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SIBLINGS OF ADULTS WITH INTELLECTUAL DISABILITIES: THEIR  
PERSPECTIVES ON GUARDIANSHIP AND ITS ALTERNATIVES

by

Anna M. Brady

A dissertation submitted in partial fulfillment  
of the requirements for the degree

of

DOCTOR OF PHILOSOPHY

in

Disability Disciplines

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Logan, Utah

2017

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## ABSTRACT

Siblings of Adults with Intellectual Disabilities: Their Perspectives On  
Guardianship and Its Alternatives

by

Anna M. Brady, Doctor of Philosophy

Utah State University, 2017

Major Professor: Keith Christensen, Ph.D.  
Department: Special Education and Rehabilitation

Adult siblings of people with intellectual and developmental disabilities (IDD) are often on the front lines of supporting their brothers and sisters with IDD through caregiving and guardianship roles after their parents pass away. However, these siblings are often uninformed or under informed about ways that they can support their brothers and sisters. This study had the following three purposes: to determine what adult siblings of adults with IDD know about guardianship and its alternatives; to explore how adult siblings view guardianship and its alternatives; and to explore what adult siblings think about their role of being a guardian or supported decision maker for their brother/sister with IDD. Ten adult siblings who had brothers and sisters with IDD were interviewed; their interviews were analyzed using a combination of grounded theory and directed analysis. This study found that siblings had a limited knowledge of guardianship and its

alternatives, viewed guardianship as necessary, and desired to be involved in future planning and decision making supports with their brother or sister in adulthood. These findings have several implications for future research, as well as for schools and disability service agencies. For example, siblings' limited knowledge about guardianship and its alternatives highlights the need for schools, disability agencies, and other disability organizations to better inform families about the full range of options available to support people with IDD in making decisions. Likewise, as the sibling participants were concerned about their brother and sister's decision-making abilities, there is a need for better training of people with IDD in self-advocacy and self-determination skills. Finally, as this study had a small sample size and the participants' demographics were relatively homogenous, future research with more diverse and larger sample sizes is needed.

(172 pages)

## PUBLIC ABSTRACT

### Siblings of Adults with Intellectual Disabilities: Their Perspectives On Guardianship and Its Alternatives

Anna M. Brady

Adult siblings of people with intellectual and developmental disabilities (IDD) are often on the front lines of supporting their brothers and sisters with IDD through caregiving and guardianship roles after their parents pass away. However, these siblings are often uninformed or under informed about ways that they can support their brothers and sisters. This study had the following three purposes: to determine what adult siblings of adults with IDD know about guardianship and its alternatives; to explore how adult siblings view guardianship and its alternatives; and to explore what adult siblings think about their role of being a guardian or supported decision maker for their brother/sister with IDD. Ten adult siblings who had brothers and sisters with IDD were interviewed; their interviews were analyzed using a combination of grounded theory and directed analysis. This study found that siblings had a limited knowledge of guardianship and its alternatives, viewed guardianship as necessary, and desired to be involved in future planning and decision making supports with their brother or sister in adulthood. These findings have several implications for future research, as well as for schools and disability service agencies. For example, siblings' limited knowledge about guardianship and its alternatives highlights the need for schools, disability agencies, and other disability organizations to better inform families about the full range of options available to support

people with IDD in making decisions. Likewise, as the sibling participants were concerned about their brother and sister's decision-making abilities, there is a need for better training of people with IDD to be able to make and express their choices in a variety of situations. Finally, as this study had a small sample size and the participants' were all White, future research with more diverse and larger sample sizes is needed.

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Anna M. Brady



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# CHAPTER I

## INTRODUCTION

### Importance of the Problem

Each day, people are confronted with a variety of choices—options about how to spend one’s time and money, as well as whom to associate with. These decisions, as well as larger decisions, such as choosing one’s housing, life partners, educational options, and employment, are fundamental human rights (United Nations, 2006). Two key skills involved in exercising these fundamental rights are self-advocacy and self-determination. Self-determination is the ability to make and express choices, and self-advocacy is the ability to assert one’s rights and to exert control over one’s life (Ryan & Deci, 2001; Test, Fowler, Wood, Brewer, & Eddy, 2005). Specifically, individuals who self-advocate understand their needs and interests and take the initiative in communicating these to others in a variety of contexts. Miller and Keys (1996) suggest that individuals who self-advocate can move from being passive recipients of discrimination to becoming more respected citizens within society. Self-advocacy and self-determination skills allow individuals with disabilities to gain access to and regulate their environments (Balcazar, Keys, Bertram, & Rizzo, 1996).

Research has repeatedly shown that self-determination and self-advocacy are foundational skills for increasing a person’s quality of life (e.g., Abery, Rudrud, Arndt, Schauben, & Eggebeen, 1995; Algozzine, Browder, Karvonen, Test, & Wood, 2001; Deci & Ryan, 1991; Millar, 2013; Miller & Keys, 1996; Roberts, Ju, & Zhang, 2016;

Ryan & Deci, 2001; Wehmeyer & Schwartz, 1998). Moreover, these skill sets are essential to adults with intellectual disabilities' everyday happiness, livelihood, and well-being (Wehmeyer & Schwartz, 1998). Importantly, many adults with disabilities have demonstrated high levels of self-advocacy and self-determination skills in areas such as health care (Bollman, Davis, & Zarcone, 2009), rights violations (Kramer, Roemer, Liljenquist, Shin, & Hart, 2014), and person-centered planning meetings (Mazzotti, Kelley, & Coco, 2015). Nevertheless, research indicates that individuals with intellectual disabilities (ID) have historically had limited opportunities to exert control over their lives (Miller & Keys, 1996).

### **Context and Significance of the Problem**

Despite the fact that adults with intellectual disabilities have repeatedly demonstrated high levels of self-advocacy and self-determination, historically, they have been discriminated against and often denied access to residential, educational, and employment settings of their choice (Friend, 2006; Linton, 1998; Miller & Keys, 1996; United States Commission on Civil Rights, 2000). While legislation in the last few decades has made it illegal for blatant discrimination against people with disabilities in residential, educational, and employment settings (e.g., IDEIA; ADA of 1990/2010), people with disabilities' decisions and preferences remain subtly ignored or completely disregarded (Salzman, 2010; Werner & Chabany, 2015). Specifically, individuals with disabilities who are placed under guardianship essentially no longer have their right to make decisions that are honored by others, such as their housing or medical preferences

(Blanck & Martinis, 2015; Millar, 2014; Salzman, 2010), an often unintentional form of discrimination. Indeed, in many states, individuals under guardianship are denied many rights as citizens of the U.S., such as voting and marriage (Center for Family Involvement, 2015; Millar, 2014).

In light of the shortcomings of the current guardianship system in the U.S., alternatives to guardianship should be considered and implemented. Unfortunately, research repeatedly indicates that full guardianship is most often used instead of less restrictive alternatives (e.g., Blanck & Martinis, 2015; Millar, 2014; Wright, 2004), which leads to unintentional discrimination. Moreover, a recent survey of over 1,000 parents of people with intellectual and developmental disabilities (IDD) revealed that most parents were not familiar with any available options besides guardianship (Jameson et al., 2015), which also leads to unintentional discrimination. This study also showed that the majority of these parents did not receive adequate training or information about guardianship. Parents' overall lack of information about guardianship alternatives is concerning, particularly because many parents have an expectation, either spoken or unspoken, that their child with IDD will eventually be cared for by his/her typically developing siblings when they, the parents, can no longer provide the caregiving and guardianship needed (Bigby, 1998; Coyle, Kramer, & Mutchler, 2014; Dew, Llewellyn, & Balandin, 2004).

Other studies that have specifically asked adult siblings (hereafter referred to as "sibling") of people with IDD (hereafter referred to as "brother" or "sister") about future caregiving plans have also found that these siblings expect to, and often do, take on

caregiving and guardianship roles (Burke, Taylor, Urbano, & Hodapp, 2012; Greenberg Seltzer, Orsmond, & Krauss, 1999; Rossetti & Hall, 2015). Not only do adult siblings take on these roles, but these siblings are also important advocates for disability rights (Burke, Arnold, & Owen 2015). However, many studies have found that adult siblings are uninformed or under informed of ways that they can support their brothers and sisters, such as navigating the adult service system (e.g., Arnold, Heller, & Kramer, 2012; Burke et al., 2012; Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Therefore, it is imperative that these siblings are well informed about the benefits of alternatives to guardianship. Moreover, as siblings are often on the front lines of supporting their brothers and sisters after their parents pass away (Burke, Fish, & Lawton, 2015; Greenberg et al., 1999; Taylor, Burke, Smith, & Hartley, 2016), these siblings are important stakeholders in discussions on alternatives to guardianship. Thus, it is essential that siblings are informed of guardianship alternatives so that they can advocate for and support their brothers and sisters. Currently, more exploration of adult siblings' knowledge and perspectives about guardianship and related alternatives is needed.

### **Research Questions**

The purpose of this study is to determine what adult siblings of adults with intellectual disabilities (ID) know about guardianship and its alternatives. A secondary purpose is to explore the perspectives and opinions of adult siblings of adults with ID about guardianship and its alternatives. A third purpose is to explore what adult siblings of adults with ID think about their role of being a guardian or supported decision maker



for their sibling with ID.

### **Definition of Key Terms**

*Advanced medical directive:* This is a type of supported decision-making where a person with a disability can designate a person to make their medical decisions. These advanced medical directives can be specific to end-of-life decisions or allow for another person to make to daily medical decisions on behalf of the person with a disability (Riggle, personal communication, August 5, 2016; Autistic Self Advocacy Network, n.d.).

*Autonomy:* Broadly, this is exercising one's personal freedoms and choices. It is an essential component of decision-making, and is part of the broader concept of self-determination (Blanck & Martinis, 2015; Henry, 2015).

*Beneficence:* This is actively doing good for someone else; it is one of the ethical principles that is often used to justify guardianship (Blanck & Martinis, 2015; Henry, 2015).

*Brother/sister:* For the purposes of this study, brother or sister will refer to the individual with an intellectual disability (Taylor et al., 2016).

*Capacity:* Capacity is most often defined as an individual's cognitive ability to make a specific decision. Regarding guardianship, capacity to make the following types of decisions is often under scrutiny: health care; personal and home management; and financial administration (Moye & Naik, 2011).

*Capacimeter:* This is a tool (such as rating scales, questionnaires, or other written

tests) that attempts to quantify an individual's capacity in order to determine whether or not a person is competent to make his/her own decisions (Kapp & Mossman, 1996).

*Caregiver:* In a study of adult siblings, Burke et al. (2012) outlined the following five domains of caregiving: “residential arrangements, financial arrangements, legal guardianship, interacting with the service system, and providing companionship and emotional support” (p. 37). Three levels of responsibility for each category are: primary responsibility, shared responsibility, or someone else (not the sibling) will be responsible.

*Competence.* Competence, when referring to guardianship, means an individual's aptitude to perform a certain task, specifically to make a decision and/or care for him/herself (Berg, Appelbaum, & Grisso, 1996; Millar, 2014).

*Conservatorship:* This term means different things depending on the state of residence. For example, in Utah, conservatorship is a type of supported decision making agreement that only covers finances, and these agreements can be written with varying degrees of control, ranging from a person with disabilities being allowed to make financial decisions up to a certain dollar amount, to a person with disabilities giving all their financial control to another (Riggle, personal communication, August 5, 2016; Utah Disability Law Center, 2016). However, in other states, conservatorship is synonymous with full guardianship and is often used to describe guardianship of an elderly person (Cornell University of Law, n.d.).

*Developmental disability (DD):* “A group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a

person's lifetime" (Center for Disease Control [CDC], 2016). Common developmental disabilities include: attention-deficit/hyperactivity disorder, autism spectrum disorder, cerebral palsy, fetal alcohol syndrome, Fragile X syndrome, and Tourette syndrome. (CDC, 2016).

*Guardianship:* In general, two types of guardianship are available in the U.S.: full or limited. Full guardianship occurs when the guardian makes all types of decisions for the person placed under guardianship, whereas in limited guardianship, the guardian only makes decisions for certain areas such as healthcare or finances (Jameson et al., 2015; Autistic Self Advocacy Network, n.d.).

*Intellectual Disability (ID):* "A disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD website, 2013).

*Power of attorneys (POAs):* POAs are documents that can be narrowly or broadly defined and can be specific to certain areas, usually financial or health care (Millar, 2013; Riggle, personal communication, August 5, 2016; Autistic Self Advocacy Network, n.d.; Yarbrough, 2011). POAs give someone else the right to make legally binding decisions for you. More than one person can be designated as a POA (e.g., an individual can designate one person for a POA health care and a different person for a financial POA). Additionally, multiple people could be appointed as a joint POA, but they must be in agreement on the decisions (Cornell University of Law, n.d.). Any individual with a disability can arrange a POA, as long as s/he has the legal capacity to do so.

*Representative payees or authorized representatives.* These are arrangements made with the Social Security Administration that designate a specific person to receive and manage a person with disabilities' disability benefits (Yarbrough, 2011).

*Self-advocacy.* This is the ability to assert one's rights and to exert control over one's life. This is composed of four key components: knowledge of self, knowledge of rights, communication, and leadership (Test et al., 2005).

*Self-determination.* This is the process of a person exerting control of his/her own life (Ryan & Deci, 2001).

*Shared decision-making contract.* An agreement where a person with a disability designates another person to help him/her make decisions, while the person with the disability remains the ultimate authority in final decisions (Riggle, personal communication; August 5, 2016).

*Sibling.* While no clear definition of sibling exists in the current literature, for the purposes of this study, "sibling" is defined as a typically developing brother or sister who grew up in the same household as a brother or sister with disabilities (Taylor et al., 2016).

*Supported decision making (SDM).* This is one proposed guardianship alternative that Texas legally recognized in 2015. SDM gives a person with a disability the opportunity to consult friends and family members whom s/he trusts to help him/her comprehend the situation at hand. Unlike guardianship, where the guardian has the final say in any and all decisions, in SDM, the person with the disability makes the final decision (Blanck & Martinis, 2015; Jameson et al., 2015). Under Texas law, any adult who is 18 or older can enter into a SDM agreement. Texas is currently the only state that

legally recognizes SDM (Autistic Self Advocacy Network, n.d.), though Delaware is in the process of legally recognizing SDM as an option for people (Supported Decision Making Network, n.d.).

### **Summary**

This chapter provided an overview of the problem that this study will address, provided context for the problem, identified the purpose and research questions, and provided definitions of key terms. Chapter II provides a review of relevant literature, including an overview of guardianship and its alternatives, current research on adult siblings of people with ID, and how this information applies to individuals with developmental disabilities. Chapter III describes the methodology used in this study, explains the participants' profiles, and gives an overview of the grounded theory approach when combined with the directive approach utilized for the qualitative coding. Chapter IV presents the results of the interviews arranged according to three main themes. Last, Chapter V provides a discussion of the findings, implications, and future research recommendations.

## **CHAPTER II**

### **LITERATURE REVIEW**

In order to understand the current U.S. system of guardianship and guardianship alternatives, it is important to know the historical background and current context surrounding guardianship and its alternatives. Also, as adult siblings of people with ID often take on caregiving roles, including guardianship, current research on these siblings will be discussed.

#### **Protecting People with Disabilities**

##### **Guardianship**

One of the main underlying assumptions that influenced the development of guardianship was the idea of protecting both people with disabilities and society. In the U.S., the current system of guardianship for adults with disabilities and adults who are aging is based on the English Commonwealth probate court (Blanck & Martinis, 2015; Lindman & McIntyre, 1961; Regan, 1972; Wright, 2004). This English guardianship system was rooted in the belief that the king had the responsibility for protecting people who were regarded as unable to protect themselves (Blanck & Martinis, 2015; Millar, 2014; Regan, 1972; Salzman, 2010). These guardianship laws allowed the Crown or its delegates to take over the person placed under guardianship's (often referred to as a *ward*) person and property (Wright, 2004). After becoming independent of Great Britain, the U.S. modeled its guardianship policies after Great Britain, in that states were granted the powers to protect citizens who were thought to be incapable of protecting themselves

(Blanck & Martinis, 2015; Lindman & McIntyre, 1961; Regan, 1972; Salzman, 2010).

One of the key reasons often cited for placing a person with a disability or an elderly person under guardianship is to help protect him/her (Blanck & Martinis, 2015; Werner & Chabany, 2015). Elderly people, people with intellectual disabilities, and people with mental illness have historically been placed under guardianship at high rates (Salzman, 2010; Wright, 2004). Moreover, individuals with intellectual disabilities are more vulnerable to being placed under guardianship than people with other types of disabilities (Millar, 2014; Riggle, personal communication, August 5, 2016; Werner & Chabany, 2015).

However, guardianship often is more beneficial for the guardian than the person under guardianship (Millar, 2014; Moye & Naik, 2011). For example, persons placed under guardianship lose control to manage their finances, which has historically led to many guardians exploiting the funds of those placed under guardianship (Regan, 1972; Werner & Chabany, 2015). For example, Werner and Chabany conducted focus groups of adults with intellectual disabilities (ID) and adults with mental illness (MI). Many adults with ID reported that their guardians were “restrictive and harmful...leading them [the wards] to feel helpless and angry” (p. 6). Additionally, adults with ID in this study gave examples of how their guardians restricted their finances, such as only allowing them to withdraw money from their bank accounts once per week. In more extreme cases, such as the Jenny Hatch case which will be described shortly, guardians have made decisions for their wards that benefit the guardian but go against the wishes of the ward (Hatch, 2015; Jenny Hatch Justice Project, 2014; Salzman, 2010). While it is recognized

that the Jenny Hatch case is an extreme example of the misuse of guardianship and that many guardians have good intentions when making decisions on behalf of their wards, it is concerning that full guardianship, as in the Jenny Hatch case, is granted much more frequently than limited guardianship or other less restrictive alternatives (Blanck & Martinis, 2015; Jameson et al., 2015).

### **Institutionalization**

Just as guardianship was originally designed with the intention of protecting people with disabilities, protectionism was also one of the key reasons for the rise of institutions for persons with disabilities in the U.S. (Regan, 1972; Salzman, 2010). Institutions were a much more overt way of limiting the choices and opportunities for people with disabilities, which also occurs when individuals are placed under guardianship. During the 1800s to mid-1900s, persons with disabilities were admitted into institutions at high rates, with the primary reason often cited as concern that a person posed a danger to him/herself and/or to society (Newman, 1967; Parallels in Time, 2016; Regan, 1972). For example, in the U.S., between 1890 and 1905, the average number of people in institutions grew from 250 people to over 500 people per institution. By the first half of the 1900s, approximately 50,000 individuals lived in institutions in the U.S. (Parallels in Time, 2016). One reason for this rise was due to the fact that during these early years of institutionalization, most institutions had very loose admissions criteria (Newman, 1967). For example, in the 1800s, after Josiah Oakes, an elderly man, married a younger woman, his family had him institutionalized, citing “unsoundness of mind in conducting his business affairs” (Regan, 1972, p. 573). Though Mr. Oakes was later



released, this case highlights how society's desire to protect individuals can lead to their exploitation.

A more recent case also illustrates how society's emphasis on protecting elderly and people with disabilities can have devastating effects. Mrs. G, an elderly woman living in her own apartment, had difficulty performing some of the basic housekeeping and cleaning tasks around her home. Consequently, her landlord called the Adult Protection Services to report that Mrs. G.'s home was a health risk. The Adult Protection Services demanded that Mrs. G. move into a nursing home, where she died within two months from cardiac failure (Salzman, 2010). Other research has also shown that many elderly people or people with mental illness die within the first year of being placed into institutions (Regan, 1972).

### **From Segregated Services to More Integrated Options**

#### **Community Living**

Historically, people with disabilities were institutionalized at high rates (Newman, 1967; Parallels in Time, 2016; Regan, 1972; Salzman, 2010); however, in the last few decades there has been a shift towards more integrated living arrangements for people with disabilities (Chowdhury & Benson, 2011; Kim, Larson, & Lakin, 2001; Residential Services and Facilities Committee, 1973). One of the catalysts for de-institutionalization of people with disabilities was Wolf Wolfensberger's Social Role Valorization Theory (SRV theory). The SRV theory was one of the first attempts to recognize the humanity of people with intellectual disabilities. Wolfensberger emphasized the need for people with

intellectual disabilities to adapt to the cultural norms of their communities. One of the main points of the SRV theory is that the social roles that a person holds largely determine how society views him/her. Moreover, how society views a person often affects that person's opportunities for advancement and participation in mainstream society (Osburn, 1998; Wolfensberger, 2000, 2011; Wolfensberger & Thomas, 1994). For example, a person who lives in a state-run institution and works in a sheltered workshop will be viewed by society as having a less valuable social role than an individual who lives in his/her own apartment and works at a restaurant or store.

Therefore, Wolfensberger and his theory had a huge role in re-conceptualizing people with intellectual disabilities. Wolfensberger was one of the leading proponents of deinstitutionalization and community integration. He believed that if a person with an intellectual disability lived and worked in a community, then that person was more likely to be perceived as valuable to society, which often led to opportunities for social role advancement (Osburn, 1998; Wolfensberger, 2000, 2011; Wolfensberger & Thomas, 1994).

Another major impetus for de-institutionalization in the U.S. occurred in response to a Supreme Court ruling in the case of *Olmstead v. L. C. and E. W.* in 1999. This case revolved around two women, L.C. and E.W., who had dual diagnoses of developmental disability and mental illness. Both women lived in state-run institutions, and both had expressed a desire to move into the community. Furthermore, the state treatment professionals had deemed both women to be eligible to live in the community; however, they remained institutionalized. Therefore, these women sued under Title II of the

Americans with Disabilities Act (ADA; Olmstead, n.d.).

The Supreme Court ruled in favor of these two women, and it determined that unwarranted institutionalization of people with disabilities is a form of discrimination that is actionable under the ADA Title II. Additionally, they stated that unwarranted segregation perpetuates the negative stereotypes and unjustified assumptions against institutionalized persons (such as the misbelief that people with disabilities are incapable or unworthy of living in the community). Furthermore, the Supreme Court stated that institutional confinement severely diminished individuals' everyday life activities, including family relations, social contacts, work, educational advancement, and cultural enrichment. Therefore, the Supreme Court recommended that states deinstitutionalize people with disabilities, promote community-based services, make reasonable accommodations, and avoid discrimination on the basis of disability. In response to the Supreme Court's ruling in this case, states each had to adopt an "Olmstead plan," which outlines how the state will eliminate unnecessary segregation of people with disabilities (Olmstead, n.d.).

## **Employment**

Just as people with disabilities have been moving out of segregated housing, they have also been moving out of segregated employment (Braddock et al., 2015; Wehman, Revell, Kregel, & Act, 1997). Historically, people with disabilities were either kept out of mainstream employment, or only allowed to work in sheltered workshops (Wehman et al., 1997). Sheltered workshops are factory-type settings where people with disabilities earned well below minimum wage for jobs such as assembling electronic devices,

packaging batteries, and shredding papers. However, a few key pieces of legislation have opened up more vocational opportunities for people with disabilities: The Vocational Rehabilitation Act (Rehab Act), the Americans with Disabilities Act (ADA), and the Workforce Innovation and Opportunity Act (WIOA).

The Rehab Act prohibits discrimination due to disability in the following vocational areas: programs run by federal agencies, programs that receive federal financial assistance, federal employment, and federal contractors (Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunity Act [WIOA], 2014). The WIOA Act of 2014 amends the Rehab Act of 1973 and prioritizes that people with disabilities should be working in competitive employment. WIOA also recognizes the importance of self-advocacy for people with disabilities, and it requires the teaching of self-advocacy to transition-aged youth (Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunity Act [WIOA], 2014). The ADA also expands rights for people with disabilities, making it illegal to discriminate against people with disabilities in employment, transportation, and other public settings (Americans with Disabilities Act and its Amendments, 1990, 2008).

## **Education**

Public school settings are another important area where people can no longer be denied entrance due to their disabilities. Historically, people with disabilities were not accommodated in schools; parents of children with disabilities were often told that schools could not teach their child. When children with disabilities were allowed to enroll in public schools, they were nearly always placed in segregated classrooms (Friend,

2006). However, the passage of the Education for All Handicapped Children Act of 1975 (later renamed the Individuals with Disabilities Education Act—IDEA), provided federal funding to schools for children with disabilities. IDEA has been re-authorized several times, and now mandates that all children with disabilities should be provided a free and appropriate public education in the least restrictive environment (Friend, 2006; Individuals with Disabilities Education Improvement Act [IDEA], 2004).

### **An Area Still Lacking Integration**

Thus, society has moved towards integrating people with disabilities into many areas—education, employment, and community living. Despite these overt inclusionary efforts, people with disabilities are still marginalized and oppressed by society in the important area of decision-making. Specifically, guardianship laws, and guardianship’s overuse without considering alternatives, limit people with disabilities’ rights and opportunities to make their own choices (Salzman, 2010; Werner & Chabany, 2015). Some posit that guardianship is in direct contradiction to the ADA and Olmstead rulings, both of which mandate that people with disabilities have access to services and programs in the least restrictive and most integrated settings (Salzman, 2010). That is, when adults are placed under guardianship, they are restricted from being allowed to make their own decisions. This restriction diminishes their access to the community, which is in direct contradiction to the Olmstead ruling. For example, a person under guardianship will most likely have more limited contact with his/her service providers, bankers, and doctors, as his/her guardian will be his/her primary spokesperson to all these community members (Salzman, 2010).

Similarly, Millar (2013) emphasizes that guardianship disaffirms self-determination. As outlined below, individuals under guardianship have fewer opportunities to make and express their choices in all areas of life. Thus, those under guardianship have decreased opportunities to be self-determined, which in turn leads to lower quality of life (Deci & Ryan, 1991; Millar et al., 2013; Ryan & Deci, 2001). Moreover, research has shown that, when given a choice, people with disabilities are more likely to choose options for themselves that will allow them to be more included in their communities (Moore & Friedman, 2017).

## **Current Guardianship Practices**

### **Guardianship Laws**

Guardianship laws in the U.S. are determined by each state; therefore, determination of an individual's being placed under guardianship varies from state to state (Blanck & Martinis, 2015). For example, states vary in how they define incapacity in terms of an individual's functioning and cognition. All too often, incapacity is determined by whether or not the individual has a diagnosed intellectual disability (Rood, Kanter, & Causton, 2014). States also fluctuate in how they define whether an individual has a necessity of risk or harm that would justify him/her being placed under guardianship (American Bar Association, 2017).

In general, two types of guardianship are available in the U.S.: full or limited. The only exceptions are the states of Texas and Delaware. Texas recently passed a law allowing for Supported Decision Making (SDM), and which will be discussed later, and

Delaware is in the process of legally recognizing SDM as an alternative to guardianship (Supported Decision Making Network, n.d.). Full guardianship occurs when the guardian makes all types of decisions for the person placed under guardianship, whereas in limited guardianship, the guardian only makes decisions for certain areas such as healthcare or finances (Autistic Self Advocacy Network, n.d.; Jameson et al., 2015). Regardless of the type, guardianship takes away a ward's rights to make choices and exert autonomy, thereby decreasing his/her self-determination. In fact, people under guardianship have fewer rights as citizens than people who are incarcerated (Blanck & Martinis, 2015).

### **Guardianship Challenges**

A recent legal case demonstrates how individuals under guardianship can become the victims of abuse and forced into situations against their will, even when their guardians are their own family members. Jenny Hatch, a young woman with Down syndrome, was placed under her parents' guardianship and consequently, against Jenny's wishes, she had to move out of her friend's home into a group home. At this home, she was not allowed to use her cell phone or laptop or even to visit her friends. Jenny describes this experience as being like a "prisoner, but I didn't do anything wrong" (Hatch, 2015, p. 34). Later, the court ruled that Jenny could use supported decision making as an alternative to guardianship (Jenny Hatch Justice Project, 2014).

There is currently an unknown number of adults under guardianship in the U.S. (Guardianship, 2003; Salzman, 2010; Sharp, personal communication, March 22, 2016), though it is estimated that over 1.5 million adults are under guardianship (Blanck & Martinis, 2015). This ambiguity is due to the fact that guardianship is usually handled by

county courts, and these records are not compiled into central databases (Sharp, personal communication, March 22, 2016; Riggle, personal communication, August 5, 2016). Consequently, it is unclear how many individuals are under guardianship in each state, let alone in the entire U.S.

A major concern of individuals who are placed under guardianship is whether or not the guardian makes decisions that align with the ward's interests and preferences (Werner & Chabany, 2015). Whitlatch, Feinberg, and Tucke (2005) compared values and preferences of individuals with cognitive impairments to their caregivers' perceptions of these individuals' values and preferences. Along with finding differences between the perceptions of caregivers and care receivers, the authors noted that individuals with cognitive impairments were still able to "participate and respond reliably and accurately to these types of questions" (p. 378). This study highlights the importance of individuals with disabilities having the opportunity to make decisions for themselves, as their caregivers may not have accurate perceptions of their preferences.

Covinsky et al. (2000) interviewed over 2,000 seriously ill patients (patients with an average 6-month survival based on their diagnosis), their surrogates (close family members), their physician, and their primary nurse. The researchers compared patient's preferences for end-of-life care with their surrogates' and medical personnel's beliefs about what their preferences were. The results showed that doctors were "only moderately better than chance at understanding patients' preferences for CPR" (p. 189). Likewise, doctors typically did not understand patients' preferences regarding living in nursing homes.



Similarly, Covinsky et al. (2000) found high levels of discrepancy between nurses' beliefs about patients' preferences and the patients' actual preferences. Moreover, the majority of nurses reported that they had no knowledge of their patients' health care preferences. Likewise, surrogates' beliefs about their family members' preferences were "only moderately better than chance" (p. 190). These high levels of mismatch between patients' preferences and others' beliefs about these preferences highlight the dangers that can occur when family members or medical personnel try to make decisions for another person.

## **Capacity**

### **Definition**

Determining an individual's capacity is one of the most important aspects when assessing whether or not a person should be placed under guardianship. Capacity is most often defined as an individual's cognitive ability to make a specific decision. Regarding guardianship, capacity to make the following types of decisions is often under scrutiny: health care; personal and home management; and financial administration (Moye & Naik, 2011). This is different than an individual's competence, which refers to a court's formal ruling on a person's legal status (Kapp & Mossman, 1996). Competence, when referring to guardianship, means an individual's aptitude to perform a certain task, specifically to make a decision and/or care for him/herself (Berg et al., 1996; Millar, 2014).

Determining an individual's capacity has repeatedly been demonstrated as a subjective and highly variable process (e.g., Applebaum, 2007; Campella, 2015; Ganzini, Volicer,

Nelson, & Derse, 2003; Kapp, & Mossman, 1996; Moye, Karel, Azar, & Gurrera, 2004).

In the medical field, an individual's capacity is often questioned when that individual refuses to consent to treatments recommended by medical or other professionals (Kapp & Mossman, 1996). An individual's culture and personal values often influence his/her decision-making, especially regarding medical decisions. For example, individuals who place a higher value on the quality of their life rather than the length of their life may reject treatments that will prolong their life but decrease its quality. In these instances, an individual's personal values and beliefs may be at odds with medical professionals' recommendations, which may cause medical personnel to question that individual's decision-making capacity (Karel, Gurrera, Hicken, & Moye, 2011).

### **Capacimeters**

Capacimeters are tools (such as rating scales, questionnaires, or other written tests) that attempt to quantify an individual's capacity in order to determine whether or not a person is competent to make his/her own decisions. However, Kapp and Mossman (1996) point out that personal biases, idiosyncrasies, and fallible clinical judgment interfere with objectively assessing capacity. Likewise, these authors pointed out that an individual's capacity may ebb and flow over time. For example, some individuals with mental illness who have episodic conditions may have varying levels of capacity, based on the whether or not their condition is in an active state. Also, individuals who are temporarily unconscious due to medical conditions may be able to once again communicate their decisions after they recover.

## Capacity Research

Ganzini et al. (2003) surveyed 395 consultation-liaison psychiatrists, geriatricians, and geriatric psychologists about the assessment process used to determine patient's decision-making capacity. Their findings highlighted many of the difficulties of assessing capacity. These professionals noted that, among other things, it is often erroneously assumed that if a person lacks capacity to make one type of decision, then it is presumed that person lacks capacity to make all types of decisions. For example, a person may lack capacity to make decisions about a life-or-death surgery (e.g., consenting to an appendectomy), but have capacity for other less-serious medical decisions, such as choosing which medical provider to select as his/her primary care provider.

Likewise, other researchers note that physicians often erroneously assume that their patients are incompetent simply because of their diagnosis, without formally assessing or exploring their actual capacity (Appelbaum, 2007; Rood et al., 2014). Researchers have pointed out that while assessing capacity is highly subjective, there are four legal standards of competency considered when assessing a person's capacity. These standards are as follows: (1) communicating a choice, (2) understanding relevant information, (3) appreciating the situation and its consequences, and (4) reasoning about treatment options (Appelbaum, 2007; Moye et al., 2004).

Moye et al. (2004) compared capacities to consent to medical treatment in adults with and without dementia. Specifically, 88 adults with mild to moderate dementia were matched to 88 controls, and all participants were assessed with three capacity instruments. While mean differences occurred between the control and dementia groups

in three of the four standards of capacity, there were no significant group differences on the capacity to communicate a choice. Another notable finding from this study was that the percentage of people within the normal limits of capacity varied based on the assessment instrument used. This variance based on the testing instrument underscores the unreliable nature of attempting to quantify capacity. In conclusion, Moye et al. stated that “most individuals with mild dementia can participate in decision making as defined by legal standards for competency, and they should be encouraged to do so, perhaps with strategies to compensate” (p. 174).

### **Ethical Concerns**

Along with the aforementioned concerns of assessing capacity, there are other ethical concerns about capacity. Specifically, the idea that capacity is a dichotomous variable (e.g., either someone is totally competent or totally incompetent) is a major shortcoming in the way that capacity is currently assessed. Kapp and Mossman (1996) argue that people have levels of decision-making abilities, with strengths in some types of decisions and areas of need in other decisions. Furthermore, these authors argue that having a capacimeter with an arbitrary cut-off point does not adequately determine whether or not a person lacks decision-making capacity.

Likewise, Berg et al. (1996) note additional difficulties with trying to develop a standard or arbitrary cut-off point for competence to make a decision. Specifically, with regards to medical decision making, it is difficult to use a one-size-fits-all model of competence. That is, certain medical decisions may be more complex than others, and sometimes there are more than just two treatment options. In these circumstances, an

individual is more likely to be found incompetent to make a decision if medical professionals do not use discretion in adopting decision-making standards.

Another difficulty of using one standard to determine decision-making competency is that this standard may be restrictive or too rigorous, which results in a high percentage of individuals being deemed as incompetent. In contrast, Berg et al. (1996) proposes that a sliding scale of decision-making competency should be used. For example, the level of understanding or appreciation for the situation (two components of decision-making competency) could vary based on the decision at hand. Berg et al. suggest that more complex decisions should require higher levels of understanding or appreciation than less complex decisions.

Berg et al. (1996) also point out that the quality of understanding about a decision (i.e., what exactly the person understands about a given situation) is an extremely important, yet difficult to measure, aspect of decision-making. Berg et al. also posit that more important and risky decisions, such as having a surgery, should require higher levels of understanding than less-risky decisions, such as deciding between two medications.

### **Autonomy Versus Beneficence**

Beneficence, or actively doing good for someone else, is one of the ethical principles that is often used to justify guardianship (Blanck & Martinis, 2015; Henry, 2015). For example, an adult's refusal to consent to a medically recommended treatment may prompt medical professionals to assess whether or not that person lacks the capacity to make his/her own decisions. If found to lack capacity, that individual may then be

placed under guardianship, and the medical treatment administered, based on the principle of beneficence (Henry, 2015).

This example of administering a treatment to someone against his/her wishes in the name of beneficence is at odds with autonomy, or exercising one's personal freedoms and choices. Autonomy is an essential component of decision-making, and is part of the broader concept of self-determination. Self-determination, or the process of a person exerting control of his/her own life, is fundamental for a person's overall well-being and psychological growth (Deci & Ryan, 1991; Ryan & Deci, 2001).

For example, Deci and Ryan (1991) posit that individuals who have increased control (self-determination) over their life choices tend to have increased intrinsic motivation and enjoy life more. Furthermore, individuals who have high levels of self-determination more often live on their own, have higher financial independence, obtain higher paying jobs, and attain more job promotions, compared to individuals with lower levels of self-determination (Jameson et al., 2015). Indeed, being able to make choices and advocate for these choices increases one's control over one's life and is linked with a higher quality of life (Salzman, 2010; Wehmeyer, 2015; Wehmeyer & Schwartz, 1998).

In contrast, individuals with less self-determination, such as the case with those under guardianship, tend to be less satisfied with life (Ryan & Deci, 2001). Other researchers have found that guardianship is correlated with reduced life competencies and diminished overall health (Blanck & Martinis, 2015). People under guardianship often have lower self-esteem than those who are not under guardianship (Jameson et al., 2015; Salzman, 2010).

## **Alternatives to Guardianship**

In light of the ethical concerns of guardianship, there are several alternatives to guardianship. While most state laws on guardianship specify that guardianship should be granted only after less restrictive alternatives have been considered and when an individual lacks the capacity to make decisions (American Bar Association, 2017; Martinis & Ellis, 2015), researchers have found that full guardianship is granted much more frequently than limited guardianship (Blanck & Martinis, 2015; Jameson et al., 2015). Along with limited guardianship, there are a variety of less restrictive alternatives to guardianship, which include power of attorney, conservatorship, advanced directives for medical decisions, representative payees, and shared decision making contracts (Center for Family Involvement, 2015.; Millar, 2014; Riggle, personal communication, August 5, 2016).

### **Conservatorship**

Conservatorship varies from state to state. For example, in Utah, conservatorship is a type of supported decision making agreement that only covers finances, and these agreements can be written with varying degrees of control, ranging from a person with disabilities being allowed to make financial decisions up to a certain dollar amount, to a person with disabilities giving all their financial control to another (Riggle, personal communication, August 5, 2016; Utah Disability Law Center, 2016). However, in other states, conservatorship is synonymous with full guardianship and is often used to describe guardianship of an elderly person (Cornell University of Law, n.d.).

**Power of Attorney**

Power of Attorneys (POAs) are documents that can be narrowly or broadly defined, and can be specific to certain areas, usually financial or health care (Millar, 2013; Riggle, personal communication, August 5, 2016; Yarbrough, 2011). Any individual with a disability can arrange a POA, as long as s/he has the legal capacity to do so. Similarly, representative payees or authorized representatives are arrangements made with the Social Security Administration that designate a specific person to receive and manage a person with disabilities' disability benefits (Yarbrough, 2011).

**Advanced Medical Directive**

Another type of supported decision-making is an advanced medical directive, where a person with a disability can designate a person to make his/her medical decisions. These advanced medical directives can be specific to end-of-life decisions or allow for another person to make to daily medical decisions on behalf of the person with a disability (Riggle, personal communication, August 5, 2016; Autistic Self Advocacy Network, n.d.).

**Shared Decision Making Contracts**

Some states have shared decision-making contracts. In this alternative, a person with a disability designates another person help him/her make decisions, while the person with the disability remains the ultimate authority in final decisions (Riggle, personal communication, August 5, 2016; Autistic Self Advocacy Network, n.d.).



## **Supported Decision Making**

Supported decision making (SDM) is one guardianship alternative that Texas legally recognized in 2015, and Delaware is in the process of legally recognizing it (Supported Decision Making Network, n.d.). SDM gives a person with a disability the opportunity to consult friends and family members whom s/he trusts to help him/her comprehend the situation at hand. However, unlike guardianship, where the guardian has the final say in any and all decisions, in SDM, the person with the disability makes the final decision (Blanck & Martinis, 2015; Jameson et al., 2015). Thus, a key difference in SDM and guardianship is that a person with a disability who uses SDM retains his/her legal rights and decision-making authority, whereas an individual under guardianship loses his/her rights and authority. Proponents of SDM point out that SDM reflects how most adults make their decisions—by talking with trusted people, weighing out all options, then making a final decision.

Texas defines SDM as “a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions...without impeding the self-determination of the adult” (Texas Est. Code §§ 1357.002(3); 1357.003). Under this law, any adult who is 18 or older can enter into a SDM agreement.

Capacity is not defined in this Texas law, but an individual with disabilities must demonstrate the capacity to agree on whom s/he decides to list as supporters. There are no restrictions on who can be listed as a supporter; for example, a family member, friend, or staff at an adult service agency can be listed as a supporter. The SDM agreement is voluntary and does not require going to court; however, it is recommended that this

agreement be notarized (LaVallo, 2016).

Texas' SDM is different from a power of attorney, because in power of attorney arrangements, another person ultimately makes decisions for someone, whereas in SDM, the individual with a disability has the final say in his/her decisions. In SDM arrangements, the supporter assists the individual with a disability in the following: understanding options and consequences of decisions; gathering information about the decision; and helping with communicating the final decision to other stakeholders. Either the person with the disability or the supporter can terminate the SDM agreement at any time. Also, if the Department of Family and Protective Services determines that the supporter is abusing or taking advantage of the person with a disability, the SDM agreement will be canceled (LaVallo, 2016).

## **Self-Advocacy**

### **Components of Self-Advocacy**

As noted earlier, one of the four legal standards used to determine capacity is the ability to communicate a choice. Test et al. (2005) describe four key components of self-advocacy, which overlap with the definition of capacity. The components of self-advocacy are knowledge of self, knowledge of rights, communication, and leadership. As noted above, the four legal standards of capacity are as follows: (1) communicating a choice, (2) understanding relevant information, (3) appreciating the situation and its consequences, and (4) reasoning about treatment options (Appelbaum, 2007; Moye et al., 2004).

## **Self-Advocacy and Capacity**

The self-advocacy components of knowledge of self and knowledge of rights overlap with the legal capacity standards of understanding relevant information, appreciating the situation and its consequences, and reasoning about treatment options. Specifically, as individuals increase their knowledge about their legal rights as well as their own needs and preferences, their capacity increases as they are better equipped to understand and make decisions (Salzman, 2010). Likewise, communication is an important component of self-advocacy, which is directly measured when determining an individual's capacity. Therefore, based on the overlap between self-advocacy and capacity, it can be argued that individuals who have higher levels of self-advocacy have higher levels of capacity. Conversely, individuals with limited opportunities to self-advocate, such as those placed under guardianship, will have lower capacity than those who regularly engage in self-advocacy (Millar, 2013; Salzman, 2010; Werner & Chabany, 2015).

## **Self-Advocacy Research**

Individuals with intellectual disabilities are more vulnerable to being placed under guardianship than people with other types of disabilities (Millar, 2014; Riggle, personal communication, August 5, 2016; Rood et al., 2014; Werner & Chabany, 2015). Specifically, in some states, a court may justify granting full guardianship for an individual mainly because that person has an intellectual disability (Rood et al., 2014). Additionally, the topic of guardianship is frequently discussed at students with intellectual disabilities' annual individualized education planning meetings (Jameson et

al., 2015; Millar, 2014). At these meetings, parents and school staff often cite concerns for the individual with ID's safety and decision-making abilities, and they propose guardianship as a way to protect the individual with ID (Millar, 2013). Some schools even have a suggested timeline for beginning guardianship discussions with families (Rood et al., 2014).

However, several studies have demonstrated that individuals with intellectual disabilities can communicate their preferences in key decisions such as their educational goals and health needs (e.g., Cease-Cook, Test, & Scroggins, 2013; Lennox et al., 2010; Snyder, 2002). Many of these studies have specifically targeted teaching individuals with intellectual and other disabilities how to increase their self-advocacy skills in areas such as health care (Bollman et al., 2009), rights violations (Kramer et al., 2014), and person-centered planning meetings (Mazzotti et al., 2015). Thus, in instances where adults with intellectual disabilities may have difficulty expressing their choices, self-advocacy training may help them increase their capacity to make decisions. Along with this training, it is imperative that adults with disabilities have relationships with trusted people in their lives who can support them with decision-making (Douglas, Bigby, Knox, & Browning, 2015). Many researchers suggest that these key supportive people include adults with disabilities' family members (e.g., Burke, Fish, & Lawton, 2015; Heller & Arnold, 2010; Millar, 2013; Taylor et al., 2016; Werner & Chabany, 2015).

### **Siblings as Supporters in Decision Making**

Siblings of adults with ID are often part of their brother or sister's natural support

systems (Burke et al., 2012; Burke, Arnold, & Owen, 2015; Hewitt et al., 2013). It is often noted that siblings are the longest-lasting relationships that a person will have (e.g., Burke Fish, & Lawton, 2015; Conway & Meyer, 2008; Rawson, 2009). Because of these long-standing relationships, researchers argue that siblings are in strategic positions to partner with adult service agencies in supporting adults with intellectual disabilities (Conway & Meyer, 2008; Hewitt et al., 2013). Furthermore, as individuals with intellectual disabilities tend to outlive their parents, their siblings often take on important caregiving and/or supportive roles (Burke et al., 2012; Burke, Lee, Arnold, & Owen, 2016; Greenberg et al., 1999; Hewitt et al., 2013; Hodapp, Urbano, & Burke, 2010; Rossetti & Hall, 2015). In a review of 23 studies on adult siblings of people with disabilities, Heller and Arnold (2010) found that siblings often acquired the following types of caregiving roles with their brothers and sisters with disabilities: becoming their legal guardian, administering financial support, and living with their sibling with an intellectual disability.

## **Current State of the Research**

### **Siblings as Advocates**

Despite these important, supportive roles that adult siblings usually acquire, research suggests that these siblings are often under-informed and ill prepared to adequately support their brothers and sisters (Burke, Arnold, & Owen, 2015; Conway & Meyer, 2008; Dew, et al., 2004; Hewitt et al., 2013; Griffiths & Unger, 1994). For example, Burke, Arnold and Owen conducted focus groups with adult siblings of

individuals with intellectual and developmental disabilities (IDD). These focus groups explored how these siblings were involved in advocacy as well as the supports that these siblings needed to advocate for their brothers and sisters. Among other things, these siblings noted that they lacked knowledge about adult service systems as well as the legal rights of their brothers and sisters. These focus group participants pointed out their need for more information so that they could better support and advocate for their brothers and sisters.

### **Siblings' Involvement in Future Planning**

Other researchers have noted that typically developing siblings often are not included in planning meetings and discussions about their sibling with a disability's future, which can lead to frustration and anxiety for these typically developing siblings (Conway & Meyer, 2008; Burke, Fish, & Lawton, 2015; Heller & Arnold, 2010; Rawson, 2009). For example, Griffiths and Unger (1994) compared 41 dyads of adult siblings and their parents on their responses to surveys about their future plans for their adult family member with ID. While over half of the siblings reported having some type of conversation with their parents about future planning, the majority (64%) of these siblings reported that they were still unsure of the exact future plans for their brother or sister. Moreover, many of these siblings stated that they were willing to take on future caregiving roles, including guardianship, with their brother or sister, but less than one-fourth of their parents wanted them to acquire these caregiving roles. These results highlight the need for explicit planning and clear communication between families regarding future plans for adults with ID.

Heller and Kramer (2009) surveyed 139 adult siblings of individuals with developmental disabilities (DD) regarding their future planning and expectations for future caregiving. These researchers targeted eleven types of future planning for the brothers and sisters with DD, including guardianship. Of the siblings who responded, only a small percentage indicated that these types of future plans were in place for their brother or sister. Moreover, a majority of the respondents (70%) reported that they would like support and more information about this type of future planning. Taken together, these results indicate the need for more information and supports for siblings to help them address future planning for their brothers and/or sisters.

### **Siblings as Caregivers**

Burke et al. (2012) described the following five domains of caregiving that siblings give their brothers and sisters: making residential arrangements; financial arrangements; providing legal guardianship; interacting with the service system; and providing companionship and emotional support. Specifically, Burke et al. surveyed 757 adult siblings of people with various disabilities in order to explore predictors for siblings providing future caregiving for their brothers and sisters. Among other things, they found that characteristics of the sibling, such as their gender and whether or not they had children impacted their anticipated level of caregiving. For example, female siblings, lone siblings (siblings who did not have other siblings), and siblings who did not have children expected to take on higher levels of future caregiving.

Another recent qualitative study of adult siblings of people with intellectual and developmental disabilities (IDD) compared and contrasted current caregivers with

anticipated caregivers of adults with IDD. Burke, Fish, and Lawton (2015) conducted focus groups with 25 adult siblings who were currently caregivers for their brothers and sisters and 17 adult siblings who anticipated taking on caregiving roles with their brothers and sisters. Many of the 25 adults already providing caregiving to their brothers and sisters were their sibling's legal guardians, and many also helped their brother or sister navigate through the adult disability service system. Several of the anticipated caregivers mentioned that they planned to take these types of roles and responsibilities with their brothers and sisters.

A recent research brief from the National Core Indicators Adult Family Survey compared sibling caregivers with other types of caregivers for adults with IDD (Reagan, Anderson, Arnold, Magaña, 2016). Over 18,000 family caregivers from 25 different states in the U.S. responded to this survey about the level of choice and control that caregivers experience. Compared with other caregivers, siblings experienced greater amounts of financial hardship and fewer degrees of choice and control. For example, siblings were less likely to report having a say in their brother or sisters' staffing as well as less likely to have information on the financial supports available for their brother or sister. This research brief highlights the need for siblings to be better informed and supported as they provide care for their brothers and sisters.

### **Siblings as Guardians**

Similarly, guardianship is a reoccurring theme in several studies of adult siblings (e.g., Arnold et al., 2012; Hodapp et al., 2010; Kramer, Hall, & Heller, 2013). Kramer et al. conducted qualitative interviews of adult siblings about the types of support they give



their brothers and sisters. Many of these siblings cited guardianship as a way that they supported their brother or sister. Likewise, Arnold et al. surveyed 139 adult siblings about the types of supports they needed. Several of these siblings mentioned that they needed more information on future planning and guardianship for their brothers and sisters. Notably, none of these aforementioned studies mentioned any types of alternatives to guardianship that these siblings were aware of, which highlights the need for more focused research in this area.

These sibling studies demonstrate the importance of siblings being equipped with knowledge and information about current disability laws and policies so that they can better assist their brothers and sisters. For example, if adult siblings are unaware of the limitations that come with guardianship and that there are alternatives to guardianship, such as SDM or POA, siblings may take on full guardianship of their brothers and sisters after their parents pass away. In this way, a sibling's lack of information may inadvertently cause their brother or sister to have restricted opportunities and rights when s/he is placed under guardianship. In a review of research on families of adolescents and adults with IDD, Taylor et al. (2016) gave several recommendations for future research on siblings that is specifically focused on examining adult siblings' perspectives and roles of caregiving.

### **Summary**

This chapter highlighted several of the ethical concerns of guardianship, such as the removal of human rights and decrease in self-determination. This chapter also

explained the difficulties with measuring capacity, and gave examples of the unreliability of surrogate decision makers acting on behalf of others, even when these decision makers are close family members or spouses. Despite these difficulties with guardianship, many adults with ID often have guardians, and oftentimes their adult siblings take on this and other supportive roles after their parents are no longer able to care for their child with ID. Moreover, as siblings of people with ID are often not included in the planning process and are under-informed of their sibling with ID's guardianship situation, these typically developing siblings may unknowingly take on overly restrictive guardianship roles. To date, adult siblings of people with ID' perspectives and knowledge about guardianship are understudied. Systematically studying these siblings on the topic of guardianship and its alternatives may uncover what these siblings know and can also reveal any knowledge gaps or support needs. Since over 70% of adults with IDD in the U.S. live with their family members (Braddock et al., 2015), as these family caregivers age, adult siblings often take on caregiving and other supportive roles (Hewitt et al., 2013).

Thus, learning about siblings' perspectives and knowledge about guardianship, such as this study explored, can drive policy changes in guardianship alternatives. For example, if this study indicates that most siblings do not know of any guardianship alternatives, then there is a need for information on these alternatives to be systematically disseminated to siblings, such as through disability organizations and service providers. Likewise, if this study indicates that most siblings view alternatives to guardianship, such as supported decision making, favorably, this can guide policy changes towards more states recognizing supported decision making as an option for people with IDD. The next

chapter will discuss the specific qualitative methods used to explore siblings' knowledge and perspectives of guardianship and its alternatives.

## **CHAPTER III**

### **METHODOLOGY**

#### **Overview**

##### **Qualitative Methods**

Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005) defined qualitative research as a “systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context” (p. 195). Qualitative methods were chosen for this study rather than quantitative (e.g., survey-based methods) because no known published research has specifically studied adult siblings of people with ID’s perspectives on guardianship alternatives. Thus, in the case of exploratory research, such as this study, the use of qualitative methods has been recommended (Brantlinger et al., 2005; Lambert & Loiselle, 2008; Whittemore, Chase, & Mandle, 2001).

Individual interviews were chosen instead of other qualitative methods, such as focus groups, for a variety of reasons. Researchers recommend that when sensitive information is discussed, as in this study where participants will be asked about future planning for their sibling with ID, participants are more likely to be honest and share more in-depth information when they are in 1:1 interview settings compared to focus groups (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014; Coenen, Stamm, Stucki, & Cieza, 2011). Additionally, individual interviews, when compared with focus groups, tend to elicit a greater variety of information (Carter et al., 2014). Last, for practical reasons, individual interviews tend to take less time with regards to recruitment,

face-to-face time, and coding, compared with focus groups (Coenen et al., 2011).

### **Research Questions**

The purpose of this study is to determine what adult siblings of adults with intellectual disabilities (ID) know about guardianship and its alternatives. A secondary purpose is to explore the perspectives and opinions of adult siblings of adults with ID on guardianship and its alternatives. A third purpose is to explore what adult siblings of adults with ID think about their role of being a guardian or supported decision maker for their sibling with ID.

### **Combined Approaches**

#### **Grounded Theory**

This study used the qualitative methods of grounded theory in combination with a directed analysis process. Glaser and Strauss developed grounded theory for the purpose of allowing researchers to generate new theories from emerging data (Glaser & Strauss, 1967). Grounded theory can also be used to gain new insight into known concepts (Skeat & Perry, 2008; Stern, 1980). Grounded theory is advantageous when the purpose of a study is to understand complex experiences and interaction or when a phenomenon is understudied, as in the case of this study on siblings' perspectives of guardianship and its alternatives (Cohen & Crabtree, 2006; Skeat & Perry, 2008). Additionally, other qualitative research with adult siblings of people with ID has utilized grounded theory methodology, particularly its constant comparative analysis (e.g., Arnold et al., 2012; Coyle et al, 2014; Burke, Fish, & Lawton, 2015). The use of grounded theory in this

study allows for in-depth knowledge about adult siblings' perspectives and knowledge about guardianship and its alternatives.

Grounded theory is also known as “ground up” reasoning, or inductive reasoning, where the researcher does not begin with a hypothesis about the subject of study. Rather, the researcher remains open to any theories that may emerge from the data itself (Charmaz, 2006; Glaser & Strauss, 1967). However, in this study, the primary researcher also incorporated a directed approach, which allowed existing evidence to be integrated into the research process. This directed approach utilizes deductive reasoning, or using existing theory to build initial codes during the analysis process (Hsieh & Shannon, 2005). The researcher integrated grounded theory and directed analysis because grounded theory is flexible and allows the researcher to have freedom in implementing grounded theory's methods (Charmaz, 2006; Ralph, Birks, & Chapman, 2015; Saldaña, 2013; Skeat & Perry, 2008).

Grounded theory includes the following core techniques: theoretical sampling, concurrent data collection and analysis, continual comparison in analysis, memo writing to assist in analysis, and integration of a theoretical background around a core category (Charmaz, 2006; Cohen & Crabtree, 2006; Saldaña, 2013; Skeat & Perry, 2008).

Theoretical sampling occurs when a researcher systematically selects participants based on their research topic. That is, the researcher chooses participants in order to learn more about an emerging topic or theory, instead of choosing participants based on their representativeness (Cohen & Crabtree, 2006; Skeat & Perry, 2008). The goal of theoretical sampling is to develop and saturate categories as they emerge from the data

(Cohen & Crabtree, 2006). The participant sample is considered complete when no new codes are identified as new participants are added to the sample (Glaser & Strauss, 1967; Skeat & Perry, 2008). More information on data saturation and participant sample size will be covered below.

Grounded theory requires that data collection and data analysis be integrated and occur simultaneously. Thus, as data were collected, the researcher engaged in ongoing data analysis. During data analysis, the primary researcher regularly compared the emerging data, asked reflective questions, and met with her peer debriefer who asked critical questions (Cohen & Crabtree, 2006; Glaser & Strauss, 1967; Skeat & Perry, 2008). (See Appendix F for the peer debriefer's questions.) The researcher recorded these comparisons and reflections in a process known as memo writing (Charmaz, 2006; Saldaña, 2013; Skeat & Perry, 2008). Memos are informal notes or diagrams that allow the researcher to interpret the data by asking questions while engaging with the data. Memos have an important role in that they provide an audit trail and record to track the researcher's developing ideas. Memos then became an additional code and category generating method and allowed the researcher to keep track of her decision-making processes, which add to the study's validity (Brantlinger et al., 2005; Saldaña, 2013; Whitemore et al., 2001). Eventually, during the data analysis process, categories were identified which allowed implications to develop that can be applied beyond just the scope of the study (Skeat & Perry, 2008).

### **Directed Analysis**

Directed analysis incorporates existing research and theory to inform both the

questions asked during the interview process and the initial codes, while still allowing for additional codes to be created as needed (Hsieh & Shannon, 2005). Combining directed analysis with the flexible approach of grounded theory allowed the researcher to use existing information and models during questioning and coding while inductively verifying them using the grounded theory principles. These existing models will be described in the axial coding section below. One of the primary risks of using a directed approach is the chance that the researcher may approach the data with a bias based on existing literature. This bias could result in the researcher focusing exclusively on confirmatory evidence rather than being open to creating new constructs (Hsieh, & Shannon, 2005). Grounded theory's focus on the context, experience, and individuality of participant's experiences can help reduce this risk of researcher bias.

The outcome of integrating grounded theory methodology with a directed approach was a systematic model used to explore the research questions. Thus, the combination of directed analysis and grounded theory was well matched for exploring adult siblings' perspectives and knowledge about guardianship and its alternatives. Currently, siblings' perspectives on this topic are understudied, as published research that has asked siblings about future planning for their brother or sister has not directly inquired about guardianship alternatives. While many sibling studies have indicated gender and birth order factors that serve as predictors for siblings' involvement with caregiving for their brother or sister (e.g., Bigby, 1998; Burke et al., 2012, 2016; Krauss, Seltzer, Gordon, & Friedman, 1996), these studies have not specifically explored these siblings' perspectives on guardianship and its alternatives. By understanding what aspects



of existing theories may be applicable to this study, as well as allowing for identification of any new potential constructs that may better explain their perspectives, service providers' ability to address siblings' unique needs may improve. The benefits of this theoretical framework include describing siblings' perspectives, knowledge, and areas of need, which will help practitioners and other professionals to have a greater understanding of how to support siblings as they transition into more formal supportive roles with their brother(s) and/or sister(s).

## **Participants**

### **Inclusion and Exclusion Criteria**

To be included in this study, participants needed to be a sibling of at least one brother or sister with an ID who were at least 18 years old. It was not necessary for participants to be a biological sibling of someone with ID, as step-siblings or adopted siblings might fill this guardianship role. As such, for the purposes of this study, a "sibling" was defined as a typically developing brother or sister who grew up in the same household as a brother or sister with disabilities (Taylor et al., 2016). Growing up in the same household was an important inclusion criterion because many prior studies have indicated that the extent that the level of involvement of typically developing siblings with their brothers/sisters with ID into adulthood is often impacted by their experiences growing up together (e.g., Burke et al., 2012; Krauss et al., 1996; Taylor et al., 2016). For example, Burke et al. (2012) surveyed 757 adult siblings of people with IDD, and they found that the extent that a sibling was involved with their brother or sister's care during

childhood predicted their involvement in adulthood. That is, siblings who were more involved with their brother or sister's care as children continued to be more involved with their care into adulthood. The minimum age of 18 was used based on prior adult sibling caregiver studies (Burke et al., 2012; Burke, Fish, & Lawton, 2015) and is based upon common legal requirements designating 18 as the minimum age for most states to become a legal guardian of another person (American Bar Association, 2016a).

Additionally, to be included in the study, the sibling's brother or sister with ID had to be at least 18 years old, as this is the age of majority. Thus, siblings whose brother or sister had not yet reached the age of majority may not be as concerned or as actively thinking about guardianship and its alternatives as siblings whose brother or sister has reached the age of majority.

## **Recruitment**

After obtaining Utah State University's Institutional Review Board (IRB) approval, recruitment began. Recruitment was done through a variety of methods: posting announcements on Utah's Sibling Leadership Network's (SLN) Facebook page, posting an announcement on the national Sibling Leadership Network's website, posting flyer advertisements around USU's campus, and emailing flyers to Utah disability service agencies (see Appendix B for Flyer). Recruitment occurred during March and April, with interviews occurring in late March and April.

The primary researcher sought to recruit a minimum of six adult (ages 18+) siblings of people with ID. Recruiting this number of people was based on existing research recommendations of four to ten interviews for doctoral work (Beail & Williams,

2014; Smith, Flowers, & Larkin, 2009). Moreover, prior research has demonstrated that 6 to 12 interviews are sufficient for theme extraction, as the majority of insights are gleaned by 12 interviews (Coenen et al., 2011; Guest, Bunce, & Johnson, 2006). Specifically, Guest et al. reviewed the data from 60 interviews, and found that a majority of the codes occurred within the first six interviews, and that 97% of the codes were identified within 12 interviews, indicating that data saturation occurs early on in the interview process.

### **Data Satiation**

However, because this study used theoretical sampling to develop and saturate categories as they emerge from the data (Cohen & Crabtree, 2006), the participant sample was considered complete when no new codes were identified as new participants are added to the sample (Glaser & Strauss, 1967; Skeat & Perry, 2008). Thus, when no new insights were gleaned from additional participants, data saturation occurred (Glaser & Strauss, 1967; Skeat & Perry, 2008). Therefore, while as few as four interviews are recommended for doctoral work (Beail & Williams, 2014; Smith et al., 2009), this study included a total of 10 participants to better ensure satiation.

A total of 30 potential participants responded from the flyers. A wait list was used to stagger the participant interviews so that initial analysis of each interview could be performed before adding each new participant. From the initial response of 16 participants, the first six individuals who responded and met criteria for inclusion were interviewed; their responses were compared using the constant comparative analysis methods (Cohen & Crabtree, 2006; Coyle et al, 2014; Burke, Fish, & Lawton, 2015;

Saldaña, 2013).

Though no new themes were uncovered after the initial six interviews, these first participants were relatively young (i.e., all under the age of 33), and none of them were currently their brother or sisters' primary caregiver, guardian, or supported decision making partner. Because prior research has indicated some differences in perspectives and roles between siblings who were future and anticipated caregivers (Burke, Fish, & Lawton, 2015), to capture the perspective of older individuals, theoretical sampling was used to select the remaining four participants, who were all older (age range 46-68 years). These last four participants were selected based on theoretical sampling methods (Cohen & Crabtree, 2006) from a wait list of ten other adult siblings who had expressed interest in participating. From these ten potential participants, two had brothers who were not yet 18 years old, so they were excluded based on the age. Four of these potential participants were also relatively young (under age 40), and the remaining four participants were over age 40. Thus, these four older siblings were invited to participate, and the final four interviews were scheduled. However, when the responses from these last four participants were compared with the codes from the initial six participants using the constant comparative method, their responses closely followed those of the initial participants, as will be discussed further in the results section. Thus, it was determined that data saturation had occurred, which corresponded to findings from previous research that data saturation occurred before 12 interviews (Coenen et al., 2011; Guest et al., 2006). Fourteen additional potential participants contacted the primary researcher after data satiation had been reached. Thus, out of thirty potential participants who expressed

interest in this study, ten adult siblings were interviewed.

### **Informed Consent**

All potential participants were fully informed of both their right to participate and their right to withdraw at any time, and informed consent forms were completed prior to the interviews. After the first participant contacted the primary researcher to express her interest in participating in the study, an appointment was scheduled to meet in a public location to conduct the interview. At the beginning of this face-to-face meeting, the primary researcher sent the participant an email link to the Qualtrics survey, which contained an electronic copy of the consent form. The primary researcher explained the purpose of the study, reviewed the consent form, and asked the participant to sign electronically and complete the survey prior to the start of the interview. After the survey was completed, the primary researcher gave the participant a paper copy of the consent form, reminded the participant that she could withdraw at any time, and verbally confirmed permission to audio-record the interview.

However, upon reviewing the survey after this initial interview had concluded, the primary researcher realized that the participant skipped many key questions on the survey (e.g., anticipated caregiving role). In order to allow future participants to more thoroughly complete the survey on their own time before the interview, and to allow the primary researcher the opportunity to review the information from the surveys before the interview meeting with participants, the link to the consent form and the electronic survey was emailed prior to the interview meeting for each subsequent participant. Then, at the beginning of each interview meeting, the primary researcher reviewed the consent form

with each participant prior to asking any interview questions (See Appendix A for informed consent form).

Participants were asked to consent to the following: (1) completing an anonymous electronic survey, (2) participating in an audio-recorded interview, and (3) responding to a member-checking follow-up after initial coding. While consenting to the first two items (survey and audio-recorded interview) were required for individuals to be included in this study, consenting to an email follow-up was optional. However, all participants consented to member checking; more information on member checking will be described below.

### **Participant Demographic Characteristics**

Table 1 gives an overview of the demographic characteristics of the participants. The majority of participants (70%) were female; all were Caucasian and had some level of college education. Four of the participants identified as Latter-Day Saints (LDS), one identified as Christian, one identified as Episcopalian, and four did not identify with any religion. There was a broad range of annual household income (from under \$20,000 to over \$100,000). Most of the participants (80%) lived a half a day's drive or more from their brothers and sisters. Seven of the participants resided in Utah. Two resided in Illinois, and one resided in Nebraska. However, their brothers and sisters with IDD lived in the following states: Arizona ( $n = 2$ ), California ( $n = 1$ ), Illinois ( $n = 1$ ), Indiana ( $n = 1$ ), North Dakota ( $n = 1$ ), Utah ( $n = 3$ ), and Wyoming ( $n = 1$ ). However, as will be discussed in Chapters IV and V, geographic diversity did not appear to influence response patterns.

Table 1

*Participant Demographics*

Characteristic	( <i>n</i> ) (total <i>n</i> = 10)
Gender	
Female	7
Male	3
Race (White)	10
Religion	
LDS	4
Christianity	1
Episcopalian	1
None	4
Education	
Some College	3
Associates	2
Bachelors	3
Masters	1
Doctorate	1
Annual Income	
Under \$20,000	2
\$40,000-59,999	2
\$60,000-79,000	2
\$100,000 or more	3
Proximity of the person with disabilities	
Within 30 min drive	2
Within half a day's drive	4
More than half a day's drive	4
Siblings with guardianship of bro/sis with disabilities	
Currently	3
Expected in Future	4
Not expected/unsure	3
Anticipated Caregiving Role	
Not a caregiving role	2
Shared caregiving role	2
Primary caregiving role	3
Not stated/unsure	3
Sibling's type of disability	
Intellectual Disability	10
Autism	5
Down Syndrome	1
Blind/Visual Impairment	1
Mental Health Diagnosis	1
Physical Disability	3
Speech/Language Impairment	3
Cornelia de Lange Syndrome	1
Dandy Walker Syndrome	1

*Note.* All participants had more than one disability; thus, numbers under the disability categories are greater than 10.

Regarding their actual or anticipated roles as guardians and/or caregivers, the participants represented a range of roles. Three participants were currently their brother or sister's guardian, four expected taking on this role in the future, and three did not expect to take or were unsure of taking on this role. Regarding caregiving roles, two siblings did not anticipate having a caregiving role, two planned to have a shared caregiving role, three planned to be primary caregivers, and three were unsure of their future caregiving role.

The participants' brothers and sisters with disabilities represented several disabilities; all had a diagnosis of ID and at least one other disability. The most commonly co-occurring disabilities were autism ( $n = 5$ ), physical disabilities ( $n = 3$ ), and speech-language disabilities ( $n = 3$ ). The brothers and sisters represented a range of challenging behaviors, as will be detailed in the following section. None of the participants currently lived with their brother or sister with disabilities; instead, their brothers and sisters lived in a range of settings. Specifically, four lived with their parents, three lived in a group home, one lived in a host home, one lived in an apartment, and one lived with his sister.

### **Specific Profiles**

Prior research has indicated that certain sibling demographic characteristics (Burke et al., 2012; Coyle et al., 2014; Taylor et al., 2016) and siblings' level of closeness (Bigby, 1998) may influence their future involvement with their brother and sisters' care. Thus, extensive explanation will be given to the demographics and siblings' relationships in this chapter, while the next chapter will give a more detailed discussion of how these demographics may correlate to participants' responses (Bloomberg & Volpe, 2008;



Creswell, 2013). Participants are described in the order they were interviewed, and all names used are pseudonyms. In the cases where the participant had more than one brother or sister with ID, they were asked to report only on one of these brothers or sisters. Specifically, they were asked to report on the brother or sister who was either closest in age to him/her or who they felt relationally closer to. Choosing to focus on only one brother or sister with ID was based on recommendations from two content experts in the field of sibling research (Arnold, personal communication, December 2016; Burke, personal communication, November 11, 2016).

**Caroline.** Caroline was a 21-year-old female enrolled in college. Caroline associated with the LDS religion and had six older brothers. Her 24-year-old sister, Kristine, loved to watch movies and spend time outside. Kristine was reported as having multiple disabilities (ID, physical disabilities, and a speech/language impairment). Kristine lived with their parents, who were her legal guardians, and required total assistance for all her activities of daily living (ADLs). Kristine did not attend any work or day programs, and she communicated through a variety of non-vocal methods: pointing, head-nodding, and thumbs-up. Caroline did not report that Kristine engaged in any challenging behaviors.

**Jordan.** Jordan was a 20-year-old female studying special education in college. She did not associate with any religion and had another older sister and two older brothers. Her 26-year-old sister, Casey, enjoyed taking walks with Jordan, and they liked to watch television together. Casey lived with their parents, who were her legal guardians. Casey was reported as having multiple disabilities (ID, autism, physical

disabilities, and a speech/language impairment) and attended an adult day program. Casey needed total assistance with all her ADLs, and often engaged in challenging behaviors such as disruptive behaviors (i.e., hitting her head with her hand), uncooperative behaviors, and repetitive behaviors. However, Jordan reported that these behaviors were not severe and did not interfere with Casey's ADLs. In fact, Jordan stated that sometimes Casey engaged in head-hitting to communicate something, such as her excitement. Casey also communicated through facial features such as grimaces or smiles.

**Harry.** Harry was a 33-year-old male with some college education who did not associate with any religion. Harry had five older sisters. His 28-year-old brother, Greg, enjoyed outdoor activities such as biking and riding a four-wheeler. Greg was reported as having Down syndrome and ID and lived with one of their sisters, who was his legal guardian. Greg needed varying levels of support to complete ADLs. For example, he could eat, use the phone, perform housework, and dress without assistance. He required some support for other ADLs, such as bathing, preparing meals, and doing laundry. Greg currently was unemployed, but had a history of working in competitive employment in the community. Greg was typically well-behaved and only occasionally uncooperative. Greg communicated in simple sentences or by pointing, crying, gestures, or body language.

**Donald.** Donald was a 30-year-old male enrolled in a Ph.D. program. He did not associate with any religion, and had one younger sister and three younger brothers. His 27-year-old brother, Gordon, loved bluegrass music and being around his family. Gordon was reported as having ID, autism, and Cornelia de Lange Syndrome, and his parents

were his legal guardians. Gordon communicated in simple sentences, but his communication was difficult for unfamiliar people to understand. He lived at home with his parents and two younger brothers, and his job coach supported him at a worksite in the community. Gordon needed various levels of support to perform ADLs. For example, he could use the phone, eat, and move around his home with no support, but required total support to take his medications, manage his money, prepare his meals, and do housework. He occasionally exhibited challenging behaviors such as hurting himself or others, being uncooperative, and engaging in repetitive behaviors.

**Jennifer.** Jennifer was a 30-year-old female with a doctorate degree who associated with the Christianity religion. She had seven step-siblings and biological siblings, and two of her biological siblings had intellectual disabilities. Jennifer was the second oldest child in her family. For this study, she chose to only discuss her relationship with her 28-year-old brother, Devin, as her other sibling with ID was much older and had moved out of the house when Jennifer was six years old. Devin loved to go out to eat with Jennifer and listen to Beatles music. Devin was reported as having ID, autism and Fragile X syndrome and resided in a group home with five other men. He communicated through 2-3 word sentences and often engaged in echolalia. His main challenging behaviors were aggression and operant vomiting. He needed a range of supports for his ADLs; he was independent in dressing and bathing, but often needed verbal prompts to remain on task in many other ADLs. Jennifer was unsure if Devin had a legal guardian.

**Rachel.** Rachel was a 24-year-old female with a bachelor's degree who associated

with the LDS religion. She had one sister and four brothers; two of her brothers had ID. Rachel was the third oldest child in her family. For the interview, she chose to talk about her twin brother, Kyle, who loved to go grocery shopping and go out to the movie theatre. Kyle was reported as having ID and autism. Kyle lived at home with their parents, who were his legal guardians, and Kyle communicated using a picture system. He needed total help for most of his ADLs, with the exception of eating, bathing, and using the restroom. He occasionally engaged in challenging behaviors such as hurting himself (i.e., hand biting), property destruction, and being uncooperative. Rachel did not report on whether or not Kyle worked or attended a day program.

**Crystal.** Crystal was a 49-year-old female with some college education. She did not associate with any religion and had one brother, Carl. Carl enjoyed watching older comedies (such as the *Three Stooges*), and he enjoyed telling others the jokes from these programs. Carl was 51 years old and was reported as having ID and autism. At this time, Crystal and their mom shared legal guardianship of Carl. He lived in a group home and worked in a sheltered workshop. Carl communicated in simple sentences, usually to express his needs (e.g., “I want...”) and did not communicate his emotions (e.g., “I’m upset about...”). He could eat, get dressed, and move around his home independently, but required total support to do his laundry, prepare meals, take medications and manage his money. He occasionally engaged in challenging behaviors such as hurting others and destroying property. He took two medications to manage these challenging behaviors.

**Sally.** Sally was a 46-year-old female with an associate’s degree who identified with the LDS religion. She had one sibling, Roger, who was 48 years old. Roger enjoyed

going out to eat and listening to music. Roger was reported as having multiple disabilities (ID and cerebral palsy), and Sally described his vocal communication as “mainly gibberish” that was difficult for most people to understand. Though Sally had been Roger’s legal guardian in the past, he was currently a ward of the State that he lived in. Roger lived in a group home with 10 other men, and he needed total support for most ADLs. For example, he had the full range of motion and use of only one of his arms, which he used to assist caregivers who were helping him get dressed. His primary challenging behaviors were aggression and biting his arm. Sally was unsure if he worked or attended a day program.

**Natalie.** Natalie was a 68-year-old female with a bachelor’s degree who self-identified with the Episcopalian religion. She had one brother who was deceased and one younger sister, Izzy. Izzy loved to go shopping, spend time at her family’s cottage, and go out to eat. She was 63 years old and lived in an apartment with two other ladies with ID. Izzy was reported as having ID, a visual impairment, and cerebral palsy. She spoke in full sentences that were easily understood by others and needed a range of supports for her ADLs. For example, she was independent in eating, dressing, and grooming, but needed full support to manage her money, take her medications, and prepare meals. Izzy worked in the community and rarely engaged in any challenging behaviors. Natalie was Izzy’s legal guardian.

**Lee.** Lee was 53-year-old male with a bachelor’s degree who identified with the LDS religion. He had four younger brothers and one younger sister, Kay. Kay loved to attend their family’s campouts and other gatherings, and she and Lee enjoyed teasing one

another. Kay was 41 years old and was reported as having multiple disabilities (ID, mental illness, physical disabilities, and Dandy Walker Syndrome). Lee, his mother, and two of their brothers were Kay's legal guardians. Kay communicated in full sentences and was easily understood by her listeners. She lived in a host family that was set up through the Department of Human Services in her state, and she worked at a sheltered workshop and in the community with the support of a job coach. Kay needed a range of supports to perform her ADLs; for example, she needed full help with managing her money and taking medications. She could use the phone, eat, get dressed, bathe, and use the restroom independently. She occasionally engaged in the following challenging behaviors: hurting herself, hurting others, destroying property, and being uncooperative.

## **Instrumentation**

### **Interview Format**

The primary researcher conducted the interviews using a semi-structured interview protocol with follow-up probe questions as needed (see Interview Protocol listed in Appendix D). These questions were developed based on the literature review and the qualitative methods selected. Additionally, two experts in the field of adults with disabilities vetted the interview questions to confirm that the questions were not too abstract or lacking clarity. Both experts have extensive experience working with individuals with disabilities as well as conducting interviews and other qualitative research. Moreover, the local chapter of the Sibling Leadership Network (Utah Sibs) vetted this series of questions and provided feedback and recommendations, which were

incorporated into the protocol (see Appendix D).

Semi-structured questions were utilized to provide flexibility for the interviewer to ask follow up or clarifying questions during the interview (Cohen & Crabtree, 2006; Lambert & Loiselle, 2008). For example, sometimes participants did not fill out certain questions on their surveys, such as their anticipated caregiving and guardianship roles, so the researcher re-asked these questions during the interviews. Semistructured interviews are a better fit than other types of interview methods, such as structured questions, which do not allow participants much room to vary their responses or expand on their responses (Cohen & Crabtree, 2006). Thus, as the purpose of this study was explorative, semi-structured interview questions were developed. The primary researcher audio-recorded all interviews and transcribed them verbatim. Four interviews were conducted in a face-to-face format, and six interviews were conducted via Zoom video conferencing, as these participants lived beyond a reasonable driving distance from Logan, Utah. All interviews were conducted in quiet locations with only the interviewer and the participant in the location. Face-to-face interviews were conducted in a study room in a university library. During the Zoom interviews, both the participant and the interviewer were the only individuals in their respective rooms. Thus, both face-to-face and video-interviews were conducted in similar quiet settings with minimal environmental distractions. Regardless of location, the participants appeared relaxed, made frequent eye contact, and seemed to answer all questions forthrightly.

Additionally, during the interview, the participant was provided with a brochure, which defined guardianship and its alternatives and had links to internet-based resources

on these topics (see Appendix E). The timing of this brochure was strategically placed in the interview protocol and was given after the participant explained his/her current understanding of guardianship and its alternatives. This brochure was intended to clarify to the participant these key definitions as well as provide additional resources if the participant decided to further investigate guardianship and/or its alternatives after the interview. The local chapter of the Sibling Leadership Network (Utah Sibs) vetted this brochure and provided feedback and recommendations, which were incorporated into the brochure.

### **Demographic Questionnaire**

Participants were asked to complete a demographic questionnaire prior to the interview. These demographic items were based on previous research, which collected key demographic information prior to participants' interviews (ADL; Seltzer & Li, 1996; Bruininks, Woodcock, Weatherman, & Hill, 1996; Burke et al., 2012; Burke, Arnold, & Owen, 2015; Burke, Fish, & Lawton, 2015b). Appendix C shows the demographic survey that participants completed. These key demographics were collected because prior research indicates that certain demographics such as age, gender, birth order and number of siblings, influence siblings of people with disabilities' level of responsibility and involvement with their brother or sister (e.g., Burke et al., 2012; Coyle et al., 2014; Taylor et al., 2016). Additionally, because several of the avenues for recruitment were based in Utah, where the Latter-Day Saints (LDS) religion is very predominant, it was assumed that many participants may have an LDS background. It was hypothesized that this religious background may influence these participants' perspectives and/or family



expectations for siblings as caregivers/guardians. Therefore, the following question was added to the demographic survey which asked participants: “What, if any religion do you associate with?”

## **Procedures**

### **Data Collection and Storage**

All audio recordings and transcripts of the interviews were stored on Utah State University’s BOX storage system, which is HIPAA compliant. Additionally, back-ups of the audio and transcripts were stored on an USB-drive that was password-protected and stored in a restricted-office location; this data will be destroyed three years after this study. Prior to initiating the recoding, participants were asked to choose a pseudonym for themselves and their brother/sister in order to protect the participants and their families’ confidentiality. Participant demographic questionnaires were de-identified by assigning a number/pseudonym to the participant. The identity key list of numbers and the corresponding participant emails was stored in a file on BOX; only the primary researcher and dissertation chair had access to this identity key. The identity key will be destroyed 3 years after the completion of this study. Likewise, the questionnaire results were de-identified and stored on Utah State University’s BOX storage system.

### **Data Analysis**

**Initial coding.** After transcribing the interviews, the primary researcher inserted each individual transcript into a two-column table in a Word document. The transcript was in the left column, and each line in the right column was numbered and used for

labeling the codes. The transcripts were analyzed using initial coding procedures, otherwise known as open coding. During open coding, the data were regularly examined and broken down into discrete parts, which helped reveal similarities and differences (Charmaz, 2006; Cohen & Crabtree, 2006; Saldaña, 2013). Line-by-line coding, or naming each line in the transcript, was used to complete this process with continual memos utilized to assist in identifying processes, trends, or patterns (Charmaz, 2006; Saldaña, 2013). These memos included the researcher's thoughts, ideas, questions, self-reflections, links to prior participant's information, connections with published studies on siblings, or potential explanations that occur during the coding process. These memos allowed re-tracing of the researcher's thoughts and interpretations; moreover, these memos then became a part of the data assessment (Charmaz, 2006; Saldaña, 2013). Peer debriefing was used throughout the initial coding process, where the primary researcher met with a third-year doctoral student to discuss her initial codes and analysis process. The peer debriefer asked critical questions of the primary researcher, which helped guide the analysis process (see Appendix F). The initial codes discovered during open coding were guided by what was observed within the content without referring to an existing list of potential codes.

**Axial coding.** After this open coding, axial coding was used (Cohen & Crabtree, 2006; Saldaña, 2013). In axial coding, related categories were combined into major categories, and redundant codes were removed. During axial coding, the most representative codes were maintained and ultimately selected. Representative codes are those that are mentioned with the highest rates of recurrence within and across participant

interviews. Axial coding also incorporated existing codes uncovered in the research to determine if they are representative of the participants. By combining similarly coded data, the number of initial codes decreased, which allowed the data to be sorted and interpreted more accurately (Saldaña, 2013). The initial axial codes included as part of the directed approach included the following topics identified in the literature review:

- Siblings as current caregivers
- Siblings as expected caregivers
- Siblings as not expecting/anticipating caregiving
- Siblings as current guardians
- Siblings as expected guardians
- Siblings as not expecting to be guardians
- Siblings' level of awareness of guardianship alternatives
  - 0 = do not know any alternatives
  - 1 = know some alternatives, but cannot describe these
  - 2 = know some alternatives and can describe most of these
  - 3 = know of all possible alternatives and can describe all of these
- Siblings having different levels of involvement based on demographic characteristics

However, based on the data analysis and the appropriateness of fit, new axial codes were established and some existing codes were removed in a process known as selective coding (Cohen & Crabtree, 2006). Table 2 gives a comparison of the initial axial and final axial codes. The final axial codes created based on the consolidating of the initial codes and the directed analysis resulted in the following axial codes:

- Sibling's level of involvement in overseeing their brother/sister's care
- Siblings' thoughts and feelings about future planning
- Siblings' future planning with parents
- Siblings' relationship and activities together
- Siblings' always planning on this
- Siblings' awareness and understanding of alternatives
- Siblings' definition of guardianship
- Siblings' explanation of the initial guardianship process

Table 2

*Axial Codes*

Initial axial codes	Final axial codes
Siblings as current caregivers	Level of involvement and overseeing care 1 = frequency and extent of contact with parents 2 = frequency and extent of contact with staff 3 = Reasons, content of discussions
Siblings as not expecting/anticipating caregiving	Thoughts and feelings about future planning  Future planning with parents 1 = Yes, with examples 0 = No, with examples
Siblings having different levels of involvement based on demographic characteristics	Relationship and activities together 1 = methods and frequency of contact 2 = types of activities together 3 = geographic distance 4 = descriptions of brother/sister (personality, characteristics, etc.)
Siblings as expected caregivers	Always planning on this
Siblings' level of awareness of guardianship alternatives 0 = do not know any alternatives 1 = know some alternatives, but cannot describe these 2 = know some alternatives and can describe most of these 3 = know of all possible alternatives and can describe all of these	Awareness and understanding of alternatives 0 = do not know any alternatives 1 = know some alternatives, but cannot describe or define these 2 = know some alternatives and can describe or define 3 = know all possible alternatives and can describe or define these
	Definition of guardianship 1 = includes legal aspects 2 = includes decision making aspects 3 = includes both legal and decision making aspects
	Explanation of the initial guardianship process 0 = no idea/no examples given 1 = only 1 step mentioned 2 = 2 steps mentioned 3 = 3 steps mentioned 4 = 4+ steps mentioned with many supporting details
Siblings as current guardians	Guardianship as protection

*(table continues)*

Initial axial codes	Final axial codes
Siblings as expected guardians	Guardianship as absolutely necessary
Siblings as not expecting to be guardians	Thoughts and feelings about guardianship and its alternatives
	Open v. closed to alternatives 0 = closed to alternatives for own family 1 = open to alternatives for own family 2 = open to alternatives for other families, but not their own 3 = open to alternatives for their families and others
	Types of supports given to brothers and sisters during decision making
	Brother/sister's decision making level 1 = age, if mentioned 2 = not sure if brother/sister can make own decisions 3 = examples of decisions that brother/sister can make
	Brother/sisters' communication methods 1 = very vocal 2 = limited vocal 3 = pictures 4 = ASL/gestures 5 = Eye Gaze 6 = Other (e.g., facial features)
	Others' misunderstanding their brother or sister 0 = always understood 1 = sometimes misunderstood 2 = frequently misunderstood

- Siblings' view guardianship as protection
- Siblings' view guardianship as absolutely necessary
- Siblings' thoughts and feelings about guardianship and its alternatives
- Siblings' openness to guardianship alternatives
- Types of supports given to brothers/sisters to make decisions
- Brothers/sisters' decision making level
- Brother/sisters' communication style
- Outsiders' (nonfamily members) misunderstanding of brother/sister

**Themes.** Though initial codes and raw data were organized into a table in a Word document, during the subsequent rounds of axial coding, themes were condensed and

moved into an Excel document. When developing the themes, the primary researcher listened to the audio recordings and read the interview transcriptions multiple times while recording significant quotes, statements, and phrases into this Excel document. Finally, units of meaning and context from the significant statements and codes were clustered into relevant themes around the three research questions. Figure 1 shows the axial codes that were combined into each of the three themes. The final themes are as follows: (1) siblings' limited knowledge of guardianship and its alternatives, (2) siblings view guardianship as necessary, and (3) siblings' desire for planning and future involvement with their brothers and sisters. These themes will be discussed in detail in Chapter IV.

### **Researcher Bias**

The primary researcher acknowledged that she, as an adult sibling of a brother with ID and other disabilities, needed to be aware of her biases. Specifically, her biases included a belief that guardianship is unnecessarily restrictive for many adults with disabilities and that alternatives to guardianship may be more appropriate for many adults with ID. To keep these biases in check, the primary researcher utilized validity checks and continuously engaged in self-reflection throughout the interviewing, coding, and analyzing of results. The primary researcher's self-reflections were recorded in analytic memos, a recommended practice for increasing validity in qualitative research (Whittemore et al., 2001). The primary researcher also engaged in reflection through peer debriefing with a second researcher and her dissertation chair who asked critical questions during the analysis period (see Appendix F). Likewise, the use of a second coder increased the credibility of the primary researcher (Brantlinger et al., 2005).

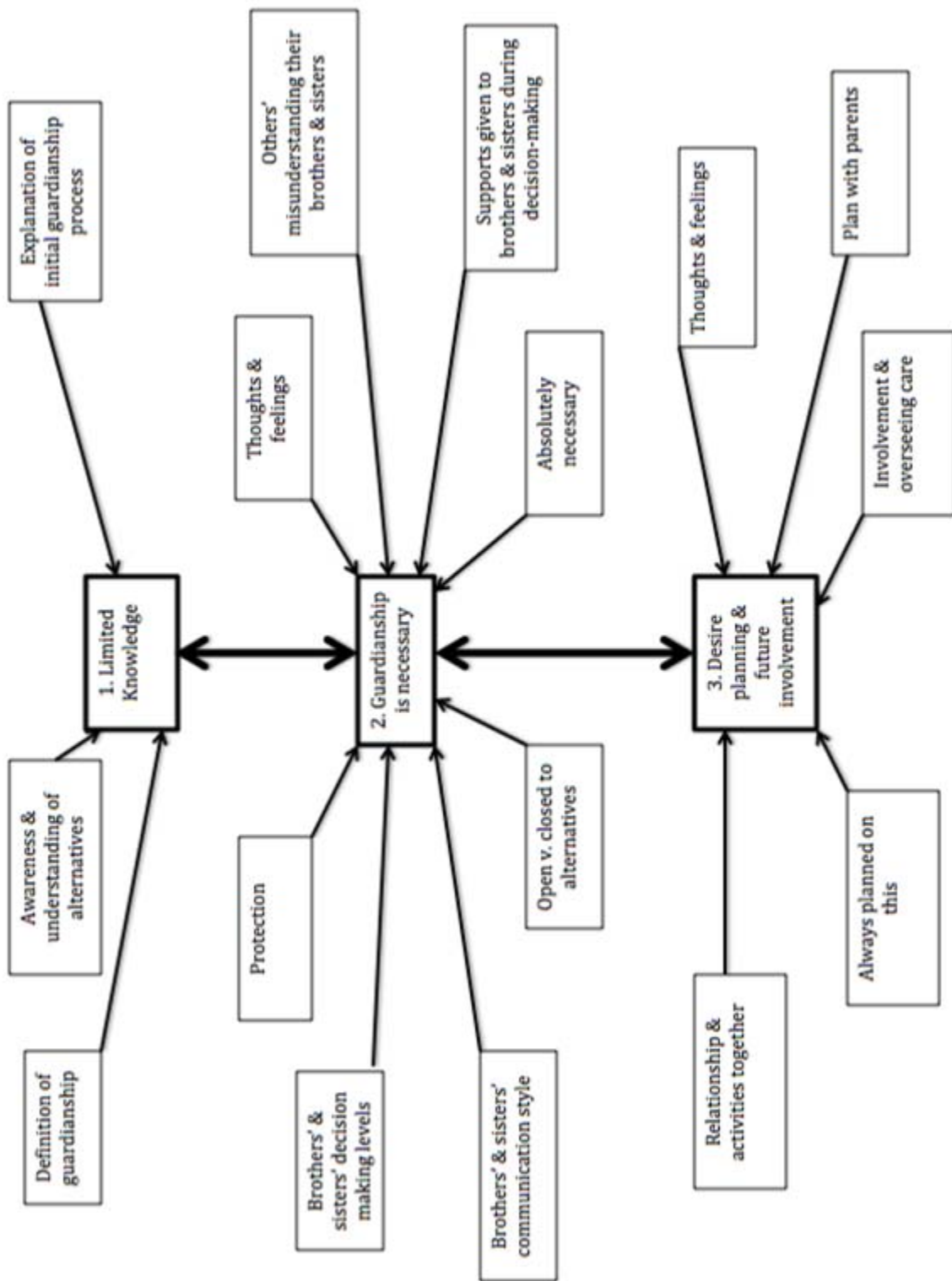


Figure 1. Codes to themes.

## Validity in Qualitative Research

In qualitative research, validity refers to the truthfulness of the findings (Whittemore, et al., 2001). Figure 2 shows the validity checks that were built-in to this study in order to minimize the risk of the author's bias on data analysis. Whittemore et al. recommend considering validity throughout the entire qualitative process, from planning to analyzing to reporting. These researchers explain primary and secondary criteria that increase validity in qualitative research. Specifically, they advocate that primary criteria that are necessary for all qualitative inquiry include the following: credibility, authenticity, criticality, and integrity. Secondary criteria include explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. These criteria refer to the reader's ability to follow the researcher's interpretive effort and process, including aspects such as the researcher's choices of methodology, his/her interpretations, and his/her investigator biases.

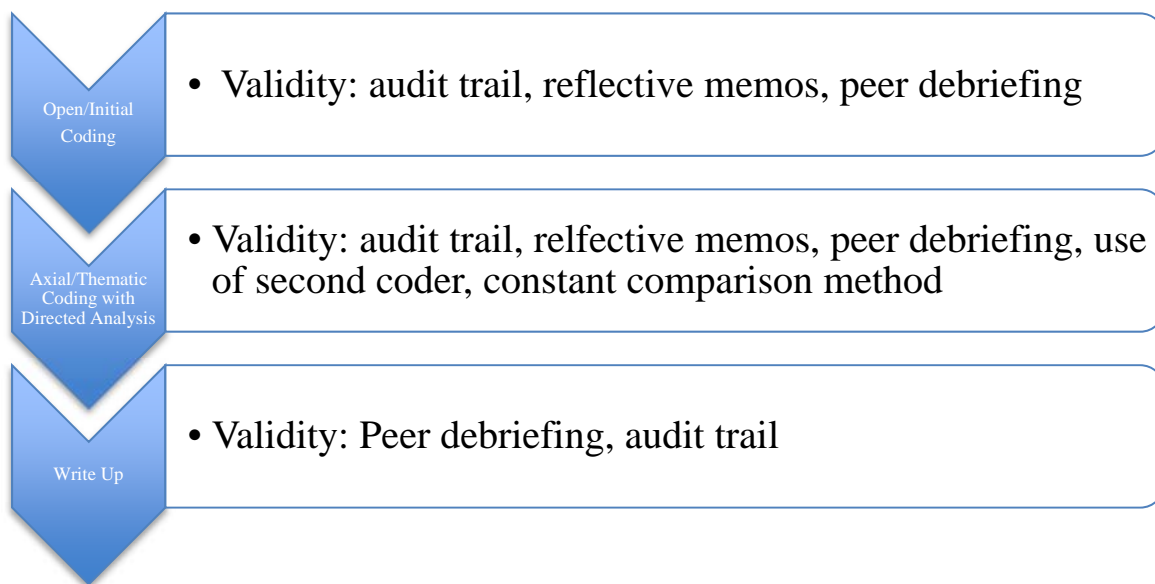


Figure 2. Analysis process and validity.



The qualitative methods used in this study were flexible and adapted or combined based on the needs and goals of the specific project (Saldaña, 2013). For this study, the following validity techniques were incorporated: member checking; memoing and reflective journaling; providing an audit trail of the decisions and study's processes; using peer debriefing throughout the analysis process; and the use of a second coder (Cohen & Crabtree, 2006; Brantlinger et al., 2005; Whittemore et al., 2001). Appendix F outlines a list of questions that the peer debriefer asked the primary researcher throughout the entire study as well as how these questions address different aspects of validity.

### **Triangulation**

Participant member checks, also known as member checking, were utilized throughout the data collection and analysis process. The primary researcher contacted the participants via email with summaries of their individual perspectives after the initial analyses to ensure that the researchers' interpretation accurately reflected the participant's intended meanings (Brantlinger et al., 2005; Hsieh & Shannon, 2005; Koch, Niesz, & McCarthy, 2014; Patton, 1999). Nine of the ten participants responded to these emails; one participant did not respond to multiple email attempts to follow-up. Of the nine that responded, seven confirmed that the researchers' summaries were accurate. Two requested minor alternations. Specifically, one asked that her brother's decision making abilities be reported as a 3-year-old's rather than a range between 3-4 years old. Another participant requested that one rather personal detail about her brother's communication methods be removed.

Along with these member checks, additional validity checks were built into this

study. For example, to increase trustworthiness of the results, a second researcher double-coded the transcripts. The primary researcher recruited this researcher from a qualitative research course; she was experienced in qualitative analysis and a third-year Ph.D. student. The primary researcher provided the second researcher a prospectus outlining the research protocol, research questions, axial codes, code book, and Excel data base to enter the codes with examples of the most representative responses.

The second coder then read through each transcript and selected the most representative statement from each participant for that code. After the second coder finished coding in the Excel document, the two researchers compared their axial codes and came to a consensus on their choice of representative statement codes. By using this constant comparative approach, the two researchers systematically analyzed the data and made comparisons between researchers and across interviews to develop themes (Cohen & Crabtree, 2006; Coyle et al, 2014; Burke, Fish, & Lawton, 2015; Saldaña, 2013). The use of this researcher triangulation enhanced the reliability and credibility of the data analysis process (Patton, 1999).

### **Summary**

This chapter gave an overview of the qualitative methods that this study used to explore the knowledge and perspectives of adult siblings of adults with ID about guardianship and its alternatives. The rationale for combining grounded theory and directed analysis was explained, and the details about the participants, instrumentation, and validity checks was also covered in this chapter. The next chapter will explain the

findings related to the three research questions from the 10 adult siblings of adults with ID who participated in this study.

## CHAPTER IV

### RESULTS

This study had the following purposes: (1) to determine what adult siblings of adults with intellectual disabilities (ID) know about guardianship and its alternatives; (2) to explore the perspectives and opinions of adult siblings of adults with ID about guardianship and its alternatives; and (3) to explore what adult siblings of adults with ID think about their role of being a guardian or supported decision maker for their sibling with ID. To explore these purposes, qualitative interviews were conducted with 10 adult siblings who had at least one brother or sister with ID. Using the analysis process described in prior chapters, and in order to answer the three research questions, the following three themes emerged: (1) siblings' limited knowledge of guardianship and its alternatives; (2) siblings view guardianship as necessary; and (3) siblings' desire for planning and future involvement with their brothers and sisters. Based on these three themes, it can be theorized that siblings with limited knowledge of guardianship alternatives view guardianship as necessary (e.g. "all or nothing"). This all or nothing approach can be addressed and alternatives presented as these siblings also desire assistance in preparing for the future and planning. Thus, these three themes are interrelated as the two-way arrows ( $\leftrightarrow$ ) indicated in Figure 1. Because this study is qualitative in nature, a thematic synthesis was used to analyze the results, and this chapter will present themes in a narrative format (Barnett-Page & Thomas, 2009).

## **Siblings' Limited Knowledge of Guardianship and Its Alternatives**

### **Knowledge of Guardianship**

Overall, participants reported knowing more about guardianship than any of the alternatives. However, as will be described shortly, none of the siblings mentioned one of the key aspects of guardianship—the loss of many legal rights for the ward. Additionally, as will be described below, four participants erroneously linked one's residential situation as a determinant of who one's guardian could be. Participants also described their knowledge about the initial process of setting up guardianship, their understanding of the definition and implications of guardianship, and their understanding about any alternatives to guardianship. As will be discussed shortly, siblings' more in-depth understanding of guardianship as opposed to its alternatives may have influenced their perspectives on guardianship and its alternatives.

**Initial guardianship process.** Participants expressed a range of knowledge about the initial guardianship process. In general, older participants explained more details about the initial guardianship process than younger participants, which may be due to the fact that most of the older participants were personally involved in setting up their brothers or sisters' initial guardianship, and/or they were currently serving in the role as guardian. In contrast, most of the younger participants were not actively involved in their brother or sister's initial guardianship and only observed their parents going through the initial process. This difference between older sibling's having more in-depth knowledge and involvement with guardianship than younger siblings has been found in previous research (Burke, Fish, & Lawton, 2015).

For example, three participants did not explain any specific details of setting up guardianship (e.g., “It just transferred to me after my mom died.” –Sally). The remaining participants explained two, three, or more steps. For example, Crystal, who was 49 years old at the time of her interview, gave rich details about getting an attorney, sending out letters to family, having a guardian ad litem, going to court, providing documentation about her brother’s disability, and talking with a judge. Likewise, Natalie, who was 68 at the time of her interview, described herself and her mother working together to set up her sister’s initial guardianship process, which included both a lawyer and a guardian ad litem.

In contrast, younger siblings tended to explain the steps that they saw their parents undergoing during the initial guardianship, but they were not personally involved in the process. Rachel, age 24, succinctly explained the process of her twin brother’s initial guardianship in this way: “it [the guardianship process] was definitely a lot more complicated than I realized. Since we were both, you know, 18 and in high school. Um, I just remember you know, there was just this huge pile of paperwork...” Rachel also referenced her parents getting a lawyer and going to court to finalize the guardianship, but she was not aware of the types of guardianship documentation or overall court processes, which older participants tended to describe in more detail. Likewise, Jordan, who was 20 years old at the time of her interview, simply described her older sister’s initial guardianship as a “whole legal process” that her parents had to go through. These differences in the level of detail given between older and younger participants may point to the level of involvement that they had in their brother or sisters’ initial guardianship, or

to the fact that three older participants were currently legal guardians. Perhaps younger siblings may learn more about the guardianship process if or when they later become their brothers or sisters' legal guardians.

**Definition.** When asked to define guardianship, siblings gave one of two answers. All siblings explained that guardianship involved making decisions on behalf of another person, which although accurate, is not the full definition of guardianship. For example, Harry described guardianship this way: "I would say, guardianship would be one that takes care of someone that is unable to accomplish financial, medical competency decisions." However, four siblings defined guardianship as not only making decisions for another person, but that this decision making was based on legal authority, which is a more complete explanation. As Donald explained:

When I become legal guardian for Gordon, I will have the same kind of responsibilities, um, uh, in terms of his care that, uh I do, for example, for my daughter. So I'd help with financial decisions, medical decision making; this is the status given to me by the law.

Thus, while all participants recognized that guardianship involves making decisions on behalf of another person, only four participants specifically stated that this surrogate decision-making was based on legal authority. However, though this legal aspect of guardianship was not specifically stated, the fact that most participants described guardianship as being set up through a lawyer and/or court indicated that they were aware that guardianship was established through legal channels. But, none of the participants mentioned that their brother or sister who was under guardianship no longer had the legal right for their decisions to be recognized by others. Thus, it is not clear if the participants realized that when their brothers and sisters became wards, they lost

many of their legal rights. Unfortunately, this study did not investigate whether or not the participants understood this issue.

Along with not mentioning their brother or sister's loss of rights as a ward, there was another reoccurring point that underscored the participants' lack of understanding about guardianship. Specifically, four participants mentioned that they thought that if their brother or sister was not living with their parents, who were their legal guardians, then their brother or sister became a ward of the state once s/he lived in a group home. For example, when asked what she thought of her sister, Casey, having a guardian, Jordan's first response was, "I wouldn't put her in a group home. If my parents couldn't take care of her, one of us [siblings] would." She further alluded to the importance of Casey living with their parents (who were her legal guardians) so that her guardianship would not be in jeopardy. Jordan's assumption that Casey needed to be living with her guardian or else her guardianship would transfer to the State was inaccurate, but this misconception was also reflected in three other participants' statements. For example, when Caroline was explaining her sister, Kristine's, guardianship, she also mentioned her apprehension that if her sister moved out of her parents' home, then she would become a ward of the State.

It is noteworthy that the four participants who expressed concern that their brother or sister would become a ward of the State if they moved out of their guardian's home were also younger participants who were not yet in the role of legal guardian. In contrast, the three oldest participants who were currently their brother or sister's legal guardians and did not live in the same home as their brothers and sisters, did not express any



concern about losing guardianship to the State based on where their brother or sister was living. Thus, siblings' level of understanding about guardianship may have been influenced by their current roles, with current guardians having a more thorough understanding of guardianship than younger participants who were not yet guardians.

### **Knowledge of Alternatives**

In contrast to their knowledge of guardianship, most participants reported little to no knowledge of guardianship alternatives. Specifically, five participants stated that they did not know of any guardianship alternatives. Donald mentioned one alternative (i.e., POA), and four participants stated two alternatives (i.e., POA, limited guardianship). Notably, none of the participants were able to describe any definitions of the alternatives; they simply gave the name of the alternative. For example, prior to reviewing the brochure, when asked if he could define or describe any alternatives to guardianship, Donald stated that power of attorney was an option, but that he had a "limited understanding of what that means. But, uh, my sense is that, uh, it involves, it's a lesser commitment [than guardianship]." This lack of knowledge of alternatives may have influenced their bias towards guardianship as a better choice for their brother or sister than alternatives. That is, because most siblings reported not knowing of any alternatives, and yet were familiar with guardianship, they may have been more inclined to prefer guardianship over alternatives simply because they did not know of any other options.

However, after reading through the brochure with the primary researcher, the majority ( $n = 9$ ) of the participants reported at least hearing about several of the alternatives before. For example, Natalie responded to the brochure by stating, "I've

certainly heard of all of them [alternatives]. Could I have, um, rattled them off?

Absolutely not. But, I have seen these before.” Jordan also explained,

A lot of these [alternatives] sound familiar, they’re just things that I wouldn’t like, recall with that question, obviously. But yet, like the advanced medical care, Power of Attorney, representative payees, like those things. Supported decision-making, I’ve heard of all these before.

Three participants reported knowing of supported decision making; this concept was new to all the other participants. This could point to the need for better dissemination to people with ID and their families about guardianship alternatives, and especially the need for better dissemination about supported decision making. Because most participants reported hearing of some of the alternatives after these were presented to them, it may be that participants simply could not think of all the names and definitions on the spot when asked during the interview. Or, it could be that the participants were not used to thinking of these alternatives as something that could work instead of guardianship. For example, Lee explained that his family had used Power of Attorney with one of his aging parents in the past, but that he did not think that this was a viable option for supporting his sister.

### **Siblings’ View Guardianship as Necessary**

#### **Views of Guardianship**

Participants were unanimous in their view of guardianship. That is, they all stated that they thought that guardianship was necessary or essential for their brother or sister. During the interview, when siblings were initially asked about what they thought of guardianship, they used phrases like, “it’s absolutely necessary;” “it’s very important;”

“it protects him;” and “it’s obviously the best option.” Even after reviewing the brochure with the definitions of guardianship and its alternatives, all siblings stated that they believed that full guardianship was the most feasible option for their brother or sister. For example, Natalie gave an illustration of how she had difficulties with a doctor not allowing her into her sister’s emergency room. Natalie had to call her lawyer and provide documentation to the hospital to prove that she could legally make medical decisions for her sister. She explained that because of this extreme example, she did not want to change her sister’s decision making options to anything less restrictive than full guardianship.

### **Views of Alternatives**

After reviewing the alternatives in the brochure with the primary researcher, all of participants explained that these were not feasible for their brother or sister. For example, Donald stated that his brother, Gordon, “needs more than that [alternatives].” Many siblings described that the alternatives would not work for their brother or sister because s/he did not have capacity to make decisions for him/herself. For example, Caroline, whose 24-year-old sister, Kristine, also had co-occurring physical disabilities and a speech-language impairment, explained that alternatives to guardianship would not work because her sister was “unable to make those decisions.” Likewise, Harry explained that for his brother, “Obviously, for my interaction or my brother, guardianship is just the— obviously makes the most sense. Like capacity, like when you talk about cognitive ability, like, he just does not have enough to get by.” Thus, siblings’ concerns about their brothers and sisters’ limited decision making abilities and/or capacity were reasons they

gave for viewing alternatives as not feasible.

Interestingly, a majority (n =8) of the siblings stated that they believed the alternatives could work for other adults with disabilities. Caroline explained,

For someone that would be more high functioning, I think that would be very important that they have those decisions. That they can, um, that they can, kinda have the final say that is in, like, the shared decision making. And I think that those alternatives definitely give more of the power to the individual with the disability, so I think in cases that would be very helpful.

Furthermore, some participants who worked or volunteered with other families with disabilities stated that they planned to share the information about guardianship alternatives with these families.

As stated above, the participants' response to the alternatives as not being feasible for their brothers or sisters may be connected to their prior knowledge of alternatives and guardianship. That is, because most participants did not know of any alternatives to guardianship, and their brothers and sisters were already under guardianship, they may have felt that brothers and sisters were already legally taken care of, and therefore they did not want explore unfamiliar alternatives. Thus, participants may have wanted to stick to what they already were familiar with and/or honor what their parents had already established. For example, Jordan mentioned that, "My parents have been doing it [guardianship] for a while, [they're] pretty capable, I'm pretty sure they know what she [my sister] needs and would want, better than anyone else really would." Thus, the parents' initial knowledge of guardianship and its alternatives may influence the siblings' choices or methods of supporting their brothers and sisters. For example, Natalie explained that when here parents first considered ways to support her sister, Izzy, in

adulthood, “It was a either medical, um, advocate or financial advocate or guardianship. Cause those were the choices at the time that we knew of.” Thus, this family’s limited knowledge of the full range of options may have led to their decision to use guardianship, which later could have impacted Natalie’s view that guardianship is the most appropriate option for her sister.

### **Decision Making**

**Decision-making levels.** Participants described their brother and sister’s decision-making levels in a variety of ways, often emphasizing their brother or sister’s low levels of decision making. As such, all participants pointed to their brother or sister’s low levels of decision making as justification for their brother or sisters’ need for full guardianship. For example, five participants estimated their brother or sister’s decision making in an age range between 3- to 5-years-old. Other participants described the basic types of simple decisions that their brother or sister made independently. For example, many participants described that their brother or sister chose their preferred snacks or clothing. Most participants focused on minor types of decisions that their brother or sister could make with varying levels of support, which will be described below.

Conversely, participants then described types of decisions that were harder for their brother or sister. All participants mentioned their brother or sister’s difficulty with making medical and financial decisions and pointed out that these were reasons for full guardianship. For example, Donald stated that his 27-year-old brother, Gordon, had never “seriously considered a financial or medical decision.” Other participants mentioned that their brother or sister struggled to make decisions beyond 1 or 2 days in the future. Lee

explained that his 41-year-old sister, Kay, who had a co-occurring mental illness, “can handle things like, in the, like, within a 24- or 48-hour time frame, but beyond that, it kind of gets fuzzy for her.” Likewise, Natalie explained that she had been working with her sister, Izzy, for several years to help Izzy plan how she would respond if diagnosed with cancer. Natalie said it was hard for Izzy to move beyond the initial emotional reaction of shock, and that they were still working on Izzy communicating her medical preferences in this hypothetical situation. Natalie used this and other examples of Izzy’s difficulties with making medical decisions as evidence for her opinion that Izzy needed full guardianship when she is faced with tough decisions.

**Capacity.** An underlying theme in participants’ responses about their brother or sisters’ decision making abilities was their concern about their brother/sister’s capacity. While only a few participants directly used the term, *capacity*, the examples they gave about their brother/sister’s abilities reflected their concerns about their capacity. As noted in chapter 2, capacity is a nebulous concept that is hard to concretely measure (American Bar Association, 2017; Berg et al., 1996; Kapp & Mossman, 1996; Rood et al., 2014), may ebb and flow over time (Kapp & Mossman, 1996), or vary based on the complexity of the decision (Ganzini et al., 2003; Kapp & Mossman). This research reflects the decades-long debate on how to measure and define capacity through “capacimeter” tools, and there is currently no clear consensus on how to objectively and globally measure capacity. Thus, just as capacimeters may not be the most objective ways to measure capacity, so to the participants in this study may view their brothers or sisters’ capacity in a more subjective light due to their desire to protect their brothers and sisters, their

concerns about their brother/sister's communication, or other aforementioned factors.

For example, when asked about his 28-year-old brother, Greg's, current decision making ability, Harry initially compared Greg to a teenager by stating that Greg could be stubborn and wanted to make a lot of decisions for himself. However, when asked to give examples of daily living and decision supports that Greg needed, Harry explained how Greg needed help with toileting and with bathing. Greg did not need physical assistance with these tasks, but rather verbal prompts and reminders. Thus, this type of support for toileting and bathing reflect a level of support which most typically developing teenagers do not need assistance with, and therefore Harry's age estimate of Greg's decision making abilities is questionable.

**Communication styles.** Though participants reported a range of communication styles for their brothers and sisters, they all pointed out that these were reasons for full guardianship. Three participants reported that their brothers or sisters used mainly non-vocal responses, such as head nods, thumbs-up, facial features, or picture-based systems. Five reported their brothers and sisters had very limited vocal abilities, such as stating simple sentences or one-to-two word utterances. Jennifer explained that because of her brother's limited abilities to communicate, "I think that it's [guardianship] good for him, um, that we can give him a voice when he doesn't have one."

Two participants (Lee and Natalie) indicated that though their sisters were very clear in their vocal communication, they still believed they needed full guardianship. For example, Lee explained that his sister, Kay, is

very high functioning verbally, and I think a lot of people misjudge her capacity because of her high level of verbal functioning that is kind of at a much higher

level than the rest of her functioning levels, so people think that she functions better than she really does.

Lee later explained that even though Kay was very high verbally, she “doesn’t have the capacity to make the financial decisions, medical decisions,” which he pointed out as reasons for her needing guardianship. These participants’ examples of the discrepancy between their perceptions of their sisters’ communication abilities and others’ perceptions further highlights the subjectivity of capacity, and points out their implicit sense of protectionism regarding their sisters with disabilities. Indeed, this sense of wanting to protect a person with a disability has historically been one of the reasons why they have been placed under guardianship (Blanck & Martinis, 2015; Newman, 1967; Regan, 1972; Werner & Chabany, 2015).

Consequently, Natalie and Lee, the two siblings who stated their sisters were very clear in their communication, were the only participants who reported that their sisters were never misunderstood; the remaining eight participants explained that their brothers and sisters were often misunderstood by people who were unfamiliar with their communication. Harry explained how Greg, his 28-year-old brother with Down syndrome, was often misunderstood when working in the community: “the layman person that is interacting with in a scenario like that, he [my brother] would say... ‘thank you,’ or ‘come again,’ and they would have no idea what he said.” Donald likewise stated that unfamiliar people would understand “next to not at all” when his younger brother was speaking. Regardless of whether or not others in the community could understand their brother or sisters’ communications, all participants emphasized that they believed their brothers or sisters needed to have a guardian to communicate decisions on their



behalf and/or for protection purposes.

Most siblings agreed that familiar people, such as long-time staff or long-time family friends, learned to understand most of their brother and sister's communication styles. However, these siblings admitted that even long-time friends and staff still have difficulties understanding their brother or sister's communication, which again highlighted their concern that their brother or sister have a guardian. Crystal described the effects of others' misunderstanding on her 51-year-old brother's communications: "that's when he [my brother] gets violent...when he's frustrated, he can't say this...it doesn't come out in a good way when he can't express himself like you or I could."

**Support with decisions.** Participants reported a variety of methods that they, their parents, and/or support staff used to help their brothers and sisters make decisions. Despite giving their brothers and sisters support with decisions, the participants still pointed out that their brothers and sisters needed guardians due to their brother or sister's limited capacity. For example, Harry explained how his family made medical decisions on behalf of his brother, Greg, who had cancer when he was 26 years old: "I don't think we ever consulted him [about treatment]. But like, intellectually, he has no idea what cancer is."

Most siblings reported additional explanations that they, other family members, or disability agency staff members, provided to their brothers and sisters to help them understand the options available for a given choice. Likewise, most siblings reported limiting their brother or sister's options between two or three choices so that s/he did not get overwhelmed by too many options. Several of the participants whose brother or sister

had co-occurring autism mentioned that their brother or sister enjoyed sticking to their established, daily routines, and they needed a great deal of support if a decision required deviating from their routine. For those brothers and sisters who enjoyed sticking to their routines, siblings noted that these routines had been structured to support their autonomy. For example, Don explained that his brother's routine had already factored in his individual preferences:

When he's at work every day, he kind of, he's had some say at the front end when he first started this, this job program. They asked him what he wanted to do, so he likes elderly people, so he wanted to deliver newspapers at the nursing home. And so, he does that. And he has a friend who works with tractors, and so he'll go and help his friend mow with the tractors. And so it's not like we ask him, like, "What do you want to do today, Gordon?" It's, you know, he's doing the stuff that he's already expressed interest in.

Likewise, Lee explained that his sister enjoyed her routine, and that if a change needed to occur in his sister's routine, then she created a whole new routine rather than trying to adapt her existing routine by inserting new tasks.

### **Siblings' Desire for Planning and Future Involvement**

#### **Current Involvement**

Overall, participants expressed a continued desire to be involved in their brother and sister's lives, which they suggested meant seeing their brothers or sisters several times each year in addition to phone calls (ranging from every few days to quarterly). Three siblings also reported using video calls with their brothers or sisters. However, the types of involvement that siblings reported with their brothers and sisters were usually not for the purpose of discussing or providing caregiving, but rather for the purpose of

leisure. All participants described their relationship with their brother or sister in positive terms; many laughed and/or smiled when describing their relationship with their brother or sister. For example, when Jennifer described her relationship with her younger brother, Devin, she stated: “We’re really close... he makes you feel really, uh, like, kind of special, because he doesn’t talk to most people, so if he does talk to you, uh, he just has this gift for making people feel really, like, special.” Likewise, Natalie described her younger sister, Izzy, as “a joy to be with.” Other siblings expressed similar positive feelings towards their brother or sister using phrases like “very attentive, very sweet, and...a very integral part of my world;” “I’m excited to see him;” and “a lot of fun.”

When participants described types of activities that they most often did with their brothers and sisters, many described doing activities that were specifically highly preferred by their brother or sister, though not always highly preferred by the participants. For example, Donald described listening to his brother, Gordon’s, preferred type of music when they were together: “We don’t necessarily enjoy the same kinds of music; he’s big into Bluegrass for some reason. I can tolerate bluegrass, but it’s not, not, my type of music.” Similarly, Crystal described watching her brother, Carl’s, preferred television programs when they were together:

He [Carl] has a fixation with the *Three Stooges*...so when I see him, uh, it’s—it’s almost immediately I have them cued up all ready to go...I love the *Stooges* because it’s one thing we can do. It’s one of the few things that we’ve ever been able to do.

Several other participants described strategically planning their outings to incorporate their brothers and sisters’ preferred activities, even if these activities were not highly preferred to the participants. Jordan, Jennifer, Lee, Natalie, Rachel, and Harry all

described planning outings that were highly preferred by their brothers and sisters. This type of planning and selecting activities together points to the participants' overall attentiveness to their brothers and sisters' preferences, and their willingness to put their brothers and sisters' preferences before their own when getting together.

This overall closeness in relationship described by participants may influence the extent of their involvement in their brothers and sisters' lives (Bigby 1998; Burke et al., 2012). That is, Bigby found that the extent of siblings' relational closeness, as measured by frequency of contact and description of their relationship, influenced their involvement with their brothers and sisters in adulthood. Conversely, this same study noted that siblings with poor relationships with their brothers or sisters were not very involved during adulthood. The current study aligns with prior research findings (e.g., Bigby 1998; Burke et al., 2012) in that all participants described their relationships in positive terms; therefore, they expressed a desire to continue to be involved in supporting their brothers and sisters.

**Caregiving discussions.** Regarding the extent that siblings discussed their brother and sister's caregiving needs with their primary caregiver, eight siblings self-reported not being very involved with these types of discussions currently. Lee and Natalie reported having ongoing conversations with their sisters' staff about their specific caregiving needs. This is noteworthy, as Lee and Natalie were two of the oldest participants, and both were currently their sisters' legal guardians. Thus, their higher level of involvement may be indicative of their status as guardian, reflective of their older age, and/or relate to their parents' lower levels of involvement. That is, Lee's father was deceased and his

mother had several health issues, so Lee and his brothers had higher levels of involvement with his sister than his mother did. Likewise, Natalie's parents were deceased, and she was Izzy's sole guardian. In contrast, most of the younger participants had one or both parents still living, and their parents were still actively involved in overseeing the care of their child with a disability. These differing levels of involvement align with previous research that has compared the different types of involvement between current sibling caregivers and expected sibling caregivers (Burke, Fish, & Lawton, 2015). Specifically, Burke, and Lawton found that current sibling caregivers provided more formal types of support, such as guardianship, whereas anticipated sibling caregivers provided mainly informal supports such as social and emotional supports to their brothers and sisters.

**Types of discussions.** Two siblings, Jordan and Rachel, reported talking with their parents often about specific health concerns of their brother and sister, but they did not inquire about other areas of their brother or sister's life (e.g., work, recreational activities, behaviors, etc.). Most participants explained that they had limited discussions with their brother or sister's caregivers because they felt that their brother or sister was well-cared for and that their conditions were relatively stable. As Donald explained, "we [my parents and I] don't talk explicitly about, um, his care needs. Although, you know, I haven't been living at home for a while, but I feel like I know him pretty well and understand, um, what taking care of him involves."

### **Desire for Discussions with Parents**

Overall, siblings reported wanting to be involved, or even more involved, in

discussions with their parents on future planning for their brothers and sisters, which aligns with previous research (e.g., Bigby, 1998; Burke, & Lawton, 2015; Heller & Kramer, 2009). Seven participants reported specifically engaging in future planning with their parents regarding their brother or sister. Two of these participants, Lee and Natalie, reported that these types of conversations began after one of their parents became terminally ill and/or died. Two of the younger siblings (Rachel and Jennifer) mentioned that they had repeatedly initiated future planning conversations with their parents, but that their parents were sometimes reluctant to discuss future plans for their brothers with them. For example, when talking about discussions with her parents about her future involvement with her 28-year-old brother, Devin, who has co-occurring autism, Jennifer explained, “I’ve made it very clear that I want to be a part of that [guardianship].” A few siblings mentioned having only vague conversations with their parents about their brother or sister’s future care, and they expressed a desire to have more pointed conversations with their parents. For example, Harry questioned his parents’ plans for his brother: “You know, do mom and dad have a legal will? What is the plan for Greg?”

These findings, that siblings want to be involved with their brothers and sisters in the future, and that they want to have more pointed discussions with their parents, align with previous research (Coyle et al., 2014; Dew et al., 2004; Heller & Kramer, 2009; Griffiths & Unger, 1994). For example, Griffiths and Unger surveyed 41 pairs of parents and adult siblings of adults with ID and found that 64% of these adult siblings were uncertain of their parents’ future plans and wishes for their adult brother or sister. This same study found that there was a mismatch between the parents’ and adult siblings’

perceived levels of stress in caring for the adult with ID, with parents tending to view caregiving as less stressful than their adult children. This difference in stress levels may point to the lack of communication between the parents and the adult children about the needs of the adult with ID, and highlights the need for parents and their adult children to plan the long-term care needs of the adult with ID. Moreover, Bigby (1998) found that when parents and their adult children discussed future planning with their children, the adult siblings' stress levels decreased.

Bigby's (1998) findings align with those of the current study, as several siblings in the current study stated their desire to discuss future plan with their parents and explained that they experienced stress from not knowing what the future plans were for their brother or sister. For example, both Rachel and Jennifer mentioned that they had repeatedly brought up the topic of future planning with their parents, and but their parents had not yet filled out legal paperwork to include them as their brother's guardians. In fact, both participants explained that their parents were hesitant to discuss future planning with them. For example, Jennifer explained that "I think it [future planning discussions] makes my parents feel a little more uncomfortable, but, uh, it's something that I think about." Likewise, Harry's frustration at the lack of future planning with his parents about his brother, Greg's care, is reflected in his statements:

...We probably need to have something in writing, [such as a] decision already made before my parents pass away. So, just, you [*sic*] kind of a clear concise time that, I mean, that I don't know, we, when my parents do end up passing away or are incapacitated by age. You know, what is the game plan?

### **I've Always Planned on This**

Although many participants were still uncertain as to their parents' exact wishes for their brother or sister with ID, most participants ( $n = 7$ ) made comments about how they had always planned to have a role in their brother or sister's future care. Jennifer explained that her planning to be her brother's future guardian is a "personal choice. It was something that I always wanted; it just didn't make me feel me uncomfortable."

Rachel explained that she discussed her future involvement in her brother's care with her husband before they married:

I mean, I think, even like as a child, before I knew that, like, guardianship was like a thing, I kind of always knew that we'd always be taking care of my brother. And so, it isn't really like, I'm not like, apprehensive about it. I'm very aware that that's what's going to be happening, you know? I mean, even when I was getting married, I made sure that that was very clear to my husband, that this is going to happen. That, you know, my brother would be coming and living with us, when my parents are, you know, unable to.

Many other siblings gave similar statements about "always knowing," or "always planning" to be future guardians of their brothers or sisters. Lee explained that his and his brothers' eventual roles as guardians of their sister was an unspoken expectation in his family: "we had kind of always known that that [guardianship] was going to happen as our parents got older, that the siblings would need to step into that role as parents were unable to do it anymore. It's just kind of always understood." Indeed, Lee later shared that when the time came that his parents could no longer be his sister's guardians, he did not hesitate to become his sister's full legal guardian. This finding that most siblings had always planned to be involved in their brothers and sisters' adult lives has been noted in previous research (Dew et al., 2004; Griffiths & Unger, 1994).



### **Demographic Characteristics as Correlates of Involvement**

While prior research has indicated several demographic predictors of siblings' future involvement with their brothers and sisters (Bigby, 1998; Burke et al., 2012, 2016; Heller & Kramer, 2009; Krauss et al., 1996), this study did not closely align with most of these prior findings. Specifically, this prior research has found that siblings with one or more of the following demographics are more likely to be involved with meeting their brother or sister's care needs after their parents are no longer able to do so: the oldest female sibling, lone siblings (those without other typically developing siblings), unmarried siblings, or siblings without dependents. In contrast, half of the siblings in this study (Jordan, Caroline, Harry, Rachel, and Jennifer) did not have any of these specific demographics, but these participants currently defined their relationship with their brothers and sisters as close. Similarly, most of these participants planned to be their brother or sisters' guardian or at least remain highly involved in their lives. For example, Caroline and Jordan were the youngest siblings in their families, but they anticipated having future caregiving roles with their sisters. Moreover, Jordan anticipated being her sister's guardian in the future. Likewise, Harry, Rachel, and Jennifer were from larger sized families, but they all expressed a desire to stay involved in their brothers' lives; Rachel and Jennifer specifically wanted to become their brothers' guardians in the future.

As highlighted in the participant profiles section in Chapter III, the siblings included in this study represented both males and females, oldest and youngest siblings in the birth order, both married and unmarried, and lone siblings as well as siblings from large families. Additionally, participants' religious affiliation did not appear to influence

their desire to be involved in future planning, caregiving, and/or guardianship. Likewise, participants' brothers and sisters challenging behaviors did not seem to influence the participants' willingness to be involved as caregivers and/or as guardians. For example, though Jennifer's younger brother, Devin, engaged in operant vomiting and aggression, she still stated that she wanted to be his guardian and be involved in overseeing his care. Likewise, Crystal and Lee's brother and sister both engaged in challenging behaviors, but these participants were still actively involved in their lives as guardians. Therefore, despite these various demographics, all participants stressed their desire to be involved in their brother or sister's life. Indeed, the three oldest participants were currently their brother or sister's legal guardian, and four younger participants anticipated taking on this role in the future.

Thus, the demographic predictors of involvement from prior research (Bigby, 1998; Burke et al., 2012, 2016; Heller & Kramer, 2009; Krauss et al., 1996) were not necessary reflected by the participants in this study. Although older participants in this study did tend to know more about the legal aspects of guardianship, and three of the oldest participants were currently their brother or sister's guardians, longitudinal research with larger and more diverse sample sizes may shed light on more specific differences in demographic predictors of sibling involvement.

### **Personal Response to Being a Guardian**

In general, participants expressed a readiness and even an enthusiasm to be their brother or sister's legal guardian. Three participants (Lee, Natalie, and Crystal) were currently their brother or sister's legal guardian; they all had full guardianship. Four

siblings (Jordan, Jennifer, Donald, and Rachel) expected to become their brother or sister's legal guardian in the future. In fact, Donald and his parents had already completed the legal paperwork that set up Donald and his wife to be next in line after his parents could no longer be guardians. The remaining participants (Harry, Sally, and Caroline) were unsure of their future roles as their brother or sisters' guardian. However, Sally had been her brother's guardian in the past, but due to current, difficult circumstances, she was no longer her brother's guardian. Harry and Caroline both expressed a desire to continue to be involved with their brother or sister in the future, and Sally mentioned that she would like to be more involved with her brother if her living situation improved.

When asked what they thought and felt about being their brother or sister's guardian, most of the participants ( $n = 7$ ) viewed being their brother or sister's guardian as just something they needed to do; they did not attach any negative emotions to this. Lee explained: "it's just a matter of fact, it was, there was no hesitations, thought processes; it was just what we needed to do." Only two participants (Crystal and Donald) stated that they initially felt like taking on guardianship of their brother was a big event for them, but they also stated that it was a role that they willingly accepted. For example, Crystal stated, "at the time, it was more of an emotional deal, just, uh, a benchmark, a milestone, you know, like really claiming responsibility for him. That was finally really happening."

Likewise, Sally expressed surprise at becoming her brother's guardian, but she also accepted the responsibilities of being her brother's guardian for several years. She explained that this surprise was due to the disheartening circumstances where she

unexpectedly become her brother's guardian. Specifically, because her father had not been a part of their family since she was a child, when her mother unexpectedly passed away when Sally was 25 years old, Sally became her brother's guardian. Sally and her mom had only limited future planning conversations about her brother's care, and so Sally was surprised to find that she was now her brother's legal guardian. In contrast, the other older participants who were currently serving as their brother or sister's guardian reported engaging in more specific future planning conversations with their parents, and they did not report being surprised when they initially took on this role.

Overall, participants expressed a willingness to take on their brother or sister's guardianship and/or caregiving, as well as desire to do so. For example, Jordan explained that when her parents were no longer able to care for her sister, Casey, then she hoped that she and her siblings would be in a stable place where they could care for Casey. Likewise, Harry explained that he was "hopeful" that he could reach one of his personal goals to "achieve a level of comfort of living that we could accommodate my brother coming and staying and being a part of my children's life."

Similarly, Rachel and Jennifer both stated that they were willing to be their brothers' guardians, and that this was their personal choice. For example, Rachel described her reaction to being her twin brother with ID's future guardian: "I kind of always knew that we'd always be taking care of my brother. And so, it isn't really like, I'm not, like, apprehensive about it, I'm very aware that that's what's going to be happening, you know?" Rachel's statement highlights both her anticipation and willingness to become her brother's guardian, a sentiment that was reflected in other

participants' responses.

Likewise, other participants stressed that though they felt it was a big responsibility to become their brother or sister's guardian, it was something they willingly did. As stated above, most siblings mentioned that they had always planned to be their brother or sister's caregiver and/or guardian, and they were not personally bothered by this role. Thus, in response to the third purpose of this study, to examine what siblings think about their role as a guardian or supported decision maker, the participants in this study overwhelmingly expressed a willingness to take these roles on, and a desire to do so.

### **Summary**

The purpose of this study was to explore adult siblings of adults with IDD's knowledge and perspectives of guardianship and its alternatives. Though each of the 10 participants' had unique family dynamics and experiences, their interview responses were categorized into the following themes: (1) siblings' limited knowledge of guardianship and its alternatives; (2) siblings view guardianship as necessary; and (3) siblings' desire for planning and future involvement with their brothers and sisters. Based on these three themes, it can be theorized that siblings with limited knowledge of guardianship alternatives view guardianship as necessary (e.g. "all or nothing"). This all or nothing approach can be addressed and alternatives presented as these siblings also desire assistance in preparing for the future and planning. The following chapter describes the implications for researchers, practitioners, and families of individuals with IDD.

## **CHAPTER V**

### **DISCUSSION**

#### **Summary and Implications**

This study's three main findings are as follows: (1) siblings' limited knowledge of guardianship and its alternatives, (2) siblings view guardianship as necessary, and (3) siblings' desire for planning and future involvement with their brothers and sisters. These findings suggest that siblings with limited knowledge of guardianship alternatives view guardianship as necessary (e.g. "all or nothing"). This all or nothing approach can be addressed and alternatives presented as these siblings also desire assistance in preparing for the future and planning. This section will briefly summarize these findings; discuss limitations; and highlight implications for families, practitioners, and researchers.

#### **Implications for Informing Families**

Regarding the first purpose of this study, to explore adult siblings' knowledge of guardianship and its alternatives, this study found that adult siblings need more information about the range of decision making supports available for their brothers and sisters. This finding aligns with prior research where adult siblings have reported wanting more information about how to support their brothers and sisters (e.g., Arnold, Heller, & Kramer et al., 2012; Heller & Kramer, 2009). This study's participants reported knowing more about the definition of guardianship than they knew about the definitions and possible uses of guardianship alternatives. Specifically, when asked to describe or define guardianship alternatives, none of the participants were able to provide any definitions or

descriptions. Half of the participants stated they did not know of any alternatives to guardianship, while the remaining half simply listed one or two alternatives. However, after reviewing the brochure with the primary researcher on the definitions of guardianship and its alternatives, many of the participants stated that they had heard of most of these alternatives before.

Thus, the contrast between most siblings stating that they had heard of most of the alternatives before but being unable to define or describe these alternatives when asked may indicate a need for most support and training for siblings and families so that they are fully informed of the range of supported decision making options. For example, when Natalie described her parents' initial decision to pursue guardianship for her sister, Izzy, she explained that they did not know of many guardianship alternatives. This demonstrates how Izzy's family's lack of knowledge about the full range of options for guardianship may have influenced their favoring guardianship because they did not know of all the alternatives such as power of attorney or supported decision making contracts. However, it should be noted that, after receiving the brochure and reviewing the definitions of guardianship, Natalie still stated that she felt guardianship was the best option for Izzy.

As stated above, siblings' and their parents' general lack of knowledge about the full range of guardianship and its alternatives highlights the need for more training and support for families. A recent survey of over 1,200 parents and guardians of people with disabilities indicated that during initial discussions with schools, disability agencies, and/or lawyers when their child approached the age of majority, full guardianship was the

option discussed most often (Jameson et al., 2015). Similarly, Rood et al. (2014) also found that many states' education departments (such as New York, Arizona, Georgia, and others) have a checklist for schools to ensure they discuss guardianship with families when a child approaches the age of majority, but that these checklists often do not include discussion of any guardianship alternatives with families. Notably, Jameson et al. also found that supported decision making was option that was least often discussed with families, which aligns with the current study's finding that this was the option that participants were least likely to be familiar with.

Thus, as noted in prior research (Jameson et al. 2015; Rood et al., 2014), families are more likely to be informed only of full guardianship, making it more likely that they will place their child with ID under full guardianship as they do not know of any alternatives. Thus, there are implications for school staff, disability agencies, and even lawyers to fully inform families of people with ID about the range of options available to support people with ID in making decisions. This will allow families to make more informed choices, which could potentially lead to families choosing less restrictive options for their family member with ID.

An example of a tool can lead to more informed choices is the American Bar Association's recently developed PRACTICAL tool, which is a checklist for lawyers and families to use when considering guardianship and its alternatives (American Bar Association, 2016b). Each letter in the word, PRACTICAL, stands for a different step in the checklist, which helps lawyers and families to consider the full range of options for supporting individuals with disabilities in adulthood. For example, the "P" is the initial



consideration for lawyers and families, and stands for “Presume guardianship is not necessary,” which reflects the concept of considering the least restrictive options before considering guardianship, which most state laws require (American Bar Association, 2017; Martinis & Ellis, 2015).

However, in order to fully inform families about the range of options for supporting people with disabilities, professionals at these referring agencies (e.g., schools, disability agencies, and lawyers) need to be fully informed of the range of decision making options. For example, as many special education teacher training programs do not have specific coursework on guardianship and its alternatives (Teacher Certification, 2016), it is unlikely that most special education teachers get adequate training on these options, unless they specifically seek out professional development on this topic. More research is needed to determine special education teacher’s and other school professional’s knowledge of guardianship and its alternatives, as well as the prevalence of these school staff passing along guardianship information to families as their children approach the age of majority. For example, as many schools encourage special education teachers to pass on guardianship information to families (Rood et al., 2014), future research could explore the extent that teacher training programs prepare teachers on the range of these supported decision making options, the extent that this impacts teachers’ disseminating guardianship and its alternatives to families, and whether or not this dissemination of information on guardianship and its alternatives influences families’ choices for these options.

### **Implications for Training People with IDD and Their Siblings**

In answer to the second purpose of this study, to explore adult siblings' perspectives on guardianship and its alternatives, this study's participants were unanimous in viewing guardianship as necessary and viewing its alternatives as not feasible for their brother or sister. However, most ( $n = 8$ ) siblings were open to the idea of using an alternative for other adults with disabilities. Siblings gave several reasons for their viewing guardianship as the best option for their brother or sister, including their brother or sister's lack of capacity for making complex decisions; their brother or sisters' limited communication abilities; and instances of their brother or sister often being misunderstood by community (i.e., nonfamily) members.

Interestingly, while all the participants were closed to the idea of using a guardianship alternative with their brother or sister, they were open to the possibility for other adults with disabilities. This could be because the siblings may have viewed their brother or sister as less capable than other adults with disabilities in making decisions, because they had seen their brothers and sisters make poor decisions in the past, or because of personal experiences of their brother or sister getting taken advantage of in the past. Future research could explore specific reasons why siblings are more open to other adults with disabilities using guardianship alternatives compared with their brother or sister using one of these alternatives.

In a recent literature review on the factors that influence an individual with disabilities' decision making and support needs, Shogren, Wehmeyer, Lassmann, and Forber-Pratt (2017) noted that family's attitudes towards their family member with

disabilities may influence the person with disabilities' decision making abilities. Specifically, Shogren et al. noted that a family's hesitant attitude for their family member with a disability to make decisions influenced that family member's decision making capacity. That is, a person with disabilities whose family members have a more reserved attitude about their decision making may also adopt this overly concerned attitude about making their own choices and limit themselves from making decisions. Overall, this attitude of heightened concern and a desire to protect their brothers and sisters was reflected in all the participants' responses in this study. That is, the participants repeatedly expressed a concern about their brothers and sisters due to their low levels of decision making abilities and capacity, a concern which may influence their brothers and sisters' willingness and/or opportunities to make their own decisions.

This view that guardianship was absolutely necessary may be reflective of the small sample size, the recruitment materials, or the fact that all of the brothers and sisters of the participants were under guardianship. For example, the wording of the title of this study (e.g., "guardianship and its alternatives,") may influence the types of participants who elect to participate. That is, using a different title during recruitment, such as "supported decision making compared with guardianship," may have caught the attention of siblings with different perspectives who were less open to guardianship and more open to using its alternatives.

For example, during the screening process, one potential participant who was excluded due to her brother's age (he was still 17), had mentioned to the primary researcher her desire to participate because she and her parents had already started the

paperwork for guardianship. This potential participant's perceived favoring of guardianship may be similar to the 10 participants' favoring guardianship who were actually interviewed. As stated above, the 10 participants were much more knowledgeable and familiar about guardianship than they were about the alternatives. Future research could use different wording in the recruitment of siblings to learn more about what they know and how they perceive the full range of guardianship options.

Another interesting aspect of the participants' unanimous view that guardianship is necessary is the fact that some of the organizations used to recruit participants favor using alternatives rather than defaulting to guardianship. For example, one of the Sibling Leadership Network's (SLN) core values is "promoting the rights of our brothers and sisters, and of all individuals with disabilities, we are committed to advocating for policies and services that meet their needs" (Sibling Leadership Network.org, n.d.). Thus, while this organization emphasizes people with disabilities' rights and favors guardianship alternatives, this viewpoint was not reflective of the out-of-state participants, who were likely recruited through this organization. Future research could examine the extent that members of the SLN understand and agree with the SLN's stance on guardianship and its alternatives.

As mentioned above, the participants' unanimous viewpoint that guardianship is necessary may be linked to their prior knowledge and relatively greater awareness of guardianship compared to its alternatives. Thus, simply being more familiar with guardianship may have influenced siblings to view guardianship more favorably. However, the responses of the participants in this study (i.e., none mentioned the ward's

loss of legal rights, and several mistakenly thought that guardianship transferred based on the ward's living situation) indicate ways that siblings need more accurate information about guardianship. Adult service providers, disability advocacy agencies, and organizations like the Sibling Leadership Network (an organization specifically dedicated to support siblings of people with disabilities), may be key avenues of dissemination of information about guardianship and its alternatives. Future research could explore training avenues for adult siblings, and whether this training influences siblings' perspectives about guardianship and its alternatives.

For instance, none of the participants mentioned the fact that once their brother or sister was placed under guardianship, they lose several rights. Future research could specifically explore whether or not siblings are aware of this, what they think of their brother or sister's loss of rights, and whether or not this fact influences their views of guardianship. For example, if siblings are unaware that their brothers and sisters lose many of their rights when they are placed under guardianship, they may tend to view guardianship as favorably, as the participants of this study did. In contrast, if siblings understood the extensive loss of rights that occurs when someone is placed under guardianship, they may view guardianship differently.

Just as siblings may need additional training on the full range of guardianship and its alternatives, likewise, their brothers and sisters with IDD may need additional training to self-advocate for their rights. That is, many of the participants in this study mentioned their concerns that their brother or sister could not effectively communicate their preferences and/or that s/he struggled to make decisions. This points to the need for

additional research-based training for people with IDD on self-determination and self-advocacy skills. Prior research has shown that as individuals increase their knowledge about their legal rights as well as their own needs and preferences, their capacity increases as they are better equipped to understand and make decisions (Bollman et al., 2009; Kramer et al., 2014; Mazzotti et al., 2015; Salzman, 2010). Therefore, based on the connection between self-advocacy and capacity, it can be argued that individuals who have higher levels of self-advocacy have higher levels of capacity. Conversely, individuals with limited opportunities to self-advocate, such as those placed under guardianship, have lower capacity than those who regularly engage in self-advocacy (Millar, 2013; Salzman, 2010; Werner & Chabany, 2015).

Likewise, as the participants in this study pointed out their concern that their brothers and sisters had difficulty comprehending the full range of choices available to them, this indicates a need for additional researched-based training of people with IDD to make informed choices. Recently, Moore and Friedman (2017) wrote a position paper on the concept of informed choice. In this paper, they highlighted the ways that several key pieces of legislation (e.g., ADA, WIOA, and the Rehab Act) mandate that people with disabilities are fully informed of their choices. Specifically, they stated that informed choice “refers to a meaningful decision between multiple, *significantly distinguishable* viable options. Choice incorporates the importance of autonomy, control, self-determination and having a variety of options to choose from” (p. 248). The participants in this study gave examples of their brothers and sisters making relatively limited choices (e.g., some did not even choose their daily meals), which underlines the need for their

brothers and sisters to be more fully informed of their options so that they can make informed choices and advocate for their own needs.

### **Implications for Family Planning Together**

Regarding the third purpose of this study, to explore what adult siblings think about their role of being a guardian or supported decision maker for their brother/sister with ID, the participants had overwhelmingly positive perspectives about currently being or someday becoming their brother or sister's guardian. As stated above, none of the participants thought an alternative was feasible for their brother or sister. The three participants who were currently guardians all stated that this was a role that they willingly accepted. Moreover, these siblings stated that being their brother or sister's guardian was a role that they had anticipated having since childhood. While Crystal, age 49, mentioned that it initially felt like a huge milestone when she became her brother's legal guardian, she also stated that she did not hesitate to accept this responsibility. The younger participants who were not current guardians all mentioned that they either planned to be their brother or sister's guardian in the future or that they planned to stay actively involved in their brother or sister's life. Like the three oldest participants who were currently serving as their brother or sister's guardians, the younger participants who anticipated being their brother or sister's guardian in the future all talked about this role in positive terms.

Despite participants' willingness to accept guardianship of their brothers and sisters, several of the participants pointed out their apprehensions about what their brother or sister's future entailed due to lack of specific planning with their parents,

which aligns with findings from prior research (e.g., Burke, Fish, & Lawton, 2015; Conway & Meyer, 2008; Heller & Arnold, 2010; Rawson, 2009). Some of the younger siblings expressed their frustration with wanting to have more pointed conversations with their parents about their brother or sister's future. For example, Jennifer, age 30, mentioned that she thought her parents felt uncomfortable discussing her brother's future care with her, so they avoided doing it. Jennifer mentioned that she often had to initiate future planning discussions with her parents, as they were hesitant to do so. Similarly, Rachel, age 24, mentioned that she often introduced future planning discussions with her parents about her brother's care.

Interestingly, none of the participants mentioned including their brother or sister with ID in their future planning conversations with their parents. Perhaps it was just a given that their brother or sister was included, so the participants did not mention it, or perhaps the brother or sister was not included. Future research could explore the extent that brothers and sisters with ID are included in their families' future planning discussions. Likewise, future research could compare brother and sisters' views about guardianship with the views of their siblings in order to examine if these views overlap or diverge.

Likewise, prior research has noted (e.g., Berg et al., 1996; American Bar Association, 2017; Ganzini et al., 2003; Kapp & Mossman, 1996; Rood et al., 2014) that capacity is a highly subjective concept, and the participants in this study also had difficulty concretely defining their brother or sisters' level of decision making. None of the participants mentioned using specific tools or forms to help their brothers or sisters



map out their decision making or to determine their capacity. However, many such decision making and future planning tools are freely available online, such as the American Bar Association's PRACTICAL tool (American Bar Association, 2016b) and the National Gateway to Self-Determination's "It's My Future!" (Bolding, Wehmeyer, Lawrence, 2010) resources, which can help families with future planning and decision making.

### **Limitations**

It is recognized that this study is limited by including only 10 participants, many of whom shared similar demographic characteristics. For example, all participants were white, had some college education, and their biological siblings had intellectual and other developmental disabilities. Additionally, most ( $n = 7$ ) siblings were from larger families (e.g., at least five total siblings). It is acknowledged that a study including more diverse demographics (e.g., culturally and linguistically diverse individuals with various educational backgrounds) may yield different findings. Likewise, step-siblings or siblings who did not grow up in the same house together may have different levels of involvement and ideas about guardianship than the participants in this study. Similarly, siblings of adults with other disabilities, such as those with only a physical disability, or those with only mental illness, may have different perspectives about guardianship and its alternatives. Future research could compare siblings of different demographics and/or siblings of brothers and sisters with different primary disabilities.

Likewise, it is acknowledged that all participants self-selected to participate in this study, and that they knew the purpose of this study was to explore their knowledge

and perspectives of guardianship and its alternatives. Moreover, all participants self-reported positive relationships with their brothers and sisters, and all planned to stay highly involved in their brother or sister's life. Thus, their favorable views of guardianship and their willingness to take on this and other caregiving roles may not be reflective of all siblings. It is unlikely that siblings with poor relationships with their brothers or sisters would anticipate having the same high levels of involvement as the participants of this study or that they would volunteer to participate in a study on this topic. Thus, adult siblings who have poorer relationships with their brothers and sisters, or those who do not intend to be involved in their care, were not represented in this study, and they may have different views of guardianship and its alternatives. Future research could seek out the knowledge and views of these less-involved siblings, and compare their demographics and perspectives to those of more involved siblings. Additionally, it could be interesting and pertinent for future research to explore siblings of the same family and compare their thoughts about their anticipated future involvement with their brother or sister. Likewise, future research could explore the perspectives of siblings who have more than one brother or sister with IDD, and compare if they have different views and/or plans for their multiple brothers and sisters with IDD. These types of comparison studies may shed light on how siblings work together to be involved in their brother or sister's life into adulthood, as well as reveal if there are other types of demographic predictors of involvement.

## Conclusion

Siblings have the potential to be the longest-lasting relationships in a person's life (Burke Fish, & Lawton, 2015; Conway & Meyer, 2008; Rawson, 2009). Moreover, this and other studies (e.g., Burk, et al., 2012, 2016; Greenberg et al., 1999; Hewitt et al., 2013; Hodapp et al., 2010; Rossetti & Hall, 2015) have found that adult siblings of adults with IDD often take on caregiving and guardianship roles with their brother or sister with IDD. However, previous research has repeatedly indicated that adult siblings are uninformed or under informed about ways that they can support their brothers and sisters (e.g., Arnold et al., 2012; Burke et al., 2012; Hewitt et al., 2013), which was also reflected in this study's participants' limited of knowledge about guardianship and its alternatives. Moreover, as siblings are often on the front lines of supporting their brothers and sisters after their parents pass away (Burke, Fish, & Lawton, 2015; Greenberg et al., 1999; Taylor et al., Hartley, 2016), these siblings are important stakeholders in family and policy discussions on alternatives to guardianship.

Therefore, the purposes of this study were as follows: to determine what adult siblings of adults with intellectual disabilities (ID) know about guardianship and its alternatives; to explore how adult siblings view guardianship and its alternatives; and to explore what adult siblings think about their role of being a guardian or supported decision maker for their brother/sister with ID. Ten adult siblings of adults with IDD were interviewed for this study, and the following three main themes were extracted from their data: (1) siblings' limited knowledge of guardianship and its alternatives; (2) siblings view guardianship as necessary; and (3) siblings' desire for planning and future

involvement with their brothers and sisters. This chapter highlighted the need for future research and examined several possible implications of this study's findings.

As this study found that siblings have a limited knowledge of guardianship and its alternatives, there are implications for schools, service agencies, and disability organizations to better disseminate and more fully inform families about the full range of options for supporting adults with IDD in making decisions. Likewise, as this study found that participants viewed guardianship as necessary and viewed alternatives as something not feasible for their brother or sister, there are implications for schools and disability agencies. Specifically, many of the participants of this study cited their concerns about their brother's or sister's communication difficulties or decision-making capacities, which potentially can be ameliorated by research-based training of their brothers and sisters in self-determination and self-advocacy skills.

Lastly, while all the participants in this study expressed a willingness to be their brother or sister's guardian and/or remain actively involved in their lives in the future, these participants also expressed concerns about the lack of strategic and specific planning with their parents regarding their brothers or sisters' future needs. This finding thus has implications for families and disability agencies that support families to have more focused, specific planning for their family members with IDD. While this study gave suggestions for types of planning tools, it is recognized that there are other tools available for future planning of adults with IDD. Moreover, as none of the participants mentioned having future planning discussions that included their brothers or sisters with IDD, families and disability agencies should actively seek to include the person with IDD

in their planning process. Overall, while this exploratory study provides several implications for researchers, practitioners, and families, it is recognized that this study's small and relatively homogeneous sample underscore the need for additional exploration of this topic.

## REFERENCES

- Abery, B., Rudrud, L., Arndt, K., Schauben, L., & Eggebeen, A. (1995). Evaluating a multicomponent program for enhancing the self-determination of youth with disabilities. *Intervention in School and Clinic, 30*(3), 170-179.
- Algozzine, B., Browder, D., Karvonen, M. Test, D. W., & Wood, W. M. (2001). Effects of interventions to promote self-determination for individuals with disabilities. *Review of Educational Research, 71*(2), 219-277.
- American Bar Association. (2017). *Capacity definition & initiation of guardianship proceedings*. Retrieved from [https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice.html](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html)
- American Bar Association. (2016a). *Guardianship and supported decision-making law and practice*. Retrieved from [http://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice.html#statelawsandpolicy](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy)
- American Bar Association. (2016b). *Practical tool for lawyers: Steps in supporting decision-making*. Retrieved from [https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/practical\\_tool.html](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html)
- Americans with Disabilities Act, Pub. L. No. 101-336, 104 Stat. 328 (1990).
- Americans with Disabilities Act as Amended, Pub. L. No. 110-325, Stat. 122 (2008).
- Appelbaum, P. S. (2007). Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine, 357*(18), 1834-1840.
- Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373-382.
- Autistic Self Advocacy Network. (n.d.). *The right to make choices: International laws and decision-making by people with disabilities*. Retrieved from <http://autisticadvocacy.org/wp-content/uploads/2016/02/Easy-Read-OSF-For-Families-v3.pdf>
- Balcazar, F. E., Keys, C. B., Bertram, J. F., & Rizzo, T. (1996). Advocate development in the field of developmental disabilities: A data-based conceptual model. *Mental Retardation, 34*(6), 341-351.
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology, 9*(59), 1-11.

- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 85-96. doi:10.1111/jar.12088
- Berg, J. W., Appelbaum, P. S., & Grisso, T. (1996). Constructing competence: Formulating standards of legal competence to make medical decisions. *Rutgers Law Review*, 48, 345-396.
- Bigby, C. (1998). Parental substitutes. *Journal of Gerontological Social Work*, 29(1), 3-21.
- Blanck, P., & Martinis, J. G. (2015). "The right to make choices": The National Resource Center for Supported Decision Making. *Inclusion*, 3(1), 24-33.
- Bloomberg, L. D. & Volpe, M. (2008). Analyzing and interpreting findings. In *Completing your qualitative dissertation: A roadmap from beginning to end* (pp. 126-153). Thousand Oaks, CA: Sage. doi: 10.4135/9781452226613.n5
- Bolding, N. L., Wehmeyer, M. L., & Lawrence, M. (2010). *It's my future! Planning for what I want in my life: A Self-directed planning process*. Retrieved from [http://www.ngsd.org/sites/default/files/its\\_my\\_future.pdf](http://www.ngsd.org/sites/default/files/its_my_future.pdf)
- Bollman, J. R., Davis, P. K., & Zarcone, J. (2009). Teaching women with intellectual disabilities to identify and report inappropriate staff-to-resident interactions. *Journal of Applied Behavior Analysis*, 42(4), 813-817.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10<sup>th</sup> ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional children*, 71(2), 195-207.
- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F. & Hill, B. K. (1996). *Scales of Independent Behavior-Revised (SIB-Royal)*. Chicago, IL: Riverside.
- Burke, M. M., Arnold, C. K., & Owen, A. L. (2015). Sibling advocacy: Perspectives about advocacy from siblings of individuals with intellectual and developmental disabilities. *Inclusion*, 3(3), 162-175.
- Burke, M. M., Fish, T., & Lawton, K. (2015). A comparative analysis of adult siblings' perceptions toward caregiving. *Intellectual and Developmental Disabilities*, 53(2), 143-157.

- Burke, M. M., Lee, C. E., Arnold, C. K., & Owen, A. (2016). Correlates of sibling relationship quality and caregiving reception of adults with disabilities. *Journal of Developmental and Physical Disabilities, 28*(5), 735-750.
- Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 33-47.
- Campanella, T. M. (2015). Supported decision-making in practice. *Inclusion, 3*(1), 35-39.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545-547.
- Cease-Cook, J., Test, D. W., & Scroggins, L. S. (2013). Effects of the CD-ROM version of the self-advocacy strategy on quality of contributions in IEP meetings of high school students with intellectual disability. *Education & Training in Autism & Developmental Disabilities, 48*(2), 258-268.
- Center for Disease Control. (2016). *Developmental disability*. Retrieved from: <http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>
- Center for Family Involvement. (2015). *Supported decision making videos*. Retrieved from <https://centerforfamilyinvolvement.vcu.edu/resources/videos/>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Chowdhury, M., & Benson, B. A. (2011). Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities, 8*(4), 256-265.
- Coenen, M., Stamm, T. A., Stucki, G., & Cieza, A. (2011). Individual interviews and focus groups in patients with rheumatoid arthritis: A comparison of two qualitative methods. *Quality of Life Research, 21*, 359-370.
- Cohen D., & Crabtree B. (2006). *Qualitative research guidelines project*. Retrieved from: <http://www.qualres.org/HomeCons-3824.html>
- Conway, S., & Meyer, D. (2008). Supporting siblings: Developing support for siblings of young people with disabilities. *Support for Learning, 23*(3), 113-117.
- Covinsky, K. E., Fuller, J. D., Yaffe, K., Johnson, C. B., Hamel, M. B., Lynn, J., ... Phillips, R. S. (2000). Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. *Journal of the American Geriatrics Society, 48*, 187-193.



- Coyle, C. E., Kramer, J., & Mutchler, J. E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 11*(4), 302-312.
- Creswell, J. C. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3<sup>rd</sup> edition). Los Angeles, CA: Sage.
- Deci, E. L., & Ryan, R. M. (1991). A motivational approach to self: integration in personality. In Dienstbier, R. A. (Ed.), *Nebraska symposium on motivation, 1990* (Vol. 38, pp. 237-288). Lincoln, NE: University of Nebraska Press.
- Dew, A., Llewellyn, G., & Balandin, S. (2004). Post-parental care: a new generation of sibling-carers. *Journal of Intellectual & Developmental Disability, 29*(2), 176-179.
- Douglas, J., Bigby, C., Knox, L., & Browning, M. (2015). Factors that underpin the delivery of effective decision-making support for people with cognitive disability. *Research and Practice in Intellectual and Developmental Disabilities, 2*(1), 37-44. doi: 10.1080/23297018.2015.1036769
- Friend, M. (2006). *Special education: Contemporary perspectives for school professionals*. Boston, MA: Pearson.
- Ganzini, L., Volicer, L., Nelson, W., & Derse, A. (2003). Pitfalls in assessment of decision-making capacity. *Psychosomatics, 44*(3), 237- 243.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick, NJ: Transaction Publisher.
- Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 50*(9), 1214-1219.
- Griffiths, D. L., & Unger, D. G. (1994). Views about planning for the future among parents and siblings of adults with mental retardation. *Family Relations, 221*-227.
- Cornell University of Law. (n.d.). *Guardian*. Retrieved from <https://www.law.cornell.edu/wex/guardian>
- “Guardianship.” (2003). Accessed from: <http://www.encyclopedia.com/topic/Guardianship.aspx>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82.
- Hatch, J. (2015). My story. *Inclusion, 3*(1), 34.

- Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practices in Intellectual Disabilities, 7*(1), 16-25.
- Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities, 47*(3), 208-219.
- Henry, M. (2015). *Toward a new approach to addressing decision-making needs of older adults representing a range of cognitive function* (Doctoral dissertation). Retrieved from ProQuest database. (UMI No. 3746376)
- Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities, 51*(5), 349-359.
- Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities, 48*(1), 52-62.
- Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.
- Individuals with Disabilities Education Improvement Act [IDEA], Pub L. No. 101-146, 104 Stat. 1142 (2004).
- 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.
- “Jenny Hatch Justice Project.” (2014). Retrieved from <http://jennyhatchjusticeproject.org>
- Kapp, M. B., & Mossman, D. (1996). Measuring decisional capacity: Cautions on the construction of a “capacimeter.” *Psychology, Public Policy, and Law, 2*(1), 73-95.
- Karel, M. J., Gurrera, R. J., Hicken, B., & Moye, J. (2011). Reasoning in the capacity to make medical decisions: The considerations of values. *Journal of Clinical Ethics, 21*(1), 58-71.
- Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalization for people with intellectual disability: A review of US studies conducted between 1980 and 1999. *Journal of Intellectual and Developmental Disability, 26*(1), 35-50.

- Koch, L. C., Niesz, T., & McCarthy, H. (2014). Understanding and reporting qualitative research: An analytical review and recommendations for submitting authors. *Rehabilitation Counseling Bulletin, 57*(3), 131-143.
- Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and social capital in sibling relationships of people with disabilities. *Mental Retardation, 51*(6), 482-495.
- Kramer, J. M., Roemer, K., Liljenquist, K., Shin, J., & Hart, S. (2014). Formative evaluation of project TEAM (Teens Making Environment and Activity Modifications). *Intellectual and Developmental Disabilities, 52*(4), 258-272. <http://doi.org/10.1352/1934-9556-52.4.258>
- Krauss, M. W., Seltzer, M. M., Gordon, R., & Friedman, D. H. (1996). Binding ties: The roles of adult siblings of persons with mental retardation. *Mental Retardation, 34*(2), 83-93.
- Lambert, S. D., & Loisel, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing Research Methodology, 62*(2), 228-237. doi: 10.1111/j.1365-2648.2007.04559.x
- LaVallo, R. (2016, March). *Supported decision-making: New alternative to guardianship?* [Webinar]. Retrieved from <http://texascasa.org/events/event/supported-decision-making-new-alternative-to-guardianship/>
- Lennox, N., Bain, C., Rey Conde, T., Taylor, M., Boyle, F. M., Purdie, D. M., & Ware, R. S. (2010). Cluster randomized controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 303-311.
- Lindman, F. T., & McIntyre, D. M. (Eds.). (1961). *The mentally disabled and the law: The report of the American Bar Foundation on the rights of the mentally ill*. Chicago, IL: University of Chicago Press.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, NY: New York University Press.
- Martinis, J., & Ellis, R. C. (2015, October). *Representing clients in guardianship actions: Winning the case for supported decision making* [Webinar]. Retrieved from [https://www.nclc.org/index.php?option=com\\_eventbooking&Itemid=864](https://www.nclc.org/index.php?option=com_eventbooking&Itemid=864)
- Mazzotti, V. L., Kelley, K. R., & Coco, C. M. (2015). Effects of self-directed summary of performance on postsecondary education students' participation in person-centered planning meetings. *The Journal of Special Education, 48*(4), 243-255.

- Millar, D. S. (2013). Guardianship alternatives: Their use affirms self-determination of individuals with intellectual disabilities. *Education and Training in Autism and Developmental Disabilities, 48*(3), 291-305.
- Millar, D. S. (2014). Addition to transition assessment resources: A template for determining the use of guardianship alternatives for students who have intellectual disability. *Education and Training in Autism and Developmental Disabilities, 49*(2), 171-188.
- Miller, A. B., & Keys, C. B. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities. *Mental Retardation, 34*(5), 312-319.
- Moore, R., & Friedman, M. (2017). The role of informed choice in advancing competitive integrated employment. *Journal of Vocational Rehabilitation, 46*(2), 245-264.
- Moye, J., Karel, M. J., Azar, A. R., & Gurrera, R. J. (2004). Capacity to consent to treatment: Empirical comparison of three instruments in older adults with and without dementia. *The Gerontologist, 44*(2), 166-175.
- Moye, J., & Naik, A. D. (2011). Preserving rights for individuals facing guardianship. *The Journal of the American Medical Association, 305*(9), 936-937.
- Newman, R. W. (Ed.). (1967). *Institutionalization of the mentally retarded: A summary and analysis of state laws governing admission to residential facilities, and legal rights and protections of institutionalized patients*. New York, NY: National Association for Retarded Children.
- “Olmstead: Community integration for everyone.” (n.d.) Retrieved from <https://www.ada.gov/olmstead/index.htm>
- Osburn, J. (1998). An overview of social role valorization theory. *The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux, 3*(1), 7-12.
- “Parallels in time: A history of developmental disabilities.” (2016). Retrieved from <http://mn.gov/mnddc/parallels/index.html>
- Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*(5), 1189-1208.
- Ralph, N., Birks, M., & Chapman, Y. (2015). The methodological dynamism of grounded theory. *International Journal of Qualitative Methods, 14*(4), 1-6. doi: 10.1177/1609406915611576

- Rawson, H. (2009). "I'm going to be here long after you're gone" - sibling perspectives of the future. *British Journal of Learning Disabilities*, 38, 225-231.
- Reagan, J., Anderson, L. L., Arnold, C. K., & Magaña, S. (2016). Sibling caregivers experience less choice and control. *Family Support Research and Training Center: Research Brief*, 1, 1-5.
- Regan, J. (1972). Protective services for the elderly commitment, guardianship, and alternatives. *William and Mary Law Review*, 13, 569.
- Rehabilitation Act and its amendment, Pub. L. No. 93-112, 87 Stat. 355 (1973).
- Residential Services and Facilities Committee, National Association for Retarded Citizens. (1973). *The right to choose: Achieving residential alternatives in the community*. Artlington, TX, ARC.
- Roberts, E. L., Ju, S., & Zhang, D. (2016). Review of practices that promote self-advocacy for students with disabilities. *Journal of Disability Policy Studies*, 26(4), 209-220.
- Rood, C. E., Kanter, A., & Causton, J. (2014). Presumption of incompetence the systematic assignment of guardianship within the transition process. *Research and Practice for Persons with Severe Disabilities*, 39(4), 319-328.
- Rossetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 40(2), 120-137.
- Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology*, 52, 141-166.
- Sadler, G. R., Lee, H. C., Lim, R. S. H., & Fullerton, J. (2010). Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing & Health Sciences*, 12(3), 369-374.
- Saldaña, J. (2013). *The coding manual for qualitative researchers* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Salzman, L. (2010). Rethinking guardianship (again): Substituted decision making as a violation of the integration mandated of Title II of the Americans with Disabilities Act. *University of Colorado Law Review*, 81, 157-245.
- Seltzer, M. M., & Li, L. W. (1996). The transitions of caregiving: Subjective and objective definitions. *The Gerontologist*, 36, 614-626.

- Shogren, K. A., Wehmeyer, M. L., Lassmann, H., & Forber-Pratt, A. J. (2017). Supported decision making: A synthesis of the literature across intellectual disability, mental health, and aging. *Education and Training in Autism and Developmental Disabilities, 52*(2), 144-157.
- Sibling Leadership Network. (n.d.). Retrieved from <http://siblingleadership.org/about/>
- Skeat, J., & Perry, A. (2008). Grounded theory as a method for research in speech and language therapy. *International Journal of Language & Communication Disorders, 43*(2), 95-109.
- Smith J. A., Flowers P. & Larkin M. (2009). *Interpretative phenomenological analysis: Theory, research, and practice*. London, UK: Sage.
- Snyder, E. P. (2002). Teaching students with combined behavioral disorders and mental retardation to lead their own IEP meetings. *Behavioral Disorders, 27*(4), 340-357.
- Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *Image, 12*(1), 20-23. doi: 10.1111/j.1547-5069.1980.tb01455.x
- Supported Decision-Making Network. (n.d). <http://supporteddecisionmaking.org/>
- Supported Decision-Making Agreement Act of 2015. Texas Est. Code §§ 1357.002—1357.003.
- Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Families of adolescents and adults with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities*.
- “Teacher Certification.” (2016). Retrieved from <http://www.teaching-certification.com/special-education-teaching-certification.html>
- Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26*(1), 43-54.
- United Nations. (2006). *The universal declaration of human rights*. Retrieved from <http://www.un.org/en/documents/udhr/>
- United States Commission on Civil Rights. (2000). *Sharing the dream: Is the ADA accommodating to all?* Washington, DC: Author. Retrieved from <http://www.usccr.gov/pubs/ada/ch1.htm>
- Utah Disability Law Center. (2016). *Utah Guardianship and Conservatorship*. Retrieved from <https://www.utcourts.gov/howto/family/GC/index.html>

- Wehman, P., Revell, G., Kregel, J., & Act, D. (1997). Supported employment: A decade of rapid growth. In P. Wehman, J. Kregel, & M. West (Eds.), *Supported employment research: Expanding competitive employment opportunities for persons with significant disabilities* (pp. 1-18). Richmond, VA: Virginia Commonwealth University.
- Wehmeyer, M. (2015). Framing the future: Self-determination. *Remedial and Special Education, 36*(1), 20-23.
- Wehmeyer, M., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*(1), 3-12.
- Werner, S., & Chabany, R. (2015). Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents. *American Journal of Orthopsychiatry*. Advance online publication. <http://dx.doi.org/10.1037/ort0000125>
- Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist, 45*(3), 370-380.
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research, 11*(4), 522-537.
- Wolfensberger, W. (2000). A brief overview of social role valorization. *Mental Retardation, 38*(2), 105-123.
- Wolfensberger, W. (2011). Social role valorization and, or versus, "empowerment." *Intellectual and Developmental Disabilities, 49*(6), 469-476.
- Wolfensberger, W., & Thomas, S. (1994). The importance of social imagery in interpreting societally devalued people to the public. *SRV-VRS: The International Social Role Valorization Journal, 1* (1) 35-37.
- Workforce Innovation and Opportunities Act [WIOA] Pub. L. No. 113-128, 128 Stat. 1425 (2014).
- Wright, J. (2004). Protecting who from what, and why, and how? A proposal for an integrated approach to adult protective proceedings. *Elder Law Journal, 53*-118.
- Yarbrough, D. (2011). *Care coordination notebook: Financing and managing your child's health care* (3<sup>rd</sup> ed.). Richmond, VA: Partnership for People with Disabilities.

APPENDICES



Appendix A  
Informed Consent



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## **Siblings of People with Intellectual Disabilities: Their Perspectives on Guardianship and Its Alternatives**

### **Introduction**

You are invited to participate in a research study conducted by Anna Brady, a doctoral candidate in the Department of Special Education and Rehabilitation at Utah State University. The purpose of this research is to learn more about adult siblings of people with intellectual disabilities' knowledge and perspectives of guardianship and its alternatives.

This form includes detailed information on the research to help you decide whether to participate in this study. Please read it carefully and ask any questions you have before you agree to participate.

### **Procedures**

Your participation will involve filling out a demographic survey about you and your brother or sister with intellectual disabilities, which should take no more than 5 minutes. You will then participate in an interview with Anna Brady, which should take between 30-45 minutes. We anticipate that 1-2 people will participate in this research study at this site, and that a total of 6-8 people will participate among all sites.

### **Risks**

This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those you encounter in everyday activities. The foreseeable risks or discomforts include loss of your confidential information about you and your brother or sister. In order to minimize those risks and discomforts, the researchers will de-identify your information as well as use pseudonyms during the interviews as well as in all transcription, analysis, and write-up of the results. Additionally, all information will be stored on a HIPAA-Compliant, encrypted, cloud-based storage system. If you have a negative research-related experience during your participation, please contact Keith Christensen, the principal investigator of this study, right away at [keith.christensen@usu.edu](mailto:keith.christensen@usu.edu).

### **Benefits**

Participation in this study may directly benefit you by informing you of guardianship and its alternatives. More broadly, this study will help the researchers learn more about adult

siblings' knowledge and perspectives on guardianship and alternatives to guardianship. Also, this study may provide insights onto the types of supports and information that other adult siblings of people with intellectual disabilities may need.

### **Confidentiality**

The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study. However, it may be possible for someone to recognize your particular story/situation/response in the written summary of this study.

We will collect your information through audio recordings and electronic surveys. This information will be securely stored in a restricted-access folder on Box.com, an encrypted, cloud-based storage system, and/or in a locked drawer in a restricted-access office. This information will be destroyed three years after the study is complete.

It is unlikely, but possible, that others (Utah State University, or state or federal officials) may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so.

The research team works to ensure confidentiality to the degree permitted by technology. It is possible, although unlikely, that unauthorized individuals could gain access to your responses because you are responding online. However, your participation in this online survey involves risks similar to a person's everyday use of the Internet.

### **Voluntary Participation, Withdrawal**

Your participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by emailing either Anna Brady ([anna.brady@usu.edu](mailto:anna.brady@usu.edu)) or Keith Christensen ([keith.christensen@usu.edu](mailto:keith.christensen@usu.edu)). If you choose to withdraw after we have already collected information about you, the audio recording of your interview and your survey responses will be destroyed.

### **IRB Review**

The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator, Keith Christensen, at [keith.christensen@usu.edu](mailto:keith.christensen@usu.edu). If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or [irb@usu.edu](mailto:irb@usu.edu).

*Please affix an electronic signature*

---

Keith Christensen, Ph.D.  
Principal Investigator

(435) 797-0507;  
[keith.christensen@usu.edu](mailto:keith.christensen@usu.edu)

Anna Brady, M.S. Ed.  
 Doctoral Candidate  
 (435) 797-8810; [anna.brady@usu.edu](mailto:anna.brady@usu.edu)

*Please affix an electronic signature*

---

### **Informed Consent to Participate**

By signing below, you agree to participate in this study by having your interview audio-recorded and completing an electronic survey. You indicate that you understand the risks and benefits of participation, and that you know what you will be asked to do. You also agree that you have asked any questions you might have, and are clear on how to stop your participation in the study if you choose to do so. Please be sure to retain a copy of this form for your records.

---

Participant's Signature

---

Participant's Name, Printed    Date

### **Interview Follow-Ups**

We would like to contact you after your interview recording has been analyzed in order to verify with you that we are interpreting your statements in ways that align with your perspectives. If you would like to be contacted to give feedback on the researcher's analysis of the information you provide, please indicate this below.

Please check one:

I would like to be contacted via email with the analysis of my interview. Please provide your email address here: \_\_\_\_\_

I would not like to be contacted via email after this interview.

Appendix B  
Recruitment Flyer



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Protocol # 8285

IRB Approval Date: March 15, 2017

Consent Document Expires: March 14, 2018

IRB Password Protected per IRB Coordinator

## Participants Needed



### **Research Participants Needed for a Utah State University Dissertation Study about Siblings of Adults with Intellectual Disabilities.**

- Who is Eligible:**
- 1) Adults (age 18+) of an adult brother or sister (age 18+) with an intellectual disability
  - 2) Adults who grew up in the same household as their brother/sister with an intellectual disability

#### **Participants will be asked to:**

Complete a short electronic survey about you and your adult sibling with intellectual disabilities' demographic information.

Participate in a 60-minute audio-recorded interview answering questions about your perspectives on guardianship and alternatives to guardianship.

Participants may be asked to review the transcript of the interview and the findings of the study to confirm they are consistent with the participant's experiences



#### **Contact:**

If you are interested in participating in this study or would like more information, please contact Anna Brady, via phone or email: [anna.brady@usu.edu](mailto:anna.brady@usu.edu) or (815) 985-2030 or Dr. Keith Christensen [keith.christensen@usu.edu](mailto:keith.christensen@usu.edu) or (435) 797-0507.

Appendix C  
Sibling Survey

*Survey Questions to be Asked of Participants*  
*Participants can choose not to respond to some questions.*  
*Based on ADL; M. M. Seltzer & Li, 1996; Bruininks, Woodcock, Weatherman, & Hill,*  
*1996; Burke, Fish, & Lawton, 2015; Van Volkom et al., 2011*

Siblings Survey

Intro: Thank you for participating in this survey!

Q1 What is your age?

- write in: \_\_\_\_\_

Q2 What is your gender?

- Female  
 Male  
 Other/describe: \_\_\_\_\_

Q3 What is your current household income?

- under \$20,000  
 \$20,000-39,999  
 \$40,000-59,999  
 \$60,000-79,999  
 \$80,000-99,999  
 \$100,000 or more

Q4 What is your highest level of education?

- Less than high school  
 High school graduate  
 Some college  
 Associate's degree  
 Bachelor's degree  
 Master's degree  
 Doctorate  
 Other/describe: \_\_\_\_\_

Q5 What is your ethnic background?

- American Indian or Alaskan Native  
 Asian American  
 Black/African American  
 Hispanic or Latino  
 Native Hawaiian or Other Pacific Islander



- White
- Two or more ethnicities

Q6 In what state do you currently reside?

- Write in: \_\_\_\_\_

Q7 What, if any, religion do you associate with?

- Write in \_\_\_\_\_

Q7 How many sisters do you have?

- 0
- 1
- 2
- 3
- 4 or more

If 0 Is Selected, Then Skip To End of Block

Q8 How old is your oldest sister?

- Write in: \_\_\_\_\_

Q9 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q10 How old is your second oldest sister?

- Write in: \_\_\_\_\_

Q11 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q12 How old is your third oldest sister?

- Write in: \_\_\_\_\_

Q13 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q14 How old is your fourth oldest sister?

- Write in: \_\_\_\_\_

Q15 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q16 How many sisters with intellectual disabilities do you have?

- 0
- 1
- 2
- 3
- 4 or more

If 0 Is Selected, Then Skip To End of Block

Q50 If you have more than one sister with an intellectual disability, please answer the following questions based on the sister you are closest in age to.

Q37 Please indicate if your sister has any of the following disabilities. Check all that apply.

- Intellectual disability (please write specific type, if applicable) \_\_\_\_\_
- Autism Spectrum Disorder
- Blind/Visual Impairment
- Cerebral Palsy
- Deaf/Hard of Hearing
- Down Syndrome
- Learning Disability
- Mental Health Diagnosis (please write specific type, if applicable)  
\_\_\_\_\_
- Physical Disability
- Physical Health Condition
- Speech/Language Impairment
- Other/describe: \_\_\_\_\_

If Intellectual disability (pl... Is Not Selected, Then Skip To End of Block

Q35 Where does your sister with an intellectual disability live?

- In your home
- In parent's home
- In a group home with less than 4 people
- In a group home with 4-16 people
- In an intermediate care facility, institution, or large group home (more than 16 people)
- Independently
- Independently with supports
- Other/describe: \_\_\_\_\_

Q36 How long does it take you to get to your sister with an intellectual disability's home?

- I live with my sister
- Within 5 minute drive

- Within 30 minute drive
- Within 60 minute drive
- Within half a day drive
- More than half a day drive

Q39 Can your sister with an intellectual disability perform the following activities with total help, some help, or without help?

	With Total Help (1)	With Some Help (2)	Without Help (3)
Housework (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Laundry (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepare Meals (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grocery Shop (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the Phone (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Manage Own Money (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take Own Medications (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get Around Own Home (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eat (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dress (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groom (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get in/out of Bed (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathe (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the Restroom (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get to Places Outside of Walking Distance (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>





Q34 For your oldest sister with an intellectual disability, are you, \_\_\_\_ (Please select all that apply)

- legal guardian
- surrogate decision maker
- power of attorney for healthcare/medical
- power of attorney for finances
- conservator
- other/describe \_\_\_\_\_
- none of the above

Q42 Which role are you likely to fulfill for your sister with an intellectual disability when your parents are no longer able to provide care?

- Not a caregiving role
- Shared caregiving role
- Primary caregiving role

Q17 How many brothers do you have?

- 0
- 1
- 2
- 3
- 4 or more

If 0 Is Selected, Then Skip To End of Block

Q14 How old is your oldest brother?

- Write in: \_\_\_\_\_

Q27 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q15 How old is your second oldest brother?

- Write in: \_\_\_\_\_

Q26 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q16 How old is your third oldest brother?

- Write in: \_\_\_\_\_

Q19 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q17 How old is your fourth oldest brother?

- Write in: \_\_\_\_\_

Q31 In what state does this sibling reside?

- Write in: \_\_\_\_\_

Q33 How many brothers with disabilities do you have?

- 0  
 1  
 2  
 3  
 4 or more

If 0 Is Selected, Then Skip To End of Block

Q51 If you have more than one brother with an intellectual disability, please answer the following questions based on the brother that you are closest in age to.

Q47 Please indicate if your brother has any of the following disabilities:

- Intellectual disability (please write specific type, if applicable) \_\_\_\_\_  
 Autism Spectrum Disorder  
 Blind/Visual Impairment  
 Cerebral Palsy  
 Deaf/Hard of Hearing  
 Down Syndrome  
 Learning Disability  
 Mental Health Diagnosis  
 Physical Disability  
 Physical Health Disability  
 Speech Language Impairment  
 Other/Describe \_\_\_\_\_

If Intellectual disability (pl... Is Not Selected, Then Skip To End of Survey

Q45 Where does your brother with an intellectual disability live?

- In your home  
 In parent's home  
 In a group home with less than 4 people  
 In a group home with 4-16 people  
 In an intermediate care facility, institution, or large group home (more than 16 people)  
 Independently  
 Independently with supports

Other/describe: \_\_\_\_\_

Q46 How long does it take to get to your brother with an intellectual disability's home?

- I live with my brother
- Within 5 minute drive
- Within 30 minute drive
- Within 60 minute drive
- Within half a day drive
- More than half a day drive

Q48 Can your brother with an intellectual disability perform the following activities with total help, some help, or without help?

	With Total Help (1)	With Some Help (2)	Without Help (3)
Housework (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Laundry (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepare Meals (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grocery Shop (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the Phone (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Manage Own Money (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take Own Medications (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get Around Own Home (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eat (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dress (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Groom (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get in/out of Bed (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathe (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use the Restroom (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get to Places Outside of Walking Distance (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>







Q44 For your oldest brother with an intellectual disability, are you,\_\_\_\_\_ (Please select all that apply.)

- legal guardian
- surrogate decision-maker
- power of attorney for medical/health care
- power of attorney for finances
- conservator \_\_\_\_\_
- other/describe \_\_\_\_\_

Q51 Which role are you likely to fulfill for your brother with an intellectual disability when your parents are no longer able to provide care?

- Not a caregiving role
- Shared caregiving role
- Primary caregiving role

Q49 Thank you for participating for this survey!

## Appendix D

### Interview Protocol Guide and Questions Used During Interviews

*Interview protocol guide and questions used during interviews.*

- Give the participant the informed consent form. Read and highlight key points with him/her. Ask if he/she has any questions about it. Re-iterate the purpose of the study.
  - After obtaining consent, give the sibling the demographic survey on Qualtrics to fill out prior to the interview.
  - Briefly explain a little of researcher's background. E.g., "Anna is also a sibling of 2 brothers with disabilities. Her older brother has intellectual and developmental disabilities and mental illness. Anna is interested in learning about other sibling's perspectives on guardianship and its alternatives."
  - If the interviewee asks probing questions about Anna, re-direct him/her by saying, "I appreciate that question, but that goes outside the scope of our time today."
- 1.) Describe your relationship with your sibling with ID.
    - a. What do you and your brother/sister do together?
    - b. What do you enjoy about your brother/sister?
    - c. How often do you see him/her?
    - d. Can you explain the types of communication you have with him/her?
      - i. How often do you have these types of communication with him/her?
  - 2.) Describe your brother/sister with ID's current living situation/support system.
    - a. (If they have a caregiver/staff other than the interviewee, ask): Do you talk with your brother/sister's caregivers/support staff about their care/needs? If so, how often? And what types of things do you talk about with the staff/caregiver?
  - 3.) Describe your sibling with ID's current level of decision-making.
    - a. E.g., what types of choices does your brother/sister make on a daily basis (e.g., does your sibling make choices about what to eat, what to wear, where to live, what type of job to do, recreational activities, who to be friends with, etc.)?
    - b. What, if any, types of decisions are more difficult for your brother/sister?
    - c. What, if any, types of supports does your brother/sister currently receive when making decisions? (e.g., does someone help explain the choices to him/her, are options worded in yes/no responses, etc.)
    - d. In what ways does your brother/sister currently express his choices/opinions/preferences?
      - i. How well do you think that others (besides you) can understand your brother/sister's communications?
      - ii. Has there ever been a time, that you know of, when your brother/sister has communicated a choice that someone else did not understand? If so, explain.
  - 4.) Does your brother/sister with disabilities currently have a guardian?
    - a. If so, what is the guardian's relation to your brother/sister (e.g., family member, friend, etc.)?
    - b. If not, will he/she have a guardian in the future?
    - c. What do you think about your brother/sister having a guardian?

- 5.) If your brother/sister has a guardian, can you explain how that process was set up (e.g., who first recommended guardianship for your brother/sister)?
  - 6.) Can you describe and define guardianship?
    - a. How/when did you first learn about guardianship?
      - i. Who told you about this? (Parent, adult service staff, your sibling's school staff, etc.)
      - ii. Did you/Have you had discussions with your parents about guardianship for your brother/sister with ID? If so, what sorts of things did you and your parents discuss about guardianship?
      - iii. How did you feel the first time you discussed guardianship with your parents? (e.g., could you give an example or explain those feelings)
      - iv. Have you talked with others about your feelings about guardianship for your brother/sister with ID? If so, who?
  - 7.) Can you describe/define any alternatives to guardianship?
    - a. How/when did you first learn about these alternatives?
      - i. Who told you about this? (Parent, adult service staff, your sibling's school staff, etc.)
      - ii. Did you/Have you had discussions with your parents about these alternatives for your brother/sister with ID?
      - iii. How did you feel about the first time you discussed these alternatives with your parents?
      - iv. Have you talked with others about your feelings about these alternatives for your brother/sister with ID?
- Second part of the interview: give the sibling a brochure with definitions. Read the definitions out loud together and then ask:
    - 1.) What do you think about the information in this brochure?
    - 2.) What, if any, information was new to you?
      - a. As a result of reviewing this information, are there certain things you plan to follow up with?
      - b. What might those be?
    - 3.) What do you think about taking on one of these alternative roles with your brother/sister?
      - a. Which, if any, option do you think is practical for your brother/sister?
      - b. Which option (e.g., either guardianship or one of its alternatives) do you think is the best option for your brother/sister?
    - 4.) Is there any information in this brochure that you agree or disagree with?
      - a. If so, please explain.

Appendix E

Brochure

## Brochure

### **Guardianship:**

In general, two types of guardianship are available in the U.S.: full or limited. Full guardianship occurs when the guardian makes all types of decisions for the person placed under guardianship, whereas in limited guardianship, the guardian only makes decisions for certain areas such as healthcare or finances (Jameson et al., 2015; Autistic Self Advocacy Network, n.d.).

### **Capacity:**

Capacity is most often defined as an individual's cognitive ability to make a specific decision. Regarding guardianship, capacity to make the following types of decisions is often under scrutiny: health care; personal and home management; and financial administration (Moye & Naik, 2011; American Bar Association, 2017).~~5~~

### **Alternatives:**

**Advanced Medical Directive.** This is a type of supported decision-making where a person with a disability can designate a person to make their medical decisions. These advanced medical directives can be specific to end-of-life decisions or allow for another person to make to daily medical decisions on behalf of the person with a disability (Riggle, 2016; Autistic Self Advocacy Network, n.d.).

**Conservatorship.** This term means different things depending on the state of residence. For example, in Utah, conservatorship is a type of supported decision making agreement that only covers finances, and these agreements can be written with varying degrees of control, ranging from a person with disabilities being allowed to make financial decisions up to a certain dollar amount, to a person with disabilities giving all their financial control to another (Riggle, 2016; Utah Guardianship, 2016). However, in other states, conservatorship is synonymous with full guardianship and is often used to describe guardianship of an elderly person (Law.cornell.edu, n.d.).

**Power of Attorneys (POAs).** These are documents that can be narrowly or broadly defined, and can be specific to certain areas, usually financial or health care (Millar, 2013; Riggle, 2016; Right to Make Choices; Yarbrough, 2011). POAs give someone else the right make legally binding decisions for you. More than one person can be designated as a POA (e.g., an individual can designate one person for a POA health care and a different person for their financial POA). Additionally, multiple people could be appointed as a joint POA, but they must be in agreement on the decisions (Law.Cornell.edu, n.d.). Any individual with a disability can arrange a POA, as long as s/he has the legal capacity to do so.

**Representative payees or authorized representatives.** These are arrangements made with



the Social Security Administration that designate a specific person to receive and manage a person with disabilities' disability benefits (Yarbrough, 2011).

**Shared Decision-Making Contract.** An agreement where a person with a disability designates another person to help him/her make decisions, while the person with the disability remains the ultimate authority in final decisions (Riggle, 2016).

**Supported Decision Making (SDM).** This is one proposed guardianship alternative that Texas legally recognized in 2015. SDM gives a person with a disability the opportunity to consult friends and family members whom s/he trusts to help him/her comprehend the situation at hand. Unlike guardianship, where the guardian has the final say in any and all decisions, in SDM, the person with the disability makes the final decision (Blanck & Martinis, 2015; Jameson et al., 2015). Under Texas law, any adult who is 18 or older can enter into a SDM agreement. Texas is currently the only state that legally recognizes SMD (Autistic Self Advocacy Network, n.d.).

#### **For More information:**

“The right to make choices: International laws and decision-making by people with disabilities.” (n.d.). The Autistic Self Advocacy Network:  
<http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>

“Guardian.” (n.d.). Cornell University of Law School:  
<https://www.law.cornell.edu/wex/guardian>

“Guardianship Laws and Practices.” (2016). American Bar Association:  
[http://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice.html#statelawsandpolicy](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy)

LaVallo, R. (2016, Mar. 3). Supported decision-making: New alternative to guardianship? [Webinar]. In *Texas Court Appointed Special Advocates*. Retrieved from:  
<http://texascasa.org/events/event/supported-decision-making-new-alternative-to-guardianship/>

“Sibling Leadership Network Home Page.” (2016). Sibling Leadership Network.  
<http://siblingleadership.org>

Supported Decision-Making Network. (n.d). <http://supporteddecisionmaking.org/>

“Supported Decision Making Videos.” (2015). Retrieved Aug. 4, 2016, from the Center for Family Involvement’s website: <https://centerforfamilyinvolvement.vcu.edu/resources/videos/>

Appendix F

Questions to Be Asked by the Peer Debriefer

*Questions to be asked by the peer debriefer (Adapted from Whittemore et al., 2001).*

Criteria Addressed	Questions	Stage of the Research Process
Credibility	Do these codes and the proposed themes represent the experience of participants in an authentic way? Does the write-up reflect the participants' experiences?	During/after Write up
Authenticity	Do these results reflect an emic perspective and acknowledge the participants' original perspectives and any differences among these perspectives?	During/after Write up
Criticality	Does the research process exhibit proof of an ongoing analytical approach? What validity measures are you using at this stage?	All phases (prior to interviews, post-interviews, during analysis, post write-up)
Integrity	Does this stage of the research project reflect recurrent and multiple checks of validity? Are the findings being presented modestly and reflective on the raw data?	All phases (prior to interviews, post-interviews, during analysis, post write-up)
Explicitness	How have the researcher biases, methodological decisions, and analyses, been accounted for? What has been the documentation for these?	All phases (prior to interviews, post-interviews, during analysis, post write-up)
Vividness	How have the participants' perspectives been portrayed with rich and truthful examples that are both clear and artistic?	During/after write up
Creativity	How have creative ways of organizing, presenting, and analyzing data been used?	During/after write up
Thoroughness	How do the findings compellingly answer the research questions? Has data saturation and completeness been reached?	During analysis, during/after write up
Congruence	Is there consistency between the process and the findings? Do the themes fit together and answer the research questions? Are there implications for the findings in a context outside the study situation?	During analysis, during/after write up
Sensitivity	Has the research project been conducted with sensitivity to the participants' human, cultural, and social contexts?	All phases

## CURRICULUM VITAE

ANNA BRADY

245 N 100 E #1  
 Logan, Utah 84321  
 (815) 985-2030  
 annabradyl323@gmail.com

**EDUCATION**

**PhD in Disability Studies**, Utah State University, Logan, Utah, August 2017  
 Emphases: Disability Studies and Applied Behavior Analysis

**Master of Science in Special Education**, Northern Illinois University, DeKalb, IL, May 2010  
 Specialization: Advanced Practices in Special Education

**Bachelor of Science in Education**, Northern Illinois University, DeKalb, IL, May 2008  
 Major: Special Education

**Associate in Science**, Rock Valley Community College, Rockford, IL, May 2005

**LICENSURES AND CERTIFICATIONS**

Licensures: Illinois Learning Behavior Specialist II: Multiple Disabilities and Assistive Technology

Licensure: Illinois Type 10, Learning Behavior Specialist I-Unlimited

Licensure: Utah Special Education Teacher, Endorsed in Severe Disabilities and Mild/Moderate Disabilities (currently being renewed)

Certificate: Perspectives on the World Christian Movement

Certificate: Beyond Suffering, from the Joni and Friends' Christian Institute on Disabilities

Certificate: Leadership Education in Neurodevelopmental Disabilities

**TEACHING EXPERIENCE**

**Graduate Research Assistant**, Utah State University, Logan, UT, August 2014—present.

- ◆ Assisted faculty with research projects and grant writing
- ◆ Supervised student worker in data entry
- ◆ Developed computer-based training and data collection system for early childhood assessment staff
- ◆ Teacher assistant in USU Special Education Department
- ◆ Instructed elementary students in social skills lesson
- ◆ Coordinated social skills day camps for elementary school students

**Project Manager, Autism Employability Training**, Utah State University, Logan, UT, November 2016—present

- ◆ Developed training workshops for people with autism, their families, their support

workers, and their employers

- ◆ Collaborated with schools, universities, autism support groups, vocational rehabilitation, and workforce services to provide trainings
- ◆ Delivered training workshops throughout the state of Utah

**Researcher and Clinician, Utah Behavior Support Clinic**, Utah State University, Logan, May 2015—present

- ◆ Conducted single subject research in applied behavior analysis
- ◆ Implemented applied behavior analysis with children in a behavior support clinic

**Case Manager**, ASSERT Autism Preschool, Utah State University, Logan, May 2016—Aug 2016

- ◆ Coordinated academic programming for preschooler with autism and other developmental disabilities
- ◆ Developed and implemented behavior programming for preschooler with autism and other developmental disabilities
- ◆ Met with parents of preschooler with autism and other developmental disabilities in their home to implement academic and behavior programming

**Lead Instructor**, ASSERT Autism Preschool, Utah State University, Logan, May 2015—Aug 2015

- ◆ Prepared materials for and instructed preschoolers with autism in 1:1 and small group settings
- ◆ Assessed student progress using curriculum-based measurements
- ◆ Helped in research projects

**Life Skills High School Teacher**, Bi-County Coop, Sterling, IL, August 2010—June 2014

- ◆ Instructed students with disabilities in vocational, functional, and academic skills
- ◆ Case-managed IEPs for fifteen students with cognitive disabilities
- ◆ Contributed technology expertise towards the purchases of several new assistive technology devices
- ◆ Organized field trips to local science museum and apple orchard
- ◆ Awarded local and state grants for community-based instruction and health curriculum

**Instructor in Special and Early Childhood Education Department**, Northern Illinois University, DeKalb, IL, June 2011—August 2011; August 2013—December 2013

- ◆ Educated graduate-level students in assistive technology and multiple disabilities coursework
- ◆ Worked with cutting-edge assistive technology programs on Windows- and Mac-based computers
- ◆ Introduced video-based instruction programs and research to graduate students

**Graduate Research Assistant**, Northern Illinois University, DeKalb, IL, August 2008—August 2010

- ◆ Trained college students and educational professionals how to use assistive technology computer programs and devices
- ◆ Assisted college faculty in classes and research involving special education technology
- ◆ Conducted thesis research in video prompting instruction
- ◆ Presented video-based instruction research at national and international conferences

- ◆ Developed video-based instruction materials for students with developmental disabilities

**Secondary Student Teacher**, Harlem High School, Machesney Park, IL, March—May 2008

- ◆ Team-taught a physical science class for students with LD and EBD
- ◆ Instructed students with severe disabilities in life skills such as community awareness

**Elementary Student Teacher**, Ledgewood School, Roscoe, IL, January—March 2008

- ◆ Conducted a functional behavior analysis and collaborated with the school's student assistance team on the findings
- ◆ Designed and implemented individualized math, reading, phonics, and spelling lessons for kindergarten, first, and second grade students with specific learning disabilities
- ◆ Created and instructed personalized phonics and reading lessons for a student with autism
- ◆ Adapted lesson plans for students with disabilities who were included in general education classrooms

**Clinical Experience**, NIU Physical Education Clinic, DeKalb, IL, August—November 2007

- ◆ Assessed locomotor, body orientation, object control, aquatics, and play skill development in a three-and-a-half-year-old child with autism
- ◆ Developed an individualized physical education program (IEP) for this child

**Clinical Experience**, Kirk School, Palatine, IL, March—May 2007

- ◆ Gathered and analyzed data to create a task analysis and lessons on a life skill activity for one student with autism
- ◆ Originated science and art units for 5<sup>th</sup>–7<sup>th</sup> grade students with autism and developmental disabilities
- ◆ Utilized picture exchange communication system (PECS) and Boardmaker technology in daily lessons and activities

**Clinical Experience**, Genoa-Kingston High School, Genoa, IL, January—March 2007

- ◆ Introduced test-taking strategies lessons for 9<sup>th</sup>–10<sup>th</sup> grade students with LD and/or EBD
- ◆ Instructed 9<sup>th</sup>–12<sup>th</sup> grade students with LD, EBD, and/or autism in math, science, economics, reading, and language arts

**Clinical Experience**, Thome School, Rock Falls, IL, October—December 2006

- ◆ Instructed 5<sup>th</sup>–7<sup>th</sup> grade students with EBD and LD in all academic areas
- ◆ Worked intensively in all academic subjects with a student with EBD and ADHD

**College Tutor**, Rock Valley College Success Center, Rockford, IL, 2004—2005

- ◆ Instructed college students with and without learning disabilities in college-level mathematics, English, science, psychology, and history
- ◆ Trained college students in study skills and strategies

## RELATED EXPERIENCE

**Home Caregiver**, IRIS Home-based care giving, Milwaukee, WI, 2009—2016

- ◆ Provided personal care for an individual with physical disabilities
- ◆ Used Hoyer lift for transferring an individual with physical disabilities
- ◆ Followed extensive care plan and feeding plan to assist an individual with physical disabilities in activities of daily living

**Camp Counselor/Program Leader**, Inspiration Center, Walworth, WI, 2004—2008

- ◆ Guided adults with physical and/or cognitive disabilities through outdoor recreational programs
- ◆ Assisted adults with disabilities in personal care/hygiene
- ◆ Organized programming activities for staff and campers

## COMMUNITY EXPERIENCE

**Teacher**, Sunday school class for children, Cache Valley Bible Fellowship in Logan, 2014—present

- ◆ Instructed children ages 3 to 10 in various Biblical topics
- ◆ Developed curriculum on various Biblical topics

**Volunteer**, Joni and Friends Family Retreat Camp, June 2014

- ◆ Coordinated activities for siblings of children with disabilities
- ◆ Assisted children with and without disabilities in camp programming

**Volunteer**, Joni and Friends Cause for Life Intern, June 2013—July 2013

- ◆ Assisted churches with implementing programs for people with disabilities
- ◆ Implemented recreational programs for an orphanage for children with disabilities in Port au Prince, Haiti
- ◆ Led programs for individuals with disabilities and their family members at two camp programs

**Volunteer**, Joni and Friends' Wheel for the World, Poland, June 2012

- ◆ Distributed wheelchairs and other mobility equipment for individuals with disabilities
- ◆ Presented information on working with family members affected by disabilities at a conference for professionals working in disability services fields

**Teacher**, Sunday school class for children, Bethel Church in Dixon, 2011—2014

- ◆ Instructed children in first through sixth grade in international church ministry
- ◆ Developed curriculum on various cultures and countries for elementary children

**Volunteer**, InterVarsity, Kenya, Africa, July 2007

- ◆ Tutored elementary children in all academic subjects
- ◆ Co-led teams of elementary children through recreational activities

**Program Coordinator**, Network of Nations Intercultural Café, January—May 2007

- ◆ Coordinated weekly discussion topics and activities for college international students
- ◆ Collaborated with other volunteers to make decisions about the Café's program structure

**Volunteer**, InterVarsity, Austin and Cabrini Green Neighborhoods, Chicago, IL, March 2006

- ◆ Coached elementary children in mathematics in an after-school program
- ◆ Assisted local churches and community centers in neighborhood development projects

## ORGANIZATIONS

- ◆ Sibling Leadership Network, Utah Chapter, 2015—present
- ◆ Council for Exceptional Children, Professional Member, 2010—present
- ◆ Association for Behavior Analysis International, Student Member, 2009—2010, 2015—

present

- ◆ Utah Association for Applied Behavior Analysis, 2015—present
- ◆ Council for Exceptional Children, Student Member, 2010
- ◆ InterVarsity Christian Fellowship: Student Leader, 2003—2007
- ◆ Deaf Pride at Northern Illinois University, 2005-2007

## HONORS

- ◆ Utah State University Dean's List, 2014—present
- ◆ Northern Illinois University Dean's List, 2005—2010
- ◆ Rock Valley College Dean's List, 2003—2005

## PUBLICATIONS RECENTLY ACCEPTED, PRINTED, OR IN PRESS

**Brady, A.**, Christensen, K., & Holt, J. (2017). The changing view of physical recreation for people with disabilities in the U.S.: Now a more inclusive perspective. *Review of Disability Studies, 13*(2), 3-17.

Ahlers, K., Gabrielsen, T., Lewis, D., **Brady, A.**, & Litchford, A. (under review). Supporting individuals with autism spectrum disorder in understanding and coping with complex social emotional issues.

**Brady, A.**, & Durán, L. (under review). A literature review of the transition of culturally and linguistically diverse students: Trends, barriers, and recommendations.

Van Laarhoven, T., Van Laarhoven-Myers, T., Cancio, E., & **Brady, A.** (2011, February). Lights, camera, action- Part II: The use of video-based supports and iPods in employment settings. *APSE Connections, 1-2*. (Invited submission)

Van Laarhoven, T., Van Laarhoven-Myers, T., Cancio, E., & **Brady, A.** (2011, January). Lights, camera, action—part one: The use of video-based supports and iPods in employment settings. *APSE Connections, 1-2*. (Invited submission)

## NATIONAL/INTERNATIONAL CONFERENCE PRESENTATIONS

Ahlers, K., **Brady, A.**, Litchford, A., Ellzey, A., Fox, J., Winter, S., Gabrielsen, T., & Carbone, P. (2017, July). *Pediatricians as initial diagnosticians within multidisciplinary autism spectrum disorder evaluations in young children*. Poster session presented at the Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities' bi-annual conference meeting of Autism CARES, Bethesda, MD.

**Brady, A.** (2017, June). *Siblings of adults with IDD: Their knowledge and perspectives on guardianship and its alternatives*. Presented at the 141<sup>st</sup> Annual American Association on Intellectual and Developmental Disabilities in Hartford, CT.

Webb, C., & **Brady, A.** (2017, June). *Supporting siblings and families of people with disabilities in faith communities*. Workshop presented at the International Summer Institute on Theology and Disability, AzU.S., CA.



- Hoffmann, A., Paskins, R., **Brady, A.**, & Sellers, T. (2017, May). *Using pictures depicting app icons to conduct an MSWO preference assessment on a tablet device*. Paper presented at the 43<sup>rd</sup> Annual Association for Behavior Analysis International Conference, Denver, CO.
- Brady, A.**, & Durán, L. (2016, Dec.). *A literature review of the transition of culturally and linguistically diverse students: Trends, barriers, and recommendations*. Paper presented at the Association for University Centers on Disability's Conference, Washington, D. C.
- Brady, A.**, Slocum, T., Paskins, R., & Holt, J. (2015, Nov.). *Systematic literature review of types of interventions to instruct self-advocacy skills to individuals with developmental disabilities*. Paper presented at the Association for University Centers on Disability's Conference, Washington, D. C.
- Olson, J., Van Laarhoven, T., **Brady, A.**, Johnson, H., & Chan, J. M. (2011, May). *The effectiveness of using an iPod Touch to teach cleaning skills: Fading from video to picture/audio prompts*. Symposium, *Using Video Prompting Via an iPod Touch to Teach Individuals with Autism and Other Developmental Disabilities*, with Cannella-Malone, H. (Chair). Paper presented at 37th annual Association for Behavior Analysis International, Denver, CO.
- Van Laarhoven, T., Chan, J. M., Wadman, L. M., Olson, J., **Brady, A.**, & Johnson, H. (2011, May). *A comparison of printed and iPod-delivered schedules for increasing independent task initiation and completion*. Paper presented at 37th annual Association for Behavior Analysis International, Denver, CO.
- Van Laarhoven, T., **Brady, A.**, & Olson, J. (2010, June). *Lights, Camera, Action! The use of Video and iPods for Increasing Independence*. Demonstration presented at the APSE National Conference in Atlanta, GA.
- Van Laarhoven, T., Van Laarhoven-Myers, T., **Brady, A.**, Olson, J., & Johnson, H. (2010, April). *Promoting Independence using Video iPods: Tips, Tricks, & Tutorials*. Paper presented at the National Council for Exceptional Children, Nashville, TN.
- Brady, A.**, Van Laarhoven, T., Chandler, L., Johnson, J., Olson, J. & Johnson, H. (2010, April). *Comparing the efficiency and effectiveness of two video fading procedures for teaching students with developmental disabilities daily living skills*. Poster presented at the National Council for Exceptional Children, Nashville, TN.
- Van Laarhoven, T., Van Laarhoven-Myers, T., Johnson, H., Olson, J., & **Brady, A.** (2010, April). *Transition Planning for Youth with Developmental Disabilities Using Technology: Project MY VOICE*. Paper presented at the National Council for Exceptional Children, Nashville, TN.
- Brady, A.**, Van Laarhoven, T., Chandler, L., Johnson, J., Olson, J. & Johnson, H. (2010, January). *Comparing the efficiency and effectiveness of two video fading procedures for teaching students with developmental disabilities daily living skills*. Poster presented at the ABA Autism Conference in Chicago, IL.

- Olson, J., Van Laarhoven, T., **Brady, A.**, & Johnson, H. (2010, January). *The effectiveness of using an iPod Touch to teach cleaning skills: Fading from video to picture/audio prompts*. Presented at the Association for Behavior Analysis International Autism Conference, Chicago, IL.
- Van Laarhoven, T., Olson, J., **Brady, A.**, & Johnson, H. (2010, January). *A comparison of written and iPod-delivered schedules for increasing independent task initiation and completion*. Presented at the Association for Behavior Analysis International Autism Conference, Chicago, IL.
- Van Laarhoven, T., Van Laarhoven-Myers, T. Olson, J., **Brady, A.**, Johnson, H., & Zurita., L. (2009, October). *M. Video iPods: Hands-On Lab for Creating Video-Based Instructional Materials*. Hands-On lab presented at the Assistive Technology Industry Association (ATIA) Conference, Schaumburg, IL.

#### STATE/REGIONAL CONFERENCE PRESENTATIONS

- Brady, A.**, Paskins, R., Sellers, T. (2017, June). *Monitoring and increasing treatment staff treatment fidelity: Tips and tricks*. Presented at the Utah Multi-Tiered Systems of Support Conference in Provo, UT.
- Brady, A.** (2017, June). *Employment skills training for adults with autism*. Interactive workshop presented at the Southwest Behavioral Health Center, Cedar City, UT.
- Brady, A.** (2017, May). *Employment skills training for adults with autism*. Interactive workshop presented at the Autism Spectrum Disorder Clinic, Salt Lake City, UT.
- Brady, A.** (2017, May). *Employment skills training for adults with autism*. Interactive workshop presented at the Workers' Compensation Fund Building, St. George, UT.
- Brady, A.**, Kroc, D., & Lamb, T. (2017, April). *Supporting people with disabilities in employment settings*. Interactive workshop for employers at the Bridgerland Technology College in Logan, UT.
- Brady, A.**, & Paskins, R. (2017, March). *Employment skills training for adults with autism*. Interactive workshop presented at the Weber Human Services Building, Ogden, UT.
- Brady, A.**, & Hoffmann, A. (2017, February). *Treatment selection for challenging behaviors in the classroom: Best practices and current research*. Presented at the Utah Council for Exceptional Children's Annual Conference, Murray, UT.
- Brady, A.** & Key, D. (2017, February). *Employment skills training for adults with autism*. Interactive workshop presented at the Center for Persons with Disabilities, Logan, UT.
- Brady, A.** (2017, January). *Train the trainer workshops for teaching employment skills for adults with autism*. Interactive workshop presented at the Center for Persons with Disabilities, Logan, UT.

- Brady, A.,** Freema, T., Housel, D., Kagabo, R., Hansen, B., & Lund, E. (2016, October). *Evaluating seclusion and restraint acceptability in public schools*. Presented at the Southwest Conference on Disability, Albuquerque, NM.
- Brady, A.,** Callard, C., & Hoffmann, A. (2016, June). *Components of an effective FBA and positive behavior intervention plan*. Presented at Utah Multi-Tiered System of Supports Conference, Layton, Utah.
- Brady, A. & Durán, L.** (2016, April). *A literature review of the transition of culturally and linguistically diverse students: Trends, barriers, and recommendations*. Poster presented at the Student Research Symposium, Logan, UT.
- Brady, A.** (2014, May). *Steppin' Into Health*. Presented at the Illinois Retired Teacher's Conference, Dixon, IL.
- Olson, J., Van Laarhoven, T., **Brady, A.,** Johnson, H., & Chan, J. M. (2011, May). *The effectiveness of using an iPod Touch to teach cleaning skills: Fading from video to picture/audio prompts*. Symposium, *Using Video Prompting Via an iPod Touch to Teach Individuals with Autism and Other Developmental Disabilities*, with Cannella-Malone, H. (Chair). Presented at 37th annual Association for Behavior Analysis International, Denver, CO.
- Brady, A.,** Van Laarhoven, T., Chandler, L., Johnson, J., Olson, J. & Johnson, H. (2011, March). *Comparing the efficiency and effectiveness of two video fading procedures for teaching students with developmental disabilities daily living skills*. Poster presented at the NIU Graduate Student Research Conference, DeKalb, IL.
- Van Laarhoven, T., **Brady, A.,** & Olson, J. (2010, April). *Lights, Camera, Action! The use of Video and iPods for Increasing Independence*. Demonstration presented at the Illinois Rehabilitation Association State Conference, Galena, IL. (Invited submission).
- Van Laarhoven, T., Van Laarhoven-Myers, T., **Brady, A.,** Olson, J., & Johnson, H. (2009, November). *Using Video iPods to Promote Independence: Tips, Tricks, & Tutorials*. Demonstration presented at the Illinois Council for Exceptional Children's (ICEC) 60<sup>th</sup> Annual Conference, Lisle, IL.
- Van Laarhoven, T., Van Laarhoven-Myers, T., **Brady, A.,** Olson, J., & Johnson, H. (2009, November). *Using Video iPods to Promote Independence: Tips, Tricks and Tutorials*. Demonstration presented at the Illinois Statewide Transition Conference, Schaumburg, IL.
- Van Laarhoven, T., Zurita, L., Zurita, B., & **Brady, A.** (2009, September). *Video Tutorials: A convenient medium for learning to use assistive technologies*. Poster presented at the Center for P-20 Engagement, DeKalb, IL.
- Van Laarhoven, T., Van Laarhoven-Myers, T., Johnson, H., **Brady, A.,** & Olson, J. (2008, October). *Video-based instruction in employment settings*. Workshop presented at the Illinois Statewide Transition Conference: Peoria, IL.

## **COURSES TAUGHT**

**TLSE 552: Assistive Technology & Multiple Disabilities.** (Graduate Level course).

**SPED 4000: Introduction to Special Education.** (Undergraduate Level course).

## **TEACHING ASSISTANTSHIPS**

**SPED 4000: Introduction to Special Education.** (Undergraduate Level course).

**SPED 5530: Technology for Teaching Exceptional Learners.** (Undergraduate Level course).

**REH 6120: Psychosocial Aspects of Disability.** (Graduate Level course).

## **GUEST LECTURES**

(2017, April). *Caregivers for Persons with Disabilities.* Lecture given to Psychosocial Aspects of Disability Graduate Class.

(2017, April). *Impact of Disability on the Family.* Lecture given to Psychosocial Aspects of Disability Graduate Class.

(2017, March). *Physical Recreation Options for People with Disabilities.* Lecture given to Psychosocial Aspects of Disability Graduate Class.

(2017, February). *Stigma Faced by People with Disabilities.* Lecture given to Psychosocial Aspects of Disability Graduate Class.

(2017, February). *Discrimination Against People with Disabilities.* Lecture given to Psychosocial Aspects of Disability Graduate Class.

(2016, November). *Autism Supports in Schools.* Lecture given to Utah Regional Leadership Education in Neurodevelopmental Disabilities Graduate Class.

(2016, April). *Low Incidence Disabilities.* Lecture given to Introduction to Special Education Undergraduate Class.

(2016, April). *Assistive Technology and Transition.* Lecture given to Introduction to Special Education Undergraduate Class.

(2016, February). *Intellectual Disabilities.* Lecture given to Introduction to Special Education Undergraduate Class.

## **GRANTS RECEIVED**

**Graduate Student Research Grant, Spring 2017**

- ◆ Amount Funded: **\$2,065**
- ◆ Utilized funds for dissertation research, travel expenses, and funding a research assistant

**Bi-County Special Foundation Mini-Grants, Spring 2012—Fall 2013**

- ◆ Amount Funded: **\$1,000 (over 4 semesters)**
- ◆ Utilized funds for community-based instruction
- ◆ Created kitchen and cooking resources for high school students with intellectual and developmental disabilities.

**Illinois Retired Teachers Fund, October 2013—May 2014**

- ◆ Amount Funded: **\$487.00**
- ◆ Supplied physical education materials, including heart-rate monitors and pedometers, for students with physical and cognitive disabilities
- ◆ Purchased health curriculum to enhance health education program for high school students with developmental disabilities.
- ◆ Presented summary of results at the IRTA conference for retired teachers at Northwest Territory Historic Center, Dixon, IL in May, 2014