is often the first prompt for parents to seek out legal resources and information regarding guardianship. This finding is not surprising and provides further evidence that individuals with disabilities, families, and educational and legal practitioners need more education and training about the full range of issues that revolve around guardianship. Finally, we found that disability category and level of inclusion had no impact on the guardianship options discussed. Consistent with all the other data, it did not matter what disability label was assigned or whether an individual with a disability received primarily inclusive or segregated special education services. Full guardianship was the most discussed option, and supported decision making was discussed the least frequently in any training and with anyone conducting the training.

At the heart of this issue are assumptions about the capacity of individuals with disabilities. That is, guardianship is predicated on the premise that individuals lack decision-making capacity. However, this premise and the assumptions on which it is based are built upon age-old and often discredited ideological stigmas associated with people with disabilities. State mandates around determinations of guardianship assume that people identified with intellectual or developmental disabilities do not have the capacity to exercise their rights as an adult (Lisi et al., 1994; Millar, 2008). Therefore, states are exercising their "authority with less concern about the needs of persons with disabilities, focusing instead on society's desire to protect itself from those deemed 'dangerous' or merely different" (Salzman, 2010, p. 164). This is

not consistent with current best practices and the ADA's language about accommodating and supporting persons with disabilities.

In contrast, authentic person-centered planning focused on the teaching of self-determination, a proven and effective way to provide supports and assistance with decision making (Agran & Krupp, 2011; Browder, Bambara, & Belfiore, 1997; Mechetti & Garcia, 2003; Wehmeyer & Abery, 2013), has the potential to serve as a foundation for supported decision-making models. Previous research leads us to believe that decisions made through a self-determined model, where the person's allies and supporters (usually peers and family) support, accommodate, and assist, are more reliable than decisions made by a single court-appointed person, who, in some states, is not required to even meet with the individual. We suggest there needs to be an increased focus on research and information dissemination focused on the processes and outcomes of supported decision making as a model of adult support and individuals with disabilities. To that end, we have several recommendations for future practice and research related to guardianship and supported decision making:

1. Professionals, who work with people with disabilities as they approach the age of majority, and their families, must be trained to present the full range of options, including supported decision making, to parents and individuals with disabilities, and promote a perspective of supporting rather than removing individual rights.
2. There is a need for the development of supported decision-making standards and guiding principles that can be universally adopted.
3. Rigorous research into both the process and the outcomes of supported decision making for individuals with disabilities is needed. Without an evidence base to support them, less restrictive alternatives to guardianship are unlikely to be recommended.
4. Parents and people who work with young people with developmental disabilities need better resources to promote independence and autonomy. They need materials, resources, and guidance that include, but are not limited to, tools that provide the following:
 - a. Education and training for parents, self-advocates, and professionals with whom students with disabilities interact prior to age 18 on the ways in which guardianship can affect young adults with disabilities.
 - b. Supported self-determination models in school curriculums for *all* students, including education on financial management, medical decisions, career decisions, living arrangements, and entering into contracts.
5. There must be an identification of barriers to reform in current guardianship practices.
6. There must be viable alternatives to restoration of rights to "wards" now as well as those who are or may be facing guardianship determinations.

Limitations

There are a number of limitations that must be acknowledged in this study. First, Internet surveys have numerous issues including potential threats to data validity including the level of respondent accuracy in responses and the closed-ended questions may have a lower validity rate. In addition, individuals targeted to participate in the study included parents and guardians of individuals with disabilities, but because the survey was web-based and accessible to many individuals, it was not feasible to collect comprehensive demographic information on the actual participants. It was also impossible to calculate a response rate due to not knowing how many individuals had access to the survey. Finally, the survey results only describe the current status of guardianship and guardianship recommendations, they do not answer why or why not guardianship was sought, and what were the outcomes of any of the forms of adult support discussed.

Conclusion

Every person with a disability, regardless of the extent of the disability, or the perceptions regarding the extent of that disability, has the right to the same choices, opportunities, and civil liberties as any individual.

People who have a disability may express their preferences/choices/decisions in nontraditional ways. Any legal system or proceeding that deprives an individual of the right to be accommodated and supported in choosing and making decisions and appoints a substitute decision maker based on a test of capacity makes that person vulnerable and deprives him or her of the right to self-determination and other civil liberties. Future research and policy must strive to find ways to promote supported decision making and provide accommodations and support to people with disabilities, so that they may maintain both their individual rights and the opportunity to live a self-determined life.

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Author Biographies

J. Matt Jameson Dr. Jameson's primary research interests include instructional strategies and inclusive educational procedures for students with significant cognitive disabilities. He has authored and coauthored articles focused on the provision of a free and appropriate public education, instructional strategies used to support students in inclusive settings, and evaluations of distance education and teacher preparation programs.

Tim Riesen is a research assistant professor in the Department of Special Education and Rehabilitation at Utah State University. He completed his education at the University of Utah where he specialized in transition, developing employment supports, and community-based service delivery for individuals with moderate to severe disabilities.

Shamby Polychronis is an associate professor in the Special Education Program at Westminster College in Salt Lake City, Utah and serves as the Director of Special Education and Undergraduate Programs. She has experience teaching students with severe disabilities in post-high programs with an emphasis on community-based education

Barbara Trader is the executive director of TASH, a leader in advancing inclusive communities through research, education, and advocacy. TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.

Susan Mizner is Disability Counsel for the ACLU. From 2003–2012 she was the Director of the San Francisco Mayor’s Office on Disability. Prior to that she worked with homeless people with disabilities as an Echoing Green fellow. She has been a member of the disability community for more than 20 years and is a graduate of Yale College and Stanford Law School.

Jonathan Martinis has over 20 years’ experience representing people with disabilities in cases under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act, Medicaid and the Constitution of the United States. He represented Jenny Hatch in the “Justice for Jenny” case – the first case to hold that a person with disabilities has a right to engage in Supported-Decision Making instead of being under a guardianship.

Dohn Hoyle is Executive Director of The Arc of Michigan and long-time advocate for the rights of people with disabilities. A respected leader and innovator in the disability movement, Dohn helped to rewrite the Michigan Mental Health Code to include person-centered planning and to eliminate the term “mental retardation.” He was instrumental in the closure of specialized nursing homes for children and people with developmental disabilities, and the Regional Centers for People with Developmental Disabilities in his state.