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Navigating Age of Majority-Related Issues in Special Education: The Current Needs and a Potential Means for Aligning Professional Values With Policy and Practice

Charles Blayne Walters

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NAVIGATING AGE OF MAJORITY-RELATED ISSUES IN SPECIAL EDUCATION: THE
CURRENT NEEDS AND A POTENTIAL MEANS FOR ALIGNING PROFESSIONAL
VALUES WITH POLICY AND PRACTICE

by

Charles Blayne Walters

Bachelor of Arts
University of South Carolina, 2013

Master of Arts in Teaching
University of South Carolina, 2015

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University of South Carolina

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Accepted by:

Anthony Plotner, Major Professor

Erik Drasgow, Committee Member

Chelsea Stinnett, Committee Member

Fred Greer, Committee Member

Cheryl L. Addy, Interim Vice Provost and Dean of the Graduate School

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ABSTRACT

The paper that follows serves to collect three articles that investigate policy and practice regarding adult decision-making support for students with disabilities receiving special education services. Each has been led by the author of this multiple-manuscript dissertation, Charles Walters. Following a short introduction to these works as Chapter One, Chapter Two provides a reformatted version of an interview-based study with special education directors at the school district level. It was originally published in Volume 35, Issue One of the *Journal of Special Education Leadership* and titled “An Exploratory Study of Special Education Director Experiences with Issues Related to Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support.” Chapter Three offers a reformatted version of a survey-based study with special education teachers. It was originally published in Volume 88, Issue Three of the *Journal of Rehabilitation* and titled “An Exploratory Study of Special Education Teacher Perceptions on Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support.” The third study, presented as Chapter Four, builds off these previous two studies. It details a Delphi-based investigation of recommendations from those with subject matter expertise on adult decision-making support in special education contexts. Finally, Chapter Five provides a brief, concluding word to follow these three articles.

TABLE OF CONTENTS

Acknowledgements.....	iii
Abstract.....	iv
List of Tables	vi
Chapter One: Introduction.....	1
Chapter Two: An Exploratory Study of Special Education Director Experiences with Issues Related to Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support.....	13
Chapter Three: An Exploratory Study of Special Education Teacher Perceptions on Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support	42
Chapter Four: A Delphi Study to Generate, Clarify, and Prioritize Professional Recommendations on Age of Majority-Related Practice in Special Education.....	61
Chapter Five: Conclusion	98
References.....	103
Appendix A: Permission to Reprint Chapter Two.....	118
Appendix B: Permission to Reprint Chapter Three	119
Appendix C: Round One Instrument for Chapter Four	120
Appendix D: Round Two Instrument for Chapter Four.....	127
Appendix F: Round Three Instrument for Chapter Four	137

LIST OF TABLES

Table 2.1 Interview participant and school district demographics	41
Table 3.1 Comparison of sample based on role	58
Table 3.2 Means, standard deviations, and t-tests by item-level indicator for setting/population served	59
Table 4.1 Demographic information for participants by round	91
Table 4.2 Final recommendations rank ordered by mean.....	93
Table 4.3 Remaining recommendations rank ordered by mean	96

CHAPTER ONE

INTRODUCTION

The legal implications of one's 18th birthday, the day on which most United States (US) citizens celebrate reaching the age of legal adulthood, are likely to be met by many people with a minimum of concern. For young adults with disabilities across the country, however, the transition to the age of legal adulthood may be far more complicated. For this group of Americans, the transition may bring with it formal and informal inquiries into their very capacity for taking on the rights and responsibilities of adulthood. In the chapters that follow, three studies have been collected that explore the movement of young adults with disabilities towards the age of legal adulthood within the context of special education policy and practice in the US. In the current chapter, a primer on this constellation of issues is offered alongside an overview of the three studies bound together in this work.

The Age of Legal Adulthood in the US

Legal and social distinctions between adulthood and adolescence are found universally throughout the world (Schlegel, 2009). In many countries, it is common to view adolescents as dependent, vulnerable, and incapable of making responsible decisions, and this is largely the way these societies view children on the whole. Adults, on the other hand, are recognized as autonomous citizens with clear rights and

responsibilities afforded to them (Steinberg, 2009). Across the US, with variation according to state and federal law, there are many different chronological markers of import. These include the age at which one can legally marry or consent to sexual relationships, the legal age for the purchase of alcohol or firearms, the age at which a minor can be tried as an adult in a criminal trial, the age of consent for medical decisions, and more (Legal Information Institute, 2021; Steinberg, 2009). A key milestone in age is that which is associated with adulthood in the US: the age of legal majority, which is often simplified to just *age of majority*.

In all but three states, the age of majority is age 18; Alabama and Nebraska have codified age 19 as the age of majority, and in Mississippi it is age 21 (World Population Review, 2022). It is at this age that one is recognized as legally responsible for their own actions and the age at which their parents are released from their obligations for support (Legal Information Institute, 2021). For all intents and purposes, the age of majority is a threshold that is established in a somewhat arbitrary way. There are no examinations or tests of readiness for young adults before the rights and responsibilities of adulthood are conferred to them. In fact, it is well understood that key areas of the brain associated with responsible behavior continue to develop well into the 20s (Schlegel, 2009), calling into question the very notion of any teenager's "readiness" for adulthood. Most young adults in the US simply go to sleep as children in the eyes of the law and wake up as adults on their 18th birthday. For young adults with disabilities receiving special education services, however, the approach to this age of legal adulthood is signaled and navigated in a way that merits close attention.

Age of Majority in the Context of Special Education

Youth with disabilities were first guaranteed free access to public schooling in the US through the Education of All Handicapped Children Act of 1975 (EAHC). In subsequent iterations of the law, the EAHC has come to be known as the Individuals with Disabilities Act (IDEA). The IDEA, much as it always has, offers statutory and regulatory language that shapes the ways in which special education services are funded, planned for, structured, and to whom they are provided (Yell et al., 2017). When the IDEA was reauthorized in 1997, it brought with it some seemingly minor changes related to students with disabilities and age of majority. At their core, these mandates amounted to informing students and their parents that educational decision-making rights are to transfer to students at the age of majority and then transferring the educational decision-making authority once held by parents to those adult students when they reach that age (Walters et al., 2022a). As some professionals pointed out shortly after these mandates were enacted, state and local compliance with these seemingly innocuous requirements may have unintended consequences (Lindsey et al., 2001).

To understand these unintended consequences, one must first understand the high stakes accountability requirements involved in special education. Failure to act in accordance with these requirements has resulted in special education's reputation as one of the most litigious areas of education in the US (DeMatthews & Knight, 2019; Pazey & Cole, 2013). As a result, special education professionals, perhaps more so than other education professionals, must devote a large amount of focus to ensuring compliance with federal and state laws. As some have observed, this hyper focus on compliance to

avoid litigation often exists to the detriment of sound, ethical practice in special education (DeMatthews & Knight, 2019).

It is in this tension between compliance and practice that these age of majority requirements were first introduced to special education professionals 25 years ago. One of the first words of caution about these new requirements came from a Council from Exceptional Children position paper authored by Lindsey and colleagues (2001). In it, the authors describe the need to do more than just comply with these new federal requirements for age of majority. These mandates, they argue, should be couched within what is known about best practice for young adults with disabilities. The authors continue by expressing the concern that special education professionals merely complying with the law “will lead to a circumstance where parents and family members will feel compelled to obtain guardianship or other legal decision-making status over their son or daughter when they might not otherwise do” (p. 13). In other words, without being appropriately contextualized, professional compliance with the IDEA involves little more than providing students and families with small bits of information that are, on their own, a potential source of major concern. Over the next 20 years, research on the topic would go on to show that Lindsey and colleagues had provided a detailed foreshadowing of the ways in which compliance-focused policy and practice in special education would affect students with disabilities.

Exploring the Context and Nature of Guardianship for Young Adults with Disabilities

The topic of guardianship for young adults with disabilities was largely absent from the landscape of empirical research at the time of Lindsey and colleagues’ position

paper. The concept of self-determination for people with disabilities, however, first discussed in depth by Nirje in 1972, was a topic that had been gaining momentum in the field since the 1980s (Ward, 2005). There are many ways of defining and understanding self-determination for people with disabilities. For the purposes of the current conversation and drawing on the work of Nirje, a fundamental understanding of self-determination involves the human need and the basic right to direct the course of one's own life (Wehmeyer, 1998). For most adults without disabilities, living a self-determined life may be a foregone conclusion; yet adults with disabilities often find themselves insulated from risk by well-intentioned people that are "overzealous in their attempts to 'protect,' 'comfort,' 'keep safe,' 'take care,' and 'watch'" (Perske, 1972, p. 25). This well-intentioned desire to insulate adults with disabilities from the risks of adult life, thereby insulating them from the ability to direct their own lives, is at the very heart of the problem with guardianship in the US today.

Guardianship, in simple terms, refers to a court mediated process with two essential outcomes. The first outcome is formally declaring an adult incompetent to make and/or communicate responsible decisions about their person or property due to disability, advanced age, or the like. The second outcome is establishing a third party, a surrogate known as a *guardian*, to make decisions on that incapacitated person's behalf (Kohn et al., 2012). Guardianship is typically a lifelong arrangement that is tremendously difficult to terminate. For young adults with disabilities, the petitioner for guardianship is typically one's parents which, in effect, allows parents to indefinitely retain the same type of authority over of their loved one that they had while they were children (National Council on Disability, 2018).

The degree of a guardian's authority as a surrogate decision maker depends upon a judge's discretion. Guardianship orders may be either partial, covering only certain areas of decision making, or they may be full, also known as plenary (Millar, 2003; National Council on Disability, 2018; Salzman, 2010). Throughout the US, the preference of courts tends to be awarding full guardianship rather than limiting the authority of the guardian through partial guardianship (Crane, 2015). For some people with disabilities, like those with intellectual and developmental disability, the rate of guardianship in some US states is as high as 89% (Bradley et al., 2019). Type of disability aside, there is evidence that the overall rate of guardianship has tripled in the US since 1995 (Uekert & Van Duizend, 2011). From the ethical problems involved in denying a person's capacity and need to live a self-determined life to the evidence suggesting a commonplace use of this form of surrogate decision-making, reasons abound for why many have turned in recent years to exploring alternatives to guardianship.

Alternatives to Guardianship and the Roles of Special Education Professionals

Guardianship is the public and typically lifelong denial of one's capacity and right to live a self-determined life (Shogren et al., 2018). Supporters of alternatives to guardianship do not deny the support needs of people with disabilities related to making and communicating responsible adult decisions. Rather, people advocating for the use of alternatives to guardianship have stressed the fact that seeking and utilizing support in handling one's affairs is a natural aspect of being an adult (Blanck & Martinis, 2015). In this way, the need for support in taking on the rights and responsibilities of adulthood is

recognized as something normal for all people. Alternatives to guardianship refers to a host of formal and informal mechanisms for adult decision-making support, and proponents of their use encourage families to begin with the least restrictive means of adult decision-making support possible before considering guardianship (Millar, 2014). A frontline for negating the use of undue and overbroad guardianship, it has been argued, is special education professionals aiding in connecting students and their families to the least restrictive decision-making supports possible (Millar & Renzaglia, 2002).

Early in the 21st century, researchers found that, for young adults with intellectual and developmental disability under guardianship in Michigan, 90% of guardianship petitions were filed by their parents while they were still in school (Millar, 2003). Additionally, 80% of those petitions used documentation like psychoeducational evaluations as evidence of incompetence (Millar & Renzaglia, 2002). Others have shown evidence to indicate that educators are the chief referral source for guardianship of young adults with disabilities (Jameson et al., 2015). In a report published on guardianship in the US, the National Council on Disability went as far as to decry the existence of a *school to guardianship pipeline* (2018). While there might not be sufficient evidence to declare the existence of such a pipeline, the use of the term is indicative of a critical mass of public opinion putting pressure on special education professionals to address their role in the use of undue and overbroad guardianship.

The ways in which special education professionals can act to ensure that students with disabilities are supported into legal adulthood in a way that preserves their autonomy and dignity is an area lacking clarity. In the simplest terms, the impetus for special education professionals to provide such support to students and their families may

be understood as an extension of the practical and ethical need to support the self-determination of students with disabilities as a dimension of quality of life and as a predictor of postschool success (Shogren et al., 2018). Raley and colleagues (2020) argued that this rationale for special education professionals to support the self-determination of students in this way is so compelling that it ought to be codified through an amendment to the IDEA. Such an amendment might serve to “move [local education agencies] and special education programs away from assuming incompetence and toward actively promoting student involvement and participation in critical life decisions” (p. 6).

Still others have called for addressing the issue in more holistic ways like the approach provided by Millar’s Guardianship Alternative Model (GAM; 2014). The GAM is a framework that delineates the concerted efforts of special education professionals to promote alternatives to guardianship in five domains: education and instruction, assessment and planning, self-determination, coordination and collaboration, and policy and process evaluation. Echoing long standing calls to effectively leverage the transition planning process to support students with disabilities approaching the age of majority and their families, each of these domains prescribe ways of conceptualizing and operationalizing such support. A natural outgrowth of the support organized by the GAM, the author details, are the local policies and procedures in special education that support it.

Although the GAM itself was not validated by primary research (Millar, 2014), it offers a promising system of organization and cohesion for the recommended age of majority-related actions suggested by scholars and advocates throughout the literature. It is important to note, however, that such calls to action in policy and practice in special

education now span more than two decades. At current, there is a clear and present need for research that contributes to (a) a better understanding of the barriers to more progressive practice contributing to undue and overbroad guardianship and (b) the full scope of actions that professionals may take at the state, district, school, and classroom levels to address such barriers. The body of work contained herein has been collected to these ends.

Setting the Stage: Chapters Two through Five

As a multiple manuscript dissertation, Chapters Two and Three, respectively, offer two, previously written manuscripts led by the author. Both studies appear exactly as they were originally written, reformatted for the purpose of this dissertation. These two studies provide important background and context for Chapter Four which details a third, related study and serves as the focal point of this dissertation. All three studies are described here to set the stage for what to expect in the chapters to follow.

Chapter Two: An Exploratory Study of Special Education Director Experiences with Issues Related to Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support. In the study offered here, a small research team led by the author set out to investigate the professional experiences of special education directors (Walters et al., 2022b). In total, eight special education directors in a single state took part in semi-structured interviews on their experiences with and perspectives on guardianship and adult decision-making support. Thematic analysis yielded three themes present across the interview content provided. First, directors spoke in many ways about the complexities of age of majority conversations with families and the professional

uncertainty and challenges that arise as a result. Second, according to these directors, special education teachers lack the support they need to support students with disabilities and their families in navigating issues that arise related to age of majority. Finally, directors had a lot to say regarding the absence of support from outside agencies, including the state education agency, to aid them in effectively supporting teachers and families in this area of practice. Despite their expertise in special education policy and practice, these directors indicated that, in many ways, they were somewhat at a loss for addressing these issues at the district, school, and classroom levels. These findings prompted two follow-up survey-based studies to better understand the perspectives of a wider array of special education professionals on age of majority-related issues (Plotner & Walters, 2022; Walters et al., 2023). Despite two separate sampling frames, both follow-up studies presented findings quite consistent with one another. One of these studies, led by the author, is described below and presented here as Chapter Three.

Chapter Three: An Exploratory Study of Special Education Teacher Perceptions on Age of Majority, Guardianship, and Alternative Options for Adult Decision-Making Support. In a multi-state survey of 272 special education teachers, the current state of age of majority-related policy and practice in special education was illuminated slightly more. With a research team led by the author, a snowball sampling method was used in two states to better understand these teachers' perspectives on their values pertaining to adult decision-making support for students with disabilities and the current state of practice in this domain. To this end, the survey instrument used two sets of parallel items to explore alignment and divergence between teacher values and their current practice. Teachers consistently indicated valuing progressive approaches to supporting the decision-making

autonomy of students with disabilities. Teachers' ratings of parallel items on the current state of affairs, however, indicated a clear gulf between that which teachers feel should happen and that which actually happens on this front. Every pair of parallel items, in fact, yielded a statistically significant difference. Moreover, as a group, the teachers that were surveyed reported lacking training in areas that might aid them in supporting students with disabilities and their families in the approach to adulthood. Taken with the findings of semi-structured interviews with special education directors, findings from this survey create a somewhat dire picture of the current ability of special education professionals and systems to respond to age of majority-related issues in a progressive fashion. The resounding question present in the wake of findings like these is a relatively simple, yet previously underexplored one: what can special education professionals do, in policy and practice, to take a stance against action or inaction that perpetuates the use of undue or overbroad guardianship?

Chapter Four: A Delphi Study to Generate, Clarify, and Prioritize Professional Recommendations on Age of Majority-Related Practice in Special Education. The final study in this series is one that attempted to outline a solution-focused response to problems like the ones presented in Chapter Two and Chapter Three. More specifically, the purpose of the study in Chapter Four was to partner with professionals who were well established in work promoting alternatives to guardianship to solicit, rate, and establish consensus on recommendations for special education professionals. To achieve this goal, a three round, online Delphi study was conducted to provide a transparent, cohesive, and replicable methodology for gathering information from a small, interdisciplinary group of people with subject matter expertise on this topic. Through a detailed narrative on the

qualitative and quantitative processes that drove these three rounds of data collection, Chapter Four culminates in presenting readers with the foremost recommendations generated over the course of the study. While these recommendations, organized using the core domains of the GAM, offer a nice arc to the scholarship collected here, they are far from a final destination.

Systemic inclinations towards undue and overbroad guardianship in special education, regardless of intent, represent a dereliction of duty for professionals in the field. Chapter Four brings readers to an optimistic vantage of a future that could involve changes to how age of majority can be more purposefully and ethically navigated. However, in sum, the three studies collected here also demonstrate that the problems and potential solutions are complex. Chapter Four surveys this complexity in the discussion it offers following the findings it presents. The discussion that concludes Chapter Four gives way to a short conclusion, the basis for the fifth and final chapter of this paper.

CHAPTER TWO

AN EXPLORATORY STUDY OF SPECIAL EDUCATION DIRECTOR
EXPERIENCES WITH ISSUES RELATED TO AGE OF MAJORITY,
GUARDIANSHIP, AND ALTERNATIVE OPTIONS FOR ADULT
DECISION-MAKING SUPPORT¹

The successful transition to adulthood of young adults with disabilities should be a chief objective of professionals in special education leadership roles (Petcu et al., 2014). As such, as students with disabilities approach the age of majority, the age typically associated with adulthood, their families and educators are charged with determining what actions are needed to provide adult decision-making support (Lindsey et al., 2001). Nearly two decades of research indicates a preference for meeting adult-decision making needs though guardianship without the consideration of less restrictive alternatives (Burke, 2016; Glen, 2014, Jameson et al., 2015; Martinis, 2015; Martinis & Gustin, 2017; Millar, 2003; Millar & Renzaglia, 2002; National Council on Disability, 2018; Payne-Christiansen & Sitlington, 2008; Salzman, 2010; Shogren, Wehmeyer, Martinis & Blanck, 2018). Many have questioned this inclination to guardianship and

¹ This study was originally authored by Charles Walters, Dr. Anthony Plotner, Makenzie Allison, and Abigail Mojica. It was published by Allen Press in the *Journal of Special Education Leadership* in 2022 (Volume 35, Issue 1). It appears here with the written permission of the editor, reformatted to fit the dissertation requirements of the University of South Carolina's Graduate School.

other forms of substitute decision making as a possible misalignment with special education law, best practice, and ethics (Arstein-Kerslake et al., 2017; Kanter, 2015; Millar, 2009; Millar, 2014a; Millar, 2014b; Raley et al., 2020; Rood, Kanter & Causton, 2014; Payne-Christiansen & Sitlington, 2008; Shogren et al., 2018; Zhang et al., 2019).

The Intersection of Guardianship, Special Education, and Self-Determination

Guardianship or conservatorship, as it is typically known, is the court petition-driven process for formally declaring an adult as lacking the capacity to make responsible decisions regarding themselves or their property due to disability or advanced age. Through this formal declaration, the court uses its authority to elect a surrogate to make decisions on behalf of the incapacitated person, commonly known as the ward. The powers of this surrogate, usually recognized as the guardian or conservator, may be limited to certain areas or full, depending on the court's findings regarding the extent of the incapacity. In this way, the guardian may be granted the authority to do things on behalf of the ward like consent to medical treatment and make decisions related to the finances, property, and living arrangements (National Council on Disability, 2018). Rather than assessing a person's individual strengths and characteristics alongside potential decision-making supports and environmental demands, the court system stands accused of using one's disability diagnosis as a sole justification for guardianship (Shogren & Wehmeyer, 2015). So begins the "vicious cycle" described by Salzman (2010, p. 170) wherein one's true decision-making potential is not fully assessed or recognized, subsequently removed through guardianship, and subject to decline over time due to not being exercised.

Between 1995 and 2011, the rate of guardianship in the United States tripled from roughly half a million to 1.5 million (Uekert & Van Duizend, 2011) with some estimates placing the current rate as high as three million (Glen, 2014). Disparate reporting requirements, a limited availability of public information, and a lack of a central data source, however, leaves more precise information on the national rate of guardianship currently out of reach (National Council on Disability, 2018; Raley et al., 2020).

Indictments of guardianship as misaligned with special education have changed little since Lindsey et al. (2001) first described the potential benefits and pitfalls of new language related to the student age of majority in the 1997 reauthorization of the IDEA. Kanter (2015) elucidated this misalignment by referring to IDEA mandates regarding transition planning and services (IDEA, 2008; see 20 U.S.C. § 1401[34]). He proposed that IDEA-mandated student involvement in the transition IEP process whenever postsecondary goals and transition services are discussed (US Dept. of Education, 2007; see 34 CFR § 300.321[b][1]) is one of the most important elements of the landscape in a discussion of how systems of special education operate. Failure to meaningfully include transition-age youth in conversations that affect their post-school lives treats them as incapable and incompetent. Like Lindsey et al. (2001), Kanter also described the way in which IDEA language on the transfer of rights at the age of majority, implemented hastily, may trigger parents to pursue guardianship. As a result, students are treated as presumptively incompetent and denied their right to self-determination under the IDEA (Kanter, 2015; Rood, Kanter & Causton, 2014).

Self-determination, a known predictor of post-school success (Mazzotti et al., 2016; Rowe et al., 2020; Test et al., 2009), is typically understood as the grouping of

skills (e.g., decision-making) responsible for autonomous behavior (Wehmeyer, 1996). Self-determination is defined and described in many different ways throughout the literature. Most of these understandings of the psychological construct trace their roots back to work done on self-determination as a theory of human motivation and personality (Wehmeyer, 1996). Deci and Ryan (1985; 2012) described self-determination as the capacity and the need for people to make choices without undue, outside influences driving those choices. Regardless of one's disability, the rights perspective of self-determination asserts that all people are entitled, or should be entitled, to self-direct their lives (Field et al., 1998; Martin, Huber Marshall & Maxson, 1993; Shogren et al., 2018; Ward, 1988; Ward, 2005; Wehmeyer, 1999). Regarding fundamental decisions about the nature of one's life with a disability, Glen (2014) asserted "that all persons have the human right to make those decisions and [...] the state has an obligation to give whatever supports are necessary" (p. 19). With this backdrop of the right to self-direction, the full or partial removal of one's ability to self-direct their own life through guardianship has been described as a "civil death" (Perlin, 2012). Not only does guardianship set up another person to make decisions of import for another, it may deny their capacity and right to self-direct "all matters related to their finance and property [...] the right to vote, the right to consent or refuse medical treatment (including forced psychiatric treatment), freedom of association, and the right to marry and have a family" (Perlin, 2012, p. 1159). In this way, guardianship can be interpreted as a threat to the self-determination of people with disabilities (Millar & Renzaglia, 2002) by undermining their civil rights.

Millar (2007) conducted a series of focus groups with young adults with disabilities (n=13), their teachers and support staff (n=17), and their parents(n=11).

Specifically, she sought to examine the perspectives and experiences of young adults with disabilities, both those under guardianship and those not under guardianship, the special education teachers currently supporting them, and their parents on issues related to guardianship. Common to all three groups was a disconnect between an agreed-upon importance of student self-determination and the implications of guardianship. Further, Millar found that wherein guardianship had been recommended to parents, it had been recommended exclusively in student IEP meetings. From this exploratory study, Millar moved on to develop case studies for two, 21-year-old students with an intellectual disability that had grown up in the same community together (2008). One young man's parents had sought and obtained guardianship and the other man's parents had not. One of the chief findings of the study involved what appeared to be a comparable level of self-determination in both young men despite having highly different support structures in place. Millar found that, rather than the abilities of the young men, the beliefs and expectations about those abilities from the adults supporting them were far more salient variables affecting a decision to obtain guardianship.

Payne-Christiansen and Sitlington (2008) offered similar findings in their study based on interviews with the parents and educators of one adult student served at a school for youth with significant disabilities and placed under guardianship upon reaching age 18. The authors described a separation between the process of planning related to adult decision-making support and the transition planning process. They claimed that education professionals are prone to make assumptions that guardianship is categorically necessary for certain groups of students. They offered a view of a reductive process for discussing adult decision-making support wherein educators failed to offer knowledge or resources

towards the consideration of less restrictive alternatives to guardianship. In response to their findings, Payne-Christiansen and Sitlington suggested that educators presume that all students have the ability to direct their own lives and educator-supported, family deliberation about guardianship be driven by detailed, individual information about one's present levels of functional performance.

In 2015, findings from a national survey of adults with disabilities and their parents (n=2,051) helped catalyze a renewed vigor for scholarship at the intersection of guardianship and special education (Jameson et al., 2015). Of the respondents with disabilities under guardianship and parents acting as guardians surveyed (n=282), 173 (61.34%) identified educators as a source of referral for guardianship. Like others before them, the authors call for an end to adult supports driven by assumptions of incompetence. Instead, they argue, professional attention should be placed on forwarding support mechanisms like Supported Decision-Making which affirm presumptions of competence and one's right to be self-determined.

Towards a New Paradigm: Supported Decision-Making and the Role of Special Education Leaders

Supported Decision-Making (SDM) is a formal or informal system through which adults with disabilities utilize trusted supporters “to help them understand the situations and choices they face so they may make their own informed decisions” (Blanck and Martinis, 2015, p. 26). Many have asserted that there exists no single means for utilizing SDM (Blanck & Martinis, 2015; Kohn, Blumenthal & Campbell, 2012; Salzman, 2010). It can be as informal as a person seeking input regarding advice regarding medical

procedures or as formal as an agreement covered by a Power of Attorney (Carney, 2013; Kohn, Blumenthal & Campbell, 2012). States that have passed legislation on SDM may require it be outlined through a SDM agreement, a formal document which details the exact nature and parameters of the supportive relationship(s) being entered into through SDM (Shogren et al., 2018; Zhang et al., 2019).

Proponents of SDM argue that, unlike guardianship, it places the individual at the center of decisions regarding their lives, preserving their right to live a self-determined life (Blanck & Martinis, 2015; Campanella, 2015). In doing so, they retain a platform by which they can act as causal agents in their lives (Blanck & Martinis, 2015), gaining skills and knowledge that will foster independence over time (Campanella, 2015). In their work addressing the perspectives of those in special education leadership roles on guardianship and less restrictive alternatives for students with disabilities, (Plotner & Walters, 2022) explored the differences between what school districts, special education teachers, and families should do alongside what they actually do regarding the support of less restrictive alternatives to guardianship. They found that professionals serving in special education leadership roles (n=118), show a high degree of variability between that which those in special education leadership roles believe should be done to avoid undue guardianship and that which is currently done.

School administrators play a critical role in improving the post-school outcomes of students with disabilities, as they are responsible for developing rigorous learning environments for all students. Specifically, effective school leaders ensure that teachers implement evidence-based practices, hold high expectations of all students, and have access to multiple opportunities for professional development. Moreover, school leaders

are responsible for a school's compliance with special education requirements. As such, they must be knowledgeable of state and federal level policies and procedures pertaining to special education and they must be familiar with evidenced based special education practices. Unfortunately, school administrators often lack the training and education necessary to effectively lead special education programs, reducing the quality of educational services students with disabilities receive (Sheef & Mahfouz, 2020). Special education directors are uniquely situated to provide school leaders with the support, resources, and staff necessary to effectively lead special education programs. Thus, it is critical to examine their knowledge and perspective of transition related topics. The current study addresses a lack of empirical observations related to experiences and perspectives of special education administrators on guardianship and less restrictive alternatives. Eight special education directors at the school district-level in South Carolina were interviewed in an effort to answer the following research question:

1. What are the experiences and perspectives of district-level special education directors on issues related to guardianship and adult decision-making support options?

Overview of Participating Special Education Directors

This study utilized semi-structured interviews with eight special education district directors from South Carolina. All eight of the special education directors interviewed for the current study were recruited through their participation in a previous, online survey on the same topic (Walters et al., 2022b). As one of the final items in the survey, all respondents were asked to (a) indicate whether or not they were willing to participate in a

follow-up interview and (b) provide their email address if they were. Fifty-one respondents provided their email address for follow-up, and of those, 14 identified themselves as special education directors at the school district-level. All 14 of these special education directors were approached by a member of the research team and invited to schedule a time to participate in a follow-up interview by phone or in-person, according to their respective preferences. Nine of the 14 directors contacted responded to schedule interviews and of those nine, eight participated in interviews. All eight of the participating special education directors were female with 11 to 25 years of experience and all had served in their current role for a minimum of 2 years. Each participant has been provided a pseudonym and information about their professional background and school districts has been provided in ranges to protect their identity in Table 2.1.

Participants were contacted via email to solicit involvement in the study. The interviews were scheduled and conducted by two members of the research team within a 7-week period. The interview process was guided by semi-structured protocol providing a framework for gathering demographic information, asking questions, and potential follow up questions based on participant responses. Specifically, the protocol was developed for this study by the researchers based on the literature. The protocol has two sections: Demographics section and guardianship and age of majority issues section. The demographic section includes questions such as the number of years working in special education, number of years as a special education director, and educational experience. In addition, information was gleaned regarding descriptions of each participant's daily activities, job responsibilities, and the district in which they serve. Following the gathering of demographic information, a series of 6 questions were asked related to

guardianship and its alternatives, district policies and procedures related to these topics, training needs, and the role of educators in age of majority conversations. The final question offered respondents an opportunity to discuss anything that had not been covered by the interview protocol. Throughout the interview process, researchers maintained a neutral positionality by adhering to this protocol to ensure congruence amongst both researchers and to avoid potential insertion of personal bias.

Interview Data Validation and Analysis

Following the interview and transcription process, data trustworthiness was conducted in two ways: member checks and peer debriefing. Approximately 2 weeks after each interview, member checks were completed with each participant to ensure accuracy (Koelsch, 2013). A brief synopsis of each transcript containing direct quotes was sent to participants and an opportunity was offered to edit, clarify, and/or change their responses. Analytic triangulation was supported by an external auditor with experience in qualitative research who was not a part of the interviews. This external auditor supported the coding and analysis process to help to uncover biases, assumptions on the researcher's part, etc. through a peer-debriefing process (Brantlinger et al., 2005). Once member checks and peer debriefing were complete with all participants, the coding process began using a grounded theory approach (Strauss & Corbin, 1994).

Each interview was recorded using a web-based audio recording and transcription platform, Otter AI. Each participant provided informed consent for their participation, including verbal consent for the recording of their interview. Upon the completion of each interview, the Otter AI system transcribed the recordings and two members of the

research team reviewed and edited the provided transcriptions for accuracy. After the transcriptions were cleaned, initial coding (Saldaña, 2011) was used to get a sense of the contents of each transcript and what connections emerged between them. Specifically, an initial list of codes was developed by the two interviewers around discussions of the personal perspectives and school experiences related to guardianship and adult decision-making support options. With the assistance of the external auditor, the initial list of codes was narrowed down to 56 codes. The next phase consisted of two researchers then separately engaged in focused coding to identify common and significant descriptions and interpretations across the transcripts to combine similar descriptions to form distinct categories. An axial coding stage was then conducted to further link the data together and break down the core themes. In each of the stages, the researchers met to discuss each instance of a code being used until agreement was reached. Further, the external auditor reviewed all transcripts and each instance of a code being used and discussed areas of disagreement with the research team until agreement was reached. This process yielded several themes that were assigned a formal definition. The research team set the inclusion criterion of every code appearing within at least 50% of interview transcripts (4/8 interviewees).

Results

Three themes were generated from related groupings of codes meeting the inclusion criterion. Findings from some of these three themes are complicated, and in some cases conflicted, by instances of codes not meeting the inclusion criterion. They are, nevertheless, of interest to this study in the contrast they provide to themes.

Therefore, each of the three themes are explored below alongside the conflicting or complicating findings through exemplary, coded interview content.

The complexities of age-of-majority conversations with families. Participants described the variability in barriers they have experienced when engaging and supporting families in age of majority conversations. As special education administrators at the district-level, participants acknowledged that their day-to-day interactions with this topic are typically a mixture of firsthand experience and secondhand information from the staff members they support. The participants discussed issues around both the nature and scope of the IEP team's role as well as navigating issues related to personal philosophy and values while providing support. The delicate nature surrounding advice and guidance to families who may not want input was prevalent throughout the interviews. Although the participants agreed this is a family decision and schools should only serve as a resource, the conversations that accompany these discussions are multi-faceted and complex due to numerous variables such as obvious misunderstandings of the process, assumptions regarding student ability, and a disconnect to the mission of the transition team.

Even while attending broadly to the transition of a young adult, some directors discussed feeling bewildered by a family's insistence on guardianship. Shanelle described her dismay at seeing the parents of Project SEARCH participants pursuing guardianship in the midst of a student demonstrating their independence in employment: "these are kids who can work independently and should be running their own checking account and making those decisions for themselves. And it was what the parent believed to be the best thing for that child."

Other interviewees like Maria described the mismatch between how IEP teams may navigate these issues and the higher degree of support parents may need to truly engage in them.

I have disseminated all that information to them I, you know, but I have no way to guarantee that they've read it all. But I think they really, I mean, 'I need face time with the teachers.' They need to have somebody really kind of walking them through what each of the differences are. Because parents are going to ask questions. What, what does this mean? [...] They need to have all the answers, quite frankly.

Further, it was also noted how individual family characteristics like socioeconomic status and education level can interfere with the ways in which these issues are typically handled and can compound support provision. Grace talked about the ways in which poverty may act as a barrier to IEP teams creating momentum around planning for independence and less restrictive alternatives to guardianship.

Our families, families in poverty, typically have multiple family members in the house. It could be the grandmother, the aunt, her kids. And none of these adults are mimicking independent living. Right? Now we want to come in and talk about independent living for a student who has a disability. But the adults who are non-disabled don't even know what that looks like. Because poverty doesn't allow them to really know what that looks like.

Or as Arianna put it, "sometimes it boils down to how educated the parents are."

Another interesting layer within this theme is the concern of special education directors regarding interfering in a family matter than the feel to be more private and consequential than that which is typically discussed. Maria put it this way.

It's a very personal kind of conversation where you're talking about a student and who's going to care for them after school and you're kind of entering into a private life that you don't usually enter into. [...] 'Mom, how are you helping?' I mean we talk about those things, but not with, not with the gravity of this type of conversation.

Many of these barriers stem from assumptions related to competence or potential for independence. In fact, many of the participants discussed family member and professional assumptions of student competence and capacity for independence. On the one hand, it houses directors discussing age of majority and adult-decision making support conversations being thwarted by parents assuming incompetence or an unduly high level of independence from their sons or daughters. On the other hand, it also included directors describing the need for guardianship based on student disability type or perceptions of their support needs.

On the assumptions of incompetence from parents, Arianna had this to say:

They assume that because the cognitive level is x, y, or z that everyone will just know that they will continue to be the parent. They don't have a real conception of the fact that once that child turns a magical age, regardless of their cognitive level, their rights, suddenly become the child's rather than the parents. Our parents are very unaware of that.

In other words, parents may assume that adult guardianship is a given provided their son or daughter's disability status. Arianna went on to describe how this assumption may be part and parcel with one's continued financial dependence on their parents: "There was no legal delegation of rights to the guardian. It was just - this is how it's done. I feed you, I clothe you, you live here. So therefore, you must do what I said."

Participants also discussed situations that arise when parents and school staff have differing opinions about what a student is capable of in terms of adult decision-making. Arianna described the need for school staff to quietly placate parents that assume they will indefinitely be making decisions on behalf of their adult children:

Whether or not the parents process what the team is sharing in terms of the data and the students wishes is not always clear. And I don't think our teachers and even our administrators want that conflict. And I think their go-to is to just quietly side with the parent or passive aggressively start with the parent at the table and then tell the kids something else in the classroom.

The depth of this theme is made clear by two directors that discussed their aspirations for making guardianship, not less restrictive alternatives, simpler for parents to obtain. In these cases, directors describe IEP team recommendations for guardianship and leveraging district resources to support parents in filing guardianship petitions. Imogen described how prompts from IEP teams ahead of students reaching the age of majority ensure families are supported to pursue guardianship before concern over the decision-making capacity of "moderate to severe children" is an issue.

We start having these conversations with them very young, [...] and that we walk them through the process with our local attorney. One of our local attorneys and one of the two that they pick or our probate judge in town. So they've already gotten guardianship by the time we reach a situation like that.

Imogen also discussed using school district attorneys to support parent petitions for guardianship: [W]e also coach them through... we have our school attorneys come talk to... if parents wish to maintain their child children's rights, how do you go about that process?". Dolly described a process by which IEP team referrals to parents for guardianship are followed up by tapping into other school district resources to help ensure it is pursued:

[I]f there are additional concerns, for example a family that doesn't follow through, but we feel strongly that the student is not capable of making decisions, then typically they would refer that to me and I would send out our... we have an individual who serves in the role of like a social worker. [...] And I would send a social worker to see, that if, if we could get some... If through assisting the families they would be willing and open to that discussion. And then sometimes that works and sometimes it doesn't.

Special education teachers lack support and training to assist students and families with age of majority issues. Throughout the interviews, the majority of the participants discussed the issue that special educators are well positioned to support families of students with disabilities; however, this is seldom the case. Specifically, participants discussed ways in which special education teachers should be better supported to

facilitate adult decision-making support planning conversations and related skill building within and outside of IEP team meetings. Further, most of the directors interviewed view adult decision-making support conversations as a central element to transition planning and programming. Some discuss the landscape of transition programming as a natural fit with promoting alternatives to guardianship and robust age of majority planning conversations in IEP team meetings.

Maria candidly elaborated on the issue of teachers potentially lacking support for practicing in this domain, stating “we're just winging it with that, you know, conversation with those kids and then instruction. And it really, I mean, if we're teaching them everything else, we need to be teaching them what all of the terms mean, what all of the differences mean moving forward [sic].”

Interestingly, there were some participants who questioned whether special education teachers should be serving as a central figure in age of majority and adult decision-making support conversations in the first place. Latoya talked about her concern that teachers might get the that part of their job is to make specific recommendations regarding adult decision-making support options:

I don't see the district's role as far as making a recommendation for one thing or the other, because I'm afraid I would have rogue teachers, not necessarily, you know, saying like, you know, ‘you should get guardianship’ where maybe, and you know for some, that may be too intrusive

The ways in which teachers are supported through professional development and informed by transition assessment data was a rich area of discussion for those

interviewed. Concern about their exact role in doing so, however, was an important layer of the subject.

The absence of aid and guidance to maximize support to families and students. Another area of broad agreement and elaboration from participants was the importance of having technical assistance, resources, and a better understanding of best practice in this area. The participants agreed that, although these are brand new issues, there is a lack of guidance on how to shape district and school level transition service delivery. The participants shared that they expect outside agencies and associations to provide more resources to transition administrators and professionals to best navigate adult decision-making support options. Latoya described the need for family and district support from outside agencies regarding adult decision-making support options as parallel to the need for transition support in broader terms: “[W]hen students leave the public school system, there needs to be a support system already in place, and it needs to be a smooth transition, and we encourage those relationships with outside agencies.” Characterized by Dolly as “significantly lacking,” the difficulty in finding support from outside agencies is a theme comprised of two codes observed across more than half of participants. Maria had this to say about the lack of information or support from outside agencies on the topic:

CEC is not doing sessions on it. State department website is impossible to find anything on so that's [...] it's not on the [state transition support] website that I've found. And I mean, I just went all through it yesterday. It might be there. But if it is, it's tiny [...] This information needs to be out there, it needs to be readily available. [...] We have not done a good job of

educating anybody. And we certainly don't do a good job of making it available and accessible.

Complicating this theme slightly is Imogen's view that the main need for school districts and families from outside agencies rests with needing support for guardianship petitions.

[O]ur limitations are that we're limited to how we operate in the scope of the school, but we need outside agencies to help walk these families through the process outside those doors. If they need a ride to the probate office that that's provided. If they need legal representation that that's provided. If they need a medical person to go support them when they go before the probate judge that the right forms are filled out.

In addition, each of the special education directors interviewed made reference to lacking support in some fashion from the State Department of Education. This lack of support is described as it relates to (a) navigating a fairly recently passed legislation in South Carolina, The Adult Students with Disabilities Education Rights Consent Act (ASDERCA, see S.C. Code § 59-33-310 to 59-33-370) and (b) broader support from the State Department of Education on age of majority issues and alternatives to guardianship. Shanelle described the lacking support related to ASDERCA, South Carolina's provision for attending to the IDEA special rule on alternative mechanisms for delegating education decision making authority for adult students [see 34 CFR § 300.520(b); 20 USC § 1415 (m)(2)]:

[W]e just, we have received, a memo stating this, this legislations come, I think there were some guidance documents about breaking down what the choices were the parents could have. But I can't say that since that came

out, like two years ago, that there's been any additional conversations at all or training being offered related to guardianship or adult decision-making.

[sic]

Dolly characterizes this lack of support as an overemphasis of State Department of Education efforts on monitoring compliance with the IDEA: “[M]onitoring is all about compliance. It's about checking a box in an IEP. It's not about really looking at what kids need.” Grace, on the other hand, describes the State Department of Education as lacking in their ability or willingness to provide more nuanced support in areas of district need in this way:

No offense to them I think they're great people, but I feel like there are things that come out and that's their focus for that year. For example, the last two years has been the South Carolina High School Credential, that's what every training is focused on. Nothing else matters, right? They don't see how all these things are connected. So next year when it's not the High School Credential, it'll be the next big thing, and all of our focus will be on that but everything we do in special ed is absolutely connected.

Discussion of Findings

It has been asserted that there is separation between transition planning processes and planning related to adult-decision-making support (Payne-Christiansen & Sitlington, 2008) and that age of majority mandates in the IDEA may impede efforts in transition if implemented solely with compliance in mind (Lindsey et al., 2001). The current study's findings indicate that in states for whom these director experiences may be

representative, both of these assertions may hold truth worth exploring further. The results of the present study shed light on various issues that could assist students and their families in navigating issues related to adult decision-making support and potential reasons why these processes remain disconnected despite their complementary nature. Although many special education directors view transfer of rights issues as central to the transition planning process, they note several challenges in effectively supporting families and school staff as they navigate these discussions. The challenges frequently encountered include insufficient teacher education and training, lack of understanding on how to work with families in this area, inaccurate assumptions of a student's ability to make decisions and/or their potential to achieve independence, and limited support and guidance from the State Department of Education, outside agencies, and professional organizations.

Alongside the directors' perceptions of challenges to supporting families and teachers covered here, however, is the existence of an unexpected and complicated element of some interviews. A small portion of directors interviewed made casual references to school recommendations for guardianship, leveraging school district resources to support those recommendations, and the on-going need for support from outside agencies to support parental petitions for guardianship. These comments are notable as they are an indication that directors themselves may not be fully aware of the perils that come with a position advocating for the removal of student rights.

One interesting finding from this study is that special education teachers are uniquely positioned to assist students and families in discussions on transfer of rights issues. However, it was further noted that teachers often lack access to frequent and

thorough professional development on the topic of guardianship and other adult decision-making support options. In other words, teachers find themselves leading conversations on transfer of rights options, yet, they are often ill-equipped to support families through the process. Given that educators have been cited as a leading source of referral for guardianship (Jameson et al., 2015), and guardianship referrals are frequently made during IEP meetings (Millar, 2007), there is possible cause to be concerned regarding their ability to effectively support families. The central role special education teachers play in leading these discussions, coupled with their lack of training on the topic is evidenced. Therefore, special education directors recognize the need to support, guide and train special education teachers on these matters.

This major issue is compounded by the fact the Special Education Directors in the current study feel there is an absence of guidance and support that will support them as administrators to in fact support their transition teams on how to do this effectively. Teacher education and training on this topic as many educators remain unfamiliar with the implications of guardianship (Millar, 2007; Rood et al., 2014). For example, one study found that many students who had an appointed guardian were signing their IEPs, a legally binding document, at the end of their IEP meetings (Millar, 2009). This is a clear indication of a lack of understanding of what placing someone under guardianship truly means. In the present study, several special education administrators interviewed questioned entirely placing the responsibility of transfer or rights discussions on teachers given their lack of education and training on these topics. While Millar (2014b) contributed a helpful framework for conceptualizing practice in this area, it is clear from

this study that the exact balance of activities and responsibilities is an area of uncertainty for administrators.

Another challenging area identified is complications related to how to even approach families in conversations related to age of majority and transfer of rights. Potential barriers to family involvement discussed by the participants included preconceived notions and assumptions of families as well as how family characteristics such as level of education, cognitive abilities, and socioeconomic status are considered while supporting students and their families as they transition. Interestingly, challenges with supporting youth through this process when zero or limited family engagement is present was not discussed. Challenges with obtaining parent participation have frequently been cited in the transition literature (Hirano et al., 2018). However, research has found that a lack of or limited parental involvement has more to do with school-wide and teacher initiatives to include families than specific family demographics such as education (Staples & Diliberto, 2010). Given that family involvement is a predictor of positive student outcomes (Mazzottii et al., 2016; Rowe et al., 2020; Test et al., 2009), it is imperative that teachers and school leaders receive the training and education necessary to foster relationships between parents and schools (Staples & Diliberto, 2010) through providing non-judgmental supports in addition to having a level of expertise in this area.

The nuance of having conflicting viewpoints on student ability is also a noteworthy finding. Expectantly, involving families in transfer of rights discussions can also be challenging when there are inconsistencies between student performance and what a family believes is in the best interest of the student. This can occur either when

families inaccurately assume that the student is not capable of making independent choices or when families hold unrealistically high expectations. These situations may be indicative of a need to improve communication efforts between the school and the family regarding a student's strengths and the areas in need of improvement. Other challenges arise when families lack a true understanding of age of majority and transfer of rights issues, such as parents incorrectly assuming they will retain all legal rights due to the type or severity of their son or daughter's disability. These findings align with previous research which has found that guardianship placement often has more to do with the assumptions and expectations of the family supporting the person with the disability, than an actual reflection of their ability to make decisions and achieve independence (Millar, 2008). All participants agreed that they are in need of guidance themselves which also play a paramount role in supporting families and schools in navigating age of majority and transfer of rights issues.

Compliance-focused and limited support from the State Department of Education was another common challenge noted by special education directors. Some interviewees commented on the lack of support in broad terms, such as a lack of easily accessible information on the topic of age of majority and transfer of rights. Others commented on the state's overreliance on compliance and/or the department's tendency to focus narrowly on one major topic and limit all professional development opportunities to that topic. As has been pointed out, special education leaders must be equipped to "lead not just a culture focused on compliance, but also a culture focused on learning and high expectations." (Sloand, 2014, p. 97). In addition to this, many referenced a lack of support in navigating the recently passed legislation in South Carolina, The Adult

Students with Disabilities Education Rights Consent Act (ASDERCA, see S.C. Code § 59-33-310 to 59-33-370).

Limitations of this Study

There are certain limitations of this study that merit recognition. First, it is likely that the research team's decision to focus on the experiences of a relatively small group of special education directors in a single state best reflects that state's unique landscape of guardianship, alternatives, and special education. As such, a great deal of caution should be exercised in attempting to make inferences to the treatment of these issues in other locales. Nevertheless, this study is meant to be an exploration that encourages closer attention to policy and practice in this domain; it is not intended to be a perfect reflection of policy and practice in this domain for special education on the whole. Second, the position of the special education director is challenging and oftentimes highly political. The research team is incredibly grateful to the women that took time from their busy lives to participate in this study and appreciates that, in some cases, total candor might have been impossible on issues that could compromise the balance they are charged with keeping in their districts. Lastly, although the position that families of young adults with disabilities and the professionals that support them should show deference to less restrictive alternatives to guardianship is well reasoned, it is worth mention that this is a likely apparent bias of the research team. In this way, this study was conceptualized, carried out, and written up from a position that must be viewed in tandem with any findings and implications forwarded here.

Considerations for Special Education Leaders and Future Research Directions

Despite the challenges many special education directors report encountering in supporting schools and families in navigating transfer of right issues, many believe that promoting alternatives to guardianship is a natural fit to the transition planning process. Others, however, believe that there is a subgroup of students for whom guardianship is appropriate to pursue. Based on the results of the present study, we believe that it is critical to provide transition professionals with education, resources, and opportunities to openly discuss the plethora of issues surrounding guardianship with students and families. The constellation of issues related to age of majority and adult decision-making support is an exemplar of the complicated intersection of laws and disparate sources of information that special education leaders must navigate “to protect both the spirit and intent of IDEA” (Sloand, 2014, p. 97). Nevertheless, with the spirit and intent of the IDEA as a guide, it is necessary to offer parent specific support and resources that will provide them with a better understanding of the process and implications of guardianship and alternative pathways for adult decision-making support.

Raley et al. (2020) make a compelling call for an amendment to the age of majority mandates in the IDEA to include a LEA responsibility for providing families explicit information on alternatives to guardianship. In the amendment they outline in kind, they propose a need for LEAs to provide information on power of attorney, educational representative (as outlined at current by the IDEA), representative payee (as outlined by the Social Security Administration), and Supported Decision-Making. While such an amendment to the IDEA might help clarify some of the issues at hand that may be contributing to undue and overbroad guardianship, it is also imperative that SEAs and

LEAs consider similar changes to their own policy without waiting on an amendment or reauthorization of the IDEA to legitimize these issues. One of the missing pieces highlighted herein is the ability of states and locales to understand the current state of guardianship. In tandem with progressive approaches to these issues in SEA and LEA policy, future research must account for the fact that real time information about the rate of guardianship in states and locales is out of reach for many (National Council on Disability, 2018; Raley et al., 2020). Moreover, clear means for objectively evaluating student outcomes as they relate mechanisms of adult decision-making support should be provided to LEAs.

As evidenced by the findings of the present study and previous research, there is a clear need to equip special education teachers with the knowledge and resources necessary to effectively lead discussions regarding guardianship and adult decision-making support options. Without access to professional development on this topic, teachers cannot be expected to successfully fulfill this role. School staff can be viewed as trustworthy and knowledgeable authority figures by families who therefore may rely solely on their recommendations. If the teachers that fulfill this role are ill equipped, families will make decisions based on limited or inaccurate information, and the consequences can be damaging to the quality of life of the student. Thus, educational leaders must provide school staff with frequent, current, and thorough professional development opportunities on the topic of guardianship and decision-making support options. In addition, given parents' misunderstandings of guardianship, reliance on special education teacher expertise, and lack of training currently accessible to teachers, it is evident that families are also in need of education and training opportunities.

Families may have varying levels of support needs on these topics, and it is the responsibility of the school to ensure families receive the level of support they need to make the most informed decision regarding transfer of rights. Further research on in-service and pre-service training efforts focusing on these issues is paramount. Simply disseminating resources on the topic and understanding the law is likely insufficient. Thus, professionals need to understand prevailing philosophies as well as processes to work parallel with transition planning and service delivery to ensure the process is well understood by students and well thought out by the transition planning team. Therefore, all relevant stakeholders need to have clearly defined roles that include multiple opportunities to discuss adult decision-making support and the implications of age of majority for individual students. The nature of these roles, from the roles of students and parents to the roles of the professionals supporting them, should be an on-going drive of research on this topic.

While a number of scholars have attempted to provide frameworks for special education practice in this domain (e.g., Millar 2014a and Shogren & Wehmeyer, 2015), there is a critical need for future research that goes even further. Special education leaders have not been given nearly enough support to effectively address policy and practice related to adult decision-making support at the local level. While research such as the current study may be helpful in highlighting some of the nuances of a complicated issue, special education leaders must be provided the tools they need to evaluate and comprehensively address this issue as it relates to the creation of effective local policy, family and student involvement, teacher training, and student development.

Table 2.1 Interview participant and school district demographics

Pseudonym	Years in SPED	Years as Special Education Director	Number of High Schools in District	Students with IEPs in District
Arriana	16-20	11-15	1	251-500
Dolly	21-25	6-10	2-3	Less than 250
Latoya	21-25	11-15	2-3	1,001 or more
Grace	11-15	2-5	2-3	501-750
Shanelle	21-25	6-10	4-5	1,0001 or more
Maria	16-20	16-20	1	251-500
Imogen	21-25	11-15	1	Less than 250
Tabitha	21-25	2-5	10+	1,0001 or more

CHAPTER THREE

AN EXPLORATORY STUDY OF SPECIAL EDUCATION TEACHER PERCEPTIONS ON AGE OF MAJORITY, GUARDIANSHIP, AND ALTERNATIVE OPTIONS FOR ADULT DECISION-MAKING SUPPORT²

There is a growing body of research that indicates special education professionals have a role in the pursuit of undue and overbroad guardianship for young adults with disabilities. This role may involve explicit recommendations or utilizing school district resources to support parental petitions for guardianship. Far more often, their role may simply be complying with federal, state, and local policy that does not provide clear guidance on mechanisms or processes for purposefully and constructively addressing supports students may need as they approach legal adulthood. In this article, the authors detail a multistate, survey-based study that explored primary and secondary special education teacher perceptions of issues related to age of majority, guardianship, and less restrictive alternatives for adult decision-making support for students with Individualized Education Programs (IEPs). A significant finding of the study indicates a gap between

² This study was originally authored by Charles Walters, Dr. Anthony Plotner, and Dr. Kathleen Oertle. It was published by the National Rehabilitation Association in the *Journal of Rehabilitation* in 2023 (Volume 88, Issue 3). It appears here with the permission of the editor, reformatted to fit the dissertation requirements of the University of South Carolina Graduate School.

what special education teachers think *should* happen in this domain of practice and that which *actually* happens in reality. Findings of the study are provided and discussed alongside limitations and implications for future research.

Introduction

In 2001, the Council for Exceptional Children's (CEC) Division on Mental Retardation and Developmental Disabilities (currently known as the Division on Autism and Developmental Disabilities) detailed the group's stance on age of majority and the transfer of educational rights for students with individualized education programs (IEPs). In short, their position paper outlined an ethical and practical warning to the field on new legislative language in the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA). This language on age of majority provides guidance for local and state education agencies to ensure that educational decision-making transfers to the student with an IEP when they reach the legal age of adulthood unless certain extenuating circumstances apply (see IDEA 34 C.F.R. Section 300.520). The authors of this paper cautioned that merely complying with these mandates may cause parents to petition for legal guardianship to maintain their educational decision-making authority (Lindsey et al., 2001).

In the decades that have followed that position paper, federal special education legislation has retained the same language that provides a process for the transition of educational decision-making authority. As such, special education professionals continue to operate without legislated guidelines for handling concerns or providing supports related to student ability for taking on that responsibility (IDEA, 2004; Raley et al.,

2020). Within this reality, educators may be a primary referral source for guardianship (Jameson et al., 2015) and even leverage school district resources to support parental petitions for guardianship (Walters et al., 2022b). Further, special education professionals may lack training on less restrictive mechanisms for supporting the decision-making of adults with disabilities (MacLeod, 2017; Millar & Renzaglia, 2002; Millar, 2003; Millar, 2007; Millar, 2008; Plotner & Walters, 2022; Walters et al., 2023).

These issues hold no shortage of consequences for young adults with disabilities and their families. The purpose of this study is to document and explore the perceptions of special education teachers on supporting students with disabilities and their families as they navigate the legal rights and responsibilities that come with adulthood. While previous research in this domain has focused on middle or high school settings, the research team decided to also include special education teachers of young children to avoid assumptions about when issues related to age of majority are navigated at the district, school, or family levels. According to Millar (2014), discussing issues related to age of majority should occur during transition planning, however, there is a modest literature base that suggests that activities related to self-determination and family involvement should occur far earlier (Papay et al., 2015). This study is driven by the following research questions:

- (1) What are the perceptions of special education professionals on issues related to guardianship, and adult decision-making support options, and in what ways do perceptions differ from the ways in which they perceive current practice in the same areas?

- (2) To what extent are there differences in perceived level of special education practice across primary and secondary settings?

The positionality of the authors of this work involves an express concern with supporting special education policy and practice that serves to negate the use of undue and overbroad guardianship (Martinis, 2014; Shogren et al., 2018). This position is framed by (a) the nature and scope of guardianship and the existing evidence for a systemic overreliance on it and (b) the critical importance of self-determination and the right of people with disabilities to act independently and autonomously in their lives. Guardianship, otherwise known in some states as conservatorship, is a court-directed mechanism in which adults, as a result of disability, advanced age, or substance abuse, are deemed lacking in their capacity to make or communicate responsible decisions. As a result, they are appointed a surrogate with the court-granted authority to act on their behalf (National Council on Disability, 2018; Salzman, 2010). Basic rights that many adults may take for granted like consenting or denying consent to medical treatment and deciding where and with whom to live may fall within the scope of authority appointed to one's guardian. Guardianship, or the formal process by which someone is adjudicated to be incompetent or incapacitated, is referred to by some scholars as a sort of civil death (Perlin, 2012; Salzman, 2010). As a result, many prominent researchers and disability organizations have decried the threat of undue and overbroad guardianship, including the disability advocacy organization TASH which asserts guardianship "to be incompatible with real self-determination and full citizenship" (2003).

The nature of guardianship should be of fundamental importance to special education professionals for many reasons, and the importance of self-determination for

students with disabilities is perhaps foremost among them. Self-determination can be understood as both the right and the ability to act with autonomy (Wehmeyer, 1996), as a predictor of post-school success (Mazzotti et al., 2016; Test et al., 2009), and as a correlate of quality of life for young adults with disabilities (Lachapelle et al., 2005). An inherent element of the guardianship relationship is surrogate decision-making, the charge of the guardian to make decisions in the best interest of the “ward.” Regardless of one’s objective ability or potential ability to act autonomously in a given area of their lives with support, their right to do so may be taken from them. Some special education leaders have indicated that decisions related to adult decision-making support for students with disabilities are be seen by the field as private, family matters (Plotner & Walters, 2022). However, IDEA mandates related to age of majority along with the ethical and practical importance of affirming student self-determination the IEP process places professional perspectives and practice front and center in these issues.

Method

Participants and Procedures

A total of 272 teachers from two states participated in the study. The two states were chosen based on convenience but are also two of the 39 states that have yet to pass state legislation to recognize the alternative to guardianship known as Supported Decision-Making (Martinis et al., 2021). Recruitment for survey respondents was based on a snowball sampling strategy (Biernacki & Waldorf, 1981) wherein special education directors at the district level were emailed directly and asked to disseminate the survey to special education teachers as they saw fit. Special education teacher participants were

asked a series of demographic items as well as items to contextualize the locus of their practice. These findings are provided as Table 3.1, separated by teachers in primary and secondary settings.

In both phases of the study, there were roughly twice as many respondents from South Carolina as there were from Utah. The vast majority had a master's degree or higher, and the settings in which they taught were highly diverse. Participants were asked to indicate the amount of training they have had in the last year related to key dimensions of guardianship and less restrictive alternatives for decision-making support: the "adult guardianship process," "IDEA regulations related to transfer of rights at age of majority," "Supported Decision-Making," "self-determination for youth with disabilities," and "assessments relevant to adult decision-making."

The majority of respondents indicated they had received "no training" on the adult guardianship process (68.1%), Supported Decision-Making (52%), and assessments related to adult decision-making (63.8%). No more than 5-14% of respondents indicated that had received four or more hours of training on any of the listed topics.

Instrumentation

The survey was developed for the purpose of this study. Items derived from both the literature base and a previous qualitative study focusing on guardianship alternatives and special education service delivery (Plotner & Walters, 2022). Teachers that volunteered to participate followed a Survey Monkey link to a 13-item survey. Two levels of survey refinement were conducted by asking 5 full-time graduate students who have served as special educators to complete a survey feedback form. The feedback

received included changes to make the instrument more understandable. The final instrument included questions to solicit responses from special education teachers regarding their perceptions related to age of majority, alternatives to guardianship, and adult decision-making support in three, main parts. Part I (items 1-7) involved the collection of personal and school-specific demographic items. Part II (item 8) was a series of statements regarding district-level, school-level, and family-level values on topics related to adult decision- making support. Respondents were provided a Likert-like scale (“Strongly Disagree,” “Disagree,” “Agree,” and “Strongly Agree”) and asked to rate their agreement with each statement. Part III (item 9) was a series of statements parallel to the statements in item 8, altered slightly so that they were phrased to reflect current practice at the district-level, school-level, and family-level for each of the respondents. Respondents were once again provided the same Likert-like scale and asked to rate their agreement with each statement.

Data Analysis

In order to answer the research questions, all data was transported to IBM SPSS Statistics. Descriptive statistics (i.e., mean and standard deviation) were computed for all responses to answer RQ1. To determine if there was a significant difference between the participants beliefs between what should be and what is currently occurring, a paired sample t-test was used which compared the mean of each pair of items (i.e., should be and current reality). Further, to answer research question 2, an Independent Sample t-test was conducted to explore if there were differences between two groups of participants (i.e., those who serve primary students vs. those who serve secondary students). Hedges’

g was used to determine the effect size as there was variability in the samples across the primary and secondary groups.

Results

Research Question 1: What are the perceptions of special education professionals on issues related to guardianship, and adult decision-making support options, and in what ways do perceptions differ from the ways in which they perceive current practice in the same areas?

The means reported for the survey items ranged between 2.25 and 3.60. The highest ranked items were, “*Special education teachers should receive the training they need to contribute meaningfully to IEP team discussions related to the transfer or rights for students approaching adulthood*” (\bar{x} = 3.60) and “*Special education teachers should understand guardianship and alternatives for adult decision-making support*” (\bar{x} = 3.49). Conversely, the lowest ranked items were, “*As a special education teacher, I understand guardianship and alternatives for adult decision-making support*” (\bar{x} = 2.43), “*Family members do not pursue guardianship without fully understanding the implications*” (\bar{x} = 2.45) and “*Family members do not pursue guardianship without considering other options for supporting their loved ones*” (\bar{x} = 2.49). See table 2 for means.

The paired sample t-test determined that there was a statistical difference between all ten pairs of items (should do vs. current reality) at the <.00 level. Interestingly, the eight items where participants rated what they believe should be occurring were the highest ranked items ranging from 2.68 to 3.60. The only item that ranked the “should be” item over the “current situations” item was, “*Special education teachers should take*

the lead on family questions about the transfer of rights for students approaching adulthood with a mean of 2.68, compared to a mean of 2.75 when asked, “As a special education teacher, I take the lead on family questions about the transfer of rights for students approaching adulthood.”

Research Question 2: To what extent are there differences in perceived level of special education practice across primary and secondary settings?

The findings show that there are some differences in how those primary and those secondary professions rate the items. In fact, the means of the primary group ranged from 2.13 to 3.66. In contrast, the secondary group had mean ranges from 2.32 to 3.56. [Table 3.2] shows the means for each group across the items. The independent sample t-test showed a significant difference of means on 8 of the 18 paired items. [Table 3.2] shows means and results of the t-test for the items and two groups of professionals.

Discussion

This study offers an exploration of special education teacher perceptions of their values and current practice related to age of majority and adult decision-making for students with disabilities. In short, the findings presented herein detail a gap between that which teachers believe *should* happen to navigate age of majority issues at the district, school, and family levels and that which *actually* happens. The nature of such a disconnect yields potentially valuable insights for developing interventions in policy and practice in this domain.

Moreover, such a gap indicates that a systemic or individual, professional orientation towards undue or overbroad guardianship may be out of step with special education teacher values on the whole. Educators are charged with assuming competence before guardianship decisions have been made (Millar & Renzaglia, 2002; Rood et al., 2014). Nevertheless, the combination of compliance-driven policy and practice and outright recommendations for guardianship in systems of special education have formed what the National Council on Disability has coined the *school to guardianship pipeline* (2018). It is a phenomenon foreshadowed by Lindsey and colleagues more than twenty years ago (2001).

As Lindsey and colleagues argued, IDEA mandates regarding secondary transition planning and services provide a context through a transfer of the rights and responsibilities of adulthood can and should be purposefully addressed by IEP teams (Lindsey et al., 2001; Millar, 2003; Millar, 2014; Plotner & Walters, 2022; Rood et al., 2014). As such, concerns related to adult decision-making capacity may be discussed with the support of the IEP team, connections to adult service agencies can be made to assist in navigating adult decision-making supports, and planning for skill building in areas critical to adult decision-making can take place. To this end, Raley and colleagues detailed an amendment to the IDEA that would build in purposeful discussions of less restrictive alternatives to guardianship to age of majority-related processes (2020). In such an amendment, the authors argue, teachers should be explicitly trained on, at minimum, the function and use of Power of Attorney for granting decision-making authority, Representative Payee for navigating Social Security benefits, Supported Decision-Making for outlining supportive arrangements, and Educational Representative

for delegating authority in the IEP process. Such policy shifts at the federal level may indeed contribute to fuller IEP team discussions and planning on age of majority.

Of the adult decision support options that Raley and colleagues argue teachers should be knowledgeable about, one of particular note referenced in the current study is Supported Decision-Making. According to many special education teachers that participated in this study, it is a practice that few are receiving training on. Just as Wehmeyer defined self-determination as a human right *and* a set of behaviors (1996), proponents of Supported Decision-Making (SDM) often speak of it as the practice *and* of the right of adults with disabilities to make decisions with support and self-direct their lives (Glen, 2014; Jameson et al., 2015; Martinis, 2014; Martinis, 2015; Martinis et al., 2021; McLeod, 2017; Rood et al., 2014; Shogren et al., 2018). SDM is no more complicated than the name indicates. It is a formal or informal arrangement whereby a person receives support from trusted friends, family members, or professionals to navigate one more or more domain of adult decision-making. Rather than a surrogate decision maker acting on one's behalf, people with disabilities using SDM benefit from the support of others to act autonomously and build skills as they do so (Martinis, 2014).

In the 12 states where SDM has been formally recognized in legislation, a more formal process may be outlined that details the exact parameters of an SDM arrangement for supporters and the person supported (Center for Public Representation, 2021; Martinis et al., 2021). As an international movement, SDM proponents simply seek to normalize the fact that adults with and without disabilities may benefit from the support of the people they trust to navigate the responsibilities of adulthood (Martinis, 2014; Martinis et al., 2021). As the world learns more about what SDM is and how it can be used to

support adults with disabilities, due caution should be given to avoiding the message that SDM is a sort of silver bullet for all people at all times. To the question of how special education professionals can help thwart undue and overbroad guardianship, the answer is likely dependent on the context of their practice.

Addressing the complicated reality of special education professionals' efforts towards avoiding undue and overbroad guardianship is an important facet of the work Millar's (2014) proposed *Guardianship Alternative Model (GAM)*. The model, based largely on early work by Test and colleagues on evidenced-based predictors of postschool success (2009), is designed to increase "exploration and use of least restrictive options to guardianship appointments; use of informative and relevant assessments; and numerous planned opportunities to implement strategies and alternatives to further develop skills associated with being self-sufficient" (p. 455). In short, the GAM depicts the possible interplay between five core areas of focus for special educators to promote the quality of life and autonomy of students with disabilities: "self-determination; assessment and planning; education and instruction; coordination and collaboration; as well as policy and process evaluation" (p. 455). While well-reasoned and comprehensive, Millar notes that the GAM chiefly offers a platform for further study in this domain of special education practice. It is, however, a line of inquiry that has not yet come to fruition. As illustrated by the current study, an important aspect of that needed inquiry may lead to a better understanding of how outside agencies support special education teachers, students with disabilities, and families to navigate age of majority-related issues.

The current study offers evidence that special education teachers are lacking support from outside agencies. Some scholars point to the imperative of vocational

rehabilitation counselors to respond to the decision-making support needs of youth and young adults with disabilities (Martinis, 2015). Still others underscore that imperative by asserting that assumptions of incompetence and similar inclinations towards guardianship directly contradict the intent and scope of specific statutes such as the Rehabilitation Act as amended (Martinis, 2015; Oertle & Riesen, 2019; WIOA, 2014) and the IDEA (Rood et al., 2014). Collaborative support in age of majority issues from vocational rehabilitation (VR) counselors is aligned with their legislative mandates to provide and/or allocate for self-advocacy instruction as one of five pre-employment transition services (Rehabilitation Act as amended in WIOA, 2014).

Moreover, professionally certified rehabilitation counselors (CRCs) are responsible to support advocacy as stated in the Code of Professional Ethics (CRCC®, 2016). Furthermore, advocacy is a core principle of rehabilitation as defined by the Rehabilitation Act as amended for VR counseling as well as centers for independent living (CILs) and community rehabilitation providers (CRPs). Including VR counselors, CIL personnel, and CRPs, less restrictive alternatives to full guardianship, such as supported decision-making, can be discussed, tried, and evaluated for the inclusion of a full array of possibilities and potentials options (Oertle & Riesen, 2019). While there is a clear rationale for such systems of collaborative support, there is still work to be done to understand the nature of those systems of collaboration and the ways in which they may contribute to the effective use of less restrictive alternatives to guardianship.

A primary consideration in navigating the selection of adult decision-making supports for students with disabilities is their right to self-determination and the skills associated with self-direction. While the importance of self-determination for students

with disabilities has been evidenced for some time, the current study indicates that it is also largely aligned with special education teachers values regarding navigating age of majority issues. As MacLeod (2017) observed in their study of navigating age of majority in a secondary setting, normalizing decision-making support for all student like Supported Decision-Making demonstrates high expectations and the presumption of student capacity to make adult decisions. In this way, professionals take on the lens of asking what supports may be necessary for student to engage in self-directed actions. Two examples of self-directed and goal-oriented research-based, person-driven approaches are *TakeCharge!* and the *Self-Determined Career Development Model* (e.g., Shogren et al., 2017a; Wehmeyer et al., 2003). The use and impact of self-determination-related interventions to more purposefully avoid the use of undue and overbroad guardianship is an important area of future inquiry.

Perhaps one of the most important aspects of such work involves better understanding the support of students in early childhood and primary school settings towards increases in self-determination across the lifespan. While the notion of supporting self-determination across the lifespan is not a novel idea in and of itself (Papay et al., 2015), metrics related to guardianship may not be widely understood as a means to objectively assess that support over time like objective measures of quality of life or self-determination. As the first express purpose of the IDEA is “to prepare students for further education, employment, and independent living” [IDEA, 2004, 34 CFR § 300.1(a)], special education professional may do well to act in concert across the lifespan of students with disabilities to ensure the address of threats to this aim (Papay et al., 2015).

Limitations and Implications for Future Research. There are a number of limitations to this study that merit discussion. First, the sampling strategy for recruiting survey participants was based on convenience sampling methodology. While this was intended to be an exploratory study on the topic, caution should be used to avoid generalizing these results beyond the population represented by the current sample. Future replication of this study with a more rigorous sampling methodology is advisable. Second, there are several foci that related research on this topic might use to increase the specificity of inquiry. For instance, this study purposefully neglected a focus on a specific subset of students with disabilities due to a limited basis in the literature for asserting that issues related to undue and overbroad guardianship are limited to, for example, students with high intensity support needs. Nevertheless, delimiting populations of interest in such a manner in future research may help to clarify the special education professionals for whom inferences may most accurately be made. Next, by nature of their timing, age of majority-related issues in the IEP process are likely most relevant for professionals working with transition-age youth and young adults with disabilities. Educators in secondary *and* primary settings were recruited to participate in the same survey, however, to ensure that this assumption was not unnecessarily delimiting research on the topic. While the research team has disaggregated data to illustrate the similarities and differences in responses between these two groups, it is possible that differing contexts for those responses affect data integrity to an unknown extent. Similar work conducted in the future may do well to delimit data to specific professional settings. It is critically important that we continue to cultivate a better understanding the role of special education professionals in limiting the use of undue and overbroad guardianship. To this

end, future research on the topic should explore specific policy and practice in this domain *and* the impact such interventions have on adult supports utilized by students and their families.

Table 3.1 Comparison of sample based on role

Demographic Information	Primary % (n)	Secondary % (n)
State		
Utah	38.6% (39)	32.7% (56)
South Carolina	61.4% (62)	67.3% (115)
Highest Degree		
Bachelor's degree	45.5% (46)	26.6% (45)
Master's degree	52.5% (53)	71.6% (121)
Doctoral degree	2% (2)	1.8% (3)
Setting		
Self-contained classroom	37.6% (38)	35.7% (61)
Resource classroom and/or co-teaching and inclusion	59.4% (60)	51.5% (88)
Other	3% (3)	12.8% (22)
Percentage of Students with Free/Reduced Lunch		
Less than 20%	14.9% (15)	14.6% (25)
21% - 40%	12.9% (13)	22.2% (38)
41% - 60%	17.8% (18)	22.2% (38)
61% - 80%	16.8% (17)	12.3% (21)
More than 80%	37.6% (38)	28.7% (49)
<i>Note. n=272 for State, Setting, and Percentage of Students with Free/Reduced Lunch, n=270 for Highest Degree</i>		

Table 3.2 Means, standard deviations, and t-tests by item-level indicator for setting/population served

Item-Level Indicator	Setting/Population Served				Independent sample t-test		
	Primary		Secondary		F	p	Hedges' G
	n	\bar{x} (SD)	n	\bar{x} (SD)			
School districts should have clear policies and procedures in place for how age of majority conversations takes place in IEP meetings and on the way in which decision-making support options are discussed. (\bar{x} =3.42)	109	3.45 (.53)	163	3.40 (.66)	-	-	-
My school district has clear policies and procedures in place for how age of majority conversations take place in IEP meetings and the way in which decision-making support options are discussed. (\bar{x} =2.66)	105	2.79 (.70)	163	2.58 (.85)	13 2	.00* *	.70
Special education teachers should understand guardianship and alternatives for adult decision-making support. (\bar{x} =3.49)	108	3.52 (.63)	161	3.48 (.66)	-	-	-
As a special education teacher, I understand guardianship and alternatives for adult decision-making support. (\bar{x} =2.43)	109	2.28 (.78)	163	2.53 (.83)	-	-	-
Special education teachers should take the lead on family questions about the transfer of rights for students approaching adulthood. (\bar{x} =2.68)	108	2.76 (.73)	160	2.62 (.84)	6. 20	.01*	.73
As a special education teacher, I take the lead on family questions about the transfer of rights for students approaching adulthood. (\bar{x} =2.75)	107	2.15 (.77)	161	2.40 (.86)	-	-	-
Special education teachers should provide transition assessments to students that yield data related to adult decision-making. (\bar{x} =3.26)	108	3.28 (.58)	162	3.23 (.71)	-	-	-
As a special education teacher, I provide assessments to students that yield data related to decision-making skills. (\bar{x} =2.75)	108	2.58 (.91)	161	2.86 (.83)	5. 37	.02*	.91
Special education teachers should help students and families to select the least restrictive means possible for	109	3.48 (.60)	161	3.26 (.79)	4. 08	.04*	.60

Item-Level Indicator	Setting/Population Served				Independent sample t-test		
	Primary		Secondary		F	p	Hedges' G
	n	\bar{x} (SD)	n	\bar{x} (SD)			
supporting adult decision-making. (\bar{x} =3.35)							
As a special education teacher, I help students and families to select the least restrictive means possible for supporting adult decision-making (\bar{x} =2.60)	106	2.51 (.65)	161	2.65 (.77)	-	-	-
Special education teachers should receive the training that they need to contribute meaningfully to IEP team discussions related to the transfer of rights for students approaching adulthood. (\bar{x} =3.60)	109	3.66 (.49)	163	3.56 (.63)	6.23	.01*	.49
As a special education teacher, I receive the training that I need to contribute meaningfully to IEP team discussions related to the transfer of rights for students approaching adulthood. (\bar{x} =2.25)	108	2.13 (.85)	162	2.32 (.85)	-	-	-
Family members should not pursue guardianship without fully understanding the implications. (\bar{x} =3.30)	109	3.21 (.65)	162	3.36 (.72)	5.25	.02*	.65
Family members do not pursue guardianship without fully understanding the implications. (\bar{x} =2.45)	102	2.44 (.76)	158	2.45 (.79)	-	-	-
Family members should not pursue guardianship without considering other options for supporting their loved ones. (\bar{x} =3.25)	108	3.13 (.63)	161	3.33 (.67)	6.07	.01*	.63
Family members do not pursue guardianship without considering other options for supporting their loved ones. (\bar{x} =2.49)	103	2.50 (.71)	158	2.49 (.76)	-	-	-
Family members should balance the importance of self-determined behavior with a desire for individual safety. (\bar{x} =3.38)	104	2.99 (.69)	161	3.15 (.68)	5.69	.02*	.52
Family members balance the importance of self-determined behavior with a desire for individual safety. (\bar{x} =3.09)	108	3.30 (.52)	161	3.43 (.61)	-	-	-

Note. * represents $p < .05$, ** represents $p < .01$, and possible values range from 1 for “Strongly Disagree” to 4 for “Strongly Agree”

CHAPTER FOUR

A DELPHI STUDY TO GENERATE, CLARIFY, AND PRIORITIZE PROFESSIONAL RECOMMENDATIONS ON AGE OF MAJORITY- RELATED PRACTICE IN SPECIAL EDUCATION

Imagine, for a moment, that all the decisions you have made as an adult are spread out in front of you like books on a shelf. As you examine this collection of decisions, what do you see? Perhaps there are some life changing decisions mingled amongst those that appear to have been of less consequence. Maybe you can pick out decisions you made to your own benefit sitting alongside decisions that may have caused harm to yourself. Regardless of the nature of these individual decisions, the freedom and autonomy to make them based on your own values, preferences, and interests has likely been a defining characteristic of your adult life.

For better or worse, most people move through adulthood without anyone questioning their need, ability, or right to direct their own lives. For young adults with disabilities approaching the age of legal adulthood, however, the promise of the right to a life as an autonomous adult is not a foregone conclusion. The complex constellation of social and legal factors that shape this reality necessitates scrutiny. One aspect of these factors in particular, special education policy and practice related to the *age of majority* for young adults with disabilities, sets the stage for the current study.

Special Education and Age of Majority

Since the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA), US special education professionals at the state and local level have had to comply with requirements related to age of majority (Lindsey et al., 2001). Age of majority, also known as the age of legal majority, refers to the threshold of legal adulthood. In all but three states where the age of majority is age 19 (Alabama and Nebraska) or 21 (Mississippi), this age of legal adulthood is broadly recognized as age 18 (Legal Information Institute, 2021; World Population Review, 2022). In large part, the age of majority requirements put forward by the IDEA since 1997 are simply a collection of mandates to ensure that special education-related processes account for the shift from students with disabilities being served as minors to being served as adults. For most students, the educational decision-making authority of their parents or legal guardians shift to them when they are legally recognized as an adult. The way in which this transfer of rights is described by the IDEA is of particular importance.

First, if students have not been declared *incompetent*, the law compels state and local education agencies (SEA; LEA) to (a) provide notice to families of this transfer of rights and (b) transfer all rights of the parents under Part B of the IDEA to adult students when they reach the age of majority, even if they are incarcerated in adult or juvenile correctional facilities [34 § 300.520(a)(1)(i-ii)]. Next, once this transfer of rights takes place, both parents and students must be notified [34 § 300.520(a)(3)]. Finally, the IDEA offers a special rule on the matter. SEAs are required to adopt formal procedures that provide a means for the appointment of an educational representative for a student that has not been declared incompetent but is also deemed unable to provide informed consent

regarding their education [34 § 300.520(b)]. Shortly after the IDEA began requiring state and local compliance with these age of majority-related regulations, the Council for Exceptional Children issued a position paper detailing the gravity of these changes to the law for students with disabilities and their families (Lindsey et al., 2001).

Lindsey and colleagues (2001) argued that while SEA and LEA compliance with these, at the time, new IDEA mandates is necessary, compliance should be contextualized by the importance of robust transition planning that centers the individual student in decisions that affect their lives. Further, they expressed their concern that a myopic approach to compliance with the law alone “will lead to a circumstance where parents and family members will feel compelled to obtain guardianship or other legal decision-making status over their son or daughter when they might not otherwise” (p. 13). To understand the implications of compliance-focused processes that prompt parents to obtain guardianship, an understanding of guardianship for young adults with disabilities is essential.

Guardianship for Young Adults with Disabilities and the School to Guardianship Pipeline

Guardianship is the court mediated process of determining whether one is *competent* and has the *capacity* to make and communicate responsible adult decisions. Should a guardianship proceeding demonstrate the *incompetence* or *incapacity* of a person with a disability, a judge may appoint a surrogate to act on that person’s behalf known as a guardian (Kohn et al., 2012). In addition to the problematic nature of guardianship laws that hinge on reductive binaries of competence vs. incompetence and

capacity vs. incapacity, the formal declaration of incompetence or incapacity associated with guardianship typically lasts a lifetime (Salzman, 2010).

The extent of one's authority as a guardian depends upon the courts' discretion. Guardianship orders may be partial, covering specified areas (e.g., healthcare), or they may be full, also known as plenary. As the descriptor suggests, full guardianship typically encompasses the entirety of one's affairs (National Council on Disability, 2018; Salzman, 2010). The preference of courts across the US has historically tended towards awarding full guardianship rather than specifying the limited authority of a guardian through partial guardianship (Crane, 2015).

Many assertions have been made about the problems with guardianship that rightfully focus on the impact it has on the person declared to be incapacitated. Such impacts include the denial of one's right to direct their own life and their ability to understand the intimate details of their own affairs (Blanck & Martinis, 2015), the burden associated with terminating or modifying guardianship orders (Salzman, 2010), the ways in which guardianship amounts to one's "civil death" (Perlin, 2012), the incompatibility of US guardianship laws with the international policy landscape (Dinerstein, 2012), and the potentially unchecked capacity for abuse from one's guardian (National Council on Disability, 2018). Other arguments for critically examining the institution of guardianship in the US speak to the use of *undue and overbroad guardianship*, a phrase alluding to the frequency of its use and the excessive breadth of guardianship orders (Hatch et al., 2015). As Turnbull argues, guardianship proceedings are too often "a ritual in which alternatives to guardianship are not considered or, if considered, not seriously taken into account (Shogren et al., 2018, p. xxiii).

While limited court oversight and the limited availability of public data on guardianship from state to state make it difficult to quantify the full scope of undue and overbroad guardianship (National Council on Disability, 2018), the data that are available are cause for alarm. For adults with intellectual and developmental disability, the rate of guardianship in some US states is as high as 89% (Bradley et al., 2019). Further, there is evidence that, across disability categories, the rate of guardianship has more than tripled in the US since 1995 (Uekert & Van Duizend, 2011). With evidence for guardianship being used more and more to protect adults with disabilities, an increasing amount of attention is being paid to the ways in which publicly funded systems may function to perpetuate the use of undue and overbroad guardianship.

In 2018, the National Council on Disability decried the existence of a *school-to-guardianship pipeline* as a major contributing factor to the use of undue and overbroad guardianship for adults with disabilities. The existence of such a pipeline, they suggest, is supported by “a great deal of evidence that special education teachers regularly encourage or even pressure parents into seeking guardianship of their transition-age children with disabilities” (p. 93). As the studies cited in National Council on Disability’s report suggest, there is indeed evidence to indicate that education professionals may be a primary referral source for guardianship (Jameson et al., 2015). More than explicit overtures in support of guardianship, however, there is far more evidence to indicate a failure of special education professionals and systems to provide individualized supports and planning in the domain of adult decision-making.

Within a few years of the 1997 reauthorization of the IDEA, Millar and Renzaglia (2002) found that 90% of young adults with intellectual and developmental disability

under guardianship in the state of Michigan had petitions for guardianship filed while they were still in school. What's more, 80% of those guardianship petitions used documents produced from special education processes (e.g., psychoeducational evaluations) to demonstrate the need for guardianship (Millar, 2003). In these reviewed cases, orders were given for full guardianship in most cases, and the arrangements prescribed in partial guardianship orders closely resembled those of full guardianship orders (Millar & Renzaglia, 2002).

In truth, evidence of widespread, systematic efforts of special education professionals to ensure young adults with disabilities are placed under guardianship is lacking. Rather, it would appear that if a school to guardianship pipeline does exist, it is facilitated less by professionals acting in bad faith and more by a confluence of slightly less dramatic, yet still important, factors. Research on the topic indicates that such factors may include professional tendencies to assume incompetence of students with disabilities (Kanter, 2015; Millar, 2007; Rood et al., 2014); a lack of understanding, difficulty with the perceived complexity, and a lack of external support related to adult decision-making support (Walters et al., 2022b); and an absence of professional training opportunities (Plotner & Walters, 2022; Walters et al., 2023). It is possible that special education professionals simply pass over age of majority in the IEP process with a minimum of concern (MacLeod, 2015), treating issues related to age of majority in a compliance-focused manner that fails to meaningfully support students and their families in the use of less restrictive alternatives to guardianship. At this juncture, the potential of a broadly adopted, alternative paradigm of adult decision-making support is a particularly worthwhile topic for discussion.

What is Supported Decision-Making?

Understanding what supported decision-making (SDM) *is not* is an important starting place to better understand SDM. SDM does not refer to a prescriptive mechanism for supporting the decisions of adults with disabilities. As such, SDM should not be reduced to an understanding that sets it up as an opposing pole to guardianship. In its most broad application, SDM is both a practice and a paradigm built on an understanding that self-determination is a fundamental human right. In this broad sense, SDM refers to the formal and informal means by which people with disabilities seek and use support to exercise that right without undue influence or limitation (Kohn, 2021). In a more specific sense, SDM often refers to a structured yet non-prescriptive means for support. In this sense, SDM is a flexible process whereby people with disabilities “seek advice, input, and information from knowledgeable friends, family, and professionals so they may make their own informed choices” (Blanck & Martinis, 2015, p. 26).

SDM as a practice is affirmed by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (Dinerstein, 2012), which “presumes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own life decisions” (Blanck & Martinis, 2015, p. 26). Moreover, SDM as a practice has been formally codified in the laws of 21% of 51 US jurisdictions (10 states and the District of Columbia). Some of these jurisdictions (e.g., Texas) require the use of a formal agreement that outlines the parameters of the support, typically referred to as a Supported Decision-Making Agreement (Martinis et al., 2021). As more and more US states and countries around the world recognize the need for adults with disabilities to be supported

with the least restrictive means possible, the time for special education professionals to act in kind is clearly at hand.

Purpose of the Current Study

There is a wealth of research that indicates the action, or more commonly, the inaction, of special education professionals that may contribute to young adults with disabilities being placed under undue and overbroad adult guardianship orders. Nevertheless, little has been done to empirically explore professional recommendations on the topic. Such recommendations have included better assessing the decision-making support needs of young adults with disabilities approaching the age of majority (Millar, 2014; Shogren et al., 2017b); improving the flow of information to students and their families on alternatives to guardianship (McLeod, 2017; Millar, 2009; Millar, 2014); amending the IDEA to include a more robust, balanced approach to age of majority (Raley et al., 2020); adopting a framework that supports special education professionals in attending to issues of adult decision-making support in multiple domains (Millar, 2014); and transition planning processes that better attend to adult decision-making support needs (Millar, 2014; Plotner & Walters, 2022). While potentially promising directions for practice negating the use of undue and overbroad guardianship, to-date, such recommendations offer disparate solutions without a clear consensus from those with subject matter expertise.

Therefore, the purpose of the current study was to work with established professionals promoting alternatives to guardianship to formally generate and establish consensus on recommendations for special education professionals to maximize student

decision-making autonomy, independence, and dignity into adulthood. Such recommendations might be used to influence needed shifts in special education policy and practice related to navigating age of majority at the national, state, and local levels. Driven by this purpose and potential benefit, this study explored one primary research question: What are the foremost recommendations of established professionals in the use of alternatives to guardianship within special education practice in the areas of self-determination, assessment and planning, education and instruction, coordination and collaboration, policy and process evaluation, and research?

Method

To explore this study's research question, an online survey-based Delphi study was conducted. The Delphi technique was developed by the Rand Corporation in the 1950s to address the effect and subsequent bias of interpersonal interactions in group decision-making processes (Goodman, 1987). At its simplest, it is a tool for facilitating the structured communication of a group of knowledgeable parties on a complex issue. Its core elements include (a) gathering information and knowledge from the group, (b) assessment of this collected information and knowledge, (c) the opportunity for the individual revision of views, and (d) anonymity of individuals throughout the process (Linstone & Turoff, 1975). To these ends, a chief strength of the Delphi approach is typically understood as its practicality for addressing real world problems (Ling & Bruckmayer, 2021).

Like many studies using the Delphi technique, the current study used three rounds of questionnaires that were distributed to established professionals (Hasson & Keeney,

2011; Powell, 2003) on age of majority issues and adult decision-making support within the context of special education practice. Each round of questionnaires was primarily intended to, in turn, *solicit* open professional feedback; *rate* that feedback; and *establish* group consensus on domain-specific, professional recommendations for age of majority and adult decision-making support-related practice in special education. Each round is described below as it relates to the instrumentation of the study followed by a description of participant selection and recruitment.

Instrumentation and Analysis

While few models exist to illustrate the address of special education practice in the support of young adults with disabilities approaching adulthood, Millar's Guardianship Alternative Model (GAM) provided a clear, theoretically sound means for doing so. As such, a foundational element of each round of this study was the five domains provided in GAM (self-determination, assessment and planning, education and instruction, coordination and collaboration, and policy and process evaluation; 2014) with the addition of a sixth domain to organize research-related recommendations. Through online surveys created in Survey Monkey, these six domains provided the structure for how recommendations were solicited from and scored by participants and, ultimately, organized as a final product of group consensus on recommendations. Instruments from each round were reviewed for clarity, utility, and feasibility by an expert in educational research with content expertise in issues related to adult decision-making support in special education contexts. Each round required participants to spend roughly 10-25 minutes to complete it, and there were approximately two weeks dedicated to data

collection for each round between November and December of 2022. From recruitment of participants to ongoing communication with active participants between rounds, detailed information was provided to ensure that everyone was adequately prepared to understand the nature of participation in the study and the intended use of their contribution (Hasson et al., 2000).

Round One: Soliciting Expert Recommendations. For the first round of this study, a 41-item online instrument was created and distributed by email. Items were organized into two sections. The first section included 13 open-ended and closed-ended response items designed to collect (a) participant demographic information (12 items) and (b) the preferred email address for use as a participant identifier to track individual and overall participation in subsequent surveys and for communication throughout the study (one item).

The second section was designed to solicit recommendations for age of majority and adult decision-making-related practice in special education contexts through seven sections of open-ended prompts. Five of these seven subsections correspond to the five domains of the GAM: self-determination, assessment and planning, education and instruction, coordination and collaboration, and policy and process evaluation. Two additional subsections, research and miscellaneous, were added to solicit recommendations that did not fall within the areas of special education practice covered by the GAM. To promote clarity, in each of these seven subsections, participants were provided with four separate prompts to provide recommendations at the classroom, school, district, and state levels, leading to 28 total items/recommendation prompts.

Responses to open-ended items were analyzed by the lead author using inductive qualitative content analysis (Graneheim et al., 2017; Wallace et al., 2016) to develop an initial list of recommendations for each domain. In the first phase of this process, recommendations were identified as either “actionable” or “non-actionable.” In the next phase, actionable recommendations were coded using a code list generated by the lead researcher. Recommendations were grouped according to their code, and similar recommendations were merged. In the third phase of this process, recommendations were edited to provide clear and consistent phrasing and to correct all issues with spelling, grammar, and syntax. Finally, all recommendations were recoded with the domain in which they best fit, eliminating the need for a seventh “miscellaneous” domain.

A data audit trail, a spreadsheet with tabs corresponding to each phase of analysis, was kept showing all decisions made by the lead author regarding this analytic process (Wallace et al., 2016). Although analysis was conducted with what would be best characterized as a low level of abstraction and interpretation (Graneheim et al., 2017), each phase of the data audit trail was reviewed by an expert in education research to ensure rigor and data trustworthiness (Koch, 1994). This outside expert flagged decisions across all phases in which they disagreed or were uncertain of the lead researcher’s decision making. The lead researcher then met with this reviewer to discuss and come to consensus on each flagged decision.

Round One culminated in the creation of a finalized list of recommendations, organized by domain. This list was integral to the instrument developed for Round Two. It is also important to note that the purpose of collecting email addresses, as was explained to participants up front, created a climate of quasi-anonymity. As McKenna

(1994) described it, quasi-anonymity refers to Delphi studies in which the identity of participants may be known to the researcher, but their participation is otherwise kept entirely anonymous.

Round Two: Rating Recommendations. For Round Two, a second online survey was created and emailed to all participants of Round One. After providing their email address for tracking participation, participants rated each recommendation on a Likert-like scale to measure their agreement with each as critical priorities for special education professionals. The scale was a four-point scale of agreement (1 = “Strongly Disagree,” 2 = “Disagree,” 3 = “Agree,” and 4 = “Strongly Agree”). As advised by Johnson and Morgan (2016), this scale employed (a) both numeric and verbal response labels; (b) opposite endpoints (e.g., Strongly Disagree vs. Strongly Agree); (c) response anchors provided along a clear continuum; and (d) negative to positive ordering of response anchors. Additionally, as a safeguard for data trustworthiness, participants were provided two closed-ended items that allowed them to provide feedback on how well their initial recommendations were reflected in this second survey (Hasson & Keeney, 2011).

The mean, median, and interquartile range of each recommendation rated in Round Two were calculated to inform the shape the Round Three questionnaire. First, the median and interquartile range were calculated to derive measures of central tendency and variance from group ratings of each recommendation (Heiko, 2012; Powell, 2003). Criteria for interquartile ranges and medians were used to serve as a consistent basis for isolating all recommendations with either (a) a high degree of variability in score or (b) a low overall score. Given the four-point scale used, the cutoff criterion for interquartile range indicative of agreement was set as anything above one (Heiko, 2012). The cutoff

criterion for agreement in median was set as three and above. Recommendations with a median score below three were removed from consideration in Round Three, and recommendations with an interquartile range above one were flagged as recommendations with high variability in Round Three. Group means for each recommendation were used to rank order each recommendation retained for Round Three within their respective domains.

Round Three: Revising Ratings Towards Consensus. In this final phase of data collection, participants were emailed and again asked to rate each recommendation in an online questionnaire. The purpose of this final questionnaire was to allow participants to see the central tendency and variance of scores for each recommendation and to provide an opportunity to change their scores based on this knowledge. To this end, an in-depth, plain language explanation on the purpose and meaning of these statistics was provided to participants within the introduction of the questionnaire for Round Three.

Like Round Two, participants were asked to provide their email address for tracking participation and to respond to two items to gather their input on how their responses in Round Two influenced the questionnaire provided in Round Three. Once this final survey closed, the median and interquartile range were calculated for each recommendation. Those with high variability in scores (i.e., interquartile range above 1) and those with unfavorable scores (i.e., median below 3) were eliminated. The mean for each recommendation was calculated to rank order recommendations and to isolate the top five recommendations in each domain.

Participants

A defining characteristic of the Delphi study is the expertise of the panel selected to participate (Landeta, 2006; Powell, 2003; Trevelyan & Robinson, 2015). Given the relative novelty of the focal topic of this study, defining expertise among professionals was particularly problematic and use of the term *expert* would have been potentially misleading. To address this issue, the sampling frame for this study consisted instead of *established professionals* in this domain of practice (Trevelyan & Robinson, 2015). Established professionals were defined as anyone meeting all of the following criteria: (a) working within a professional role that involves advocating or building capacity in special education contexts for least restrictive adult decision-making supports, (b) conducting this work at the state- or national-level, (c) working primarily in United States, and (d) working in this domain for at least three years. In this way, established professionals were understood as individuals that had a strong grasp on age of majority issues at both the individual and systems level, understood the US special education policy landscape, and who had remained committed to their work on these issues for a reasonable amount of time.

The ideal number of participants needed for a Delphi study is an area of debate among researchers. Some scholars argue that the chief issue at play in determining the size of the sample in a Delphi study is the degree of homogeneity in group make-up; in short, with a more homogenous group, a smaller sample (e.g., 8-15 participants) is more acceptable (Trevelyan & Robinson, 2015). Still, others argue that there is little research to support the notion that the reliability or validity of a Delphi study is contingent on the size (Murphy et al, 1998) or representativeness (Powell, 2003) of the sample. To aid in selecting the largest possible group of participants that fit these criteria set for established

professionals across professional disciplines (e.g., education, law, higher education, etc.), a nominated expert sampling strategy was employed (Trotter, 2012). Working with the lead researcher of this study to understand the criteria of established professionals, a nomination list was compiled by two people that led national multidisciplinary projects related to supported decision making. Identified as two of a very limited number of people serving in such roles, both nominating professionals had access to and regular contact with other professionals throughout the country meeting the criteria for participation in this study. These two nominators passed along the names and contact information for a total of 30 people within their professional networks that met the criteria of established professionals for this study.

All 30 nominated parties were emailed an invitation to participate in the study with a link provided to the Round One questionnaire. All Round One participants received an email invitation to participate in Round Two, and all Round Two participants received an email invitation to participate in the third and final round. Participants that completed all three rounds of questionnaires were offered two \$50 Visa gift cards to incentivize their participation. Of the 30 professionals nominated, half participated in Round One (n=15). Of these 15 participants, 12 participated in Round Two and Round Three, representing 40% of the total pool of nominees. All 15 participants were presented with an item in the Round One questionnaire prompting them to verify whether they met the criteria for established professionals, and all 15 participants verified that they did indeed meet those criteria. Table 4.1 provides a detailed overview of the demographic make-up of participants across all three rounds of the study.

Findings

Round One

Across the 15 participants in the Round One questionnaire, a total of 282 recommendations were provided across seven domains (self-determination, assessment and planning, education and instruction, coordination and collaboration, policy and process evaluation, research, and miscellaneous). To reduce the number of recommendations to more manageable numbers and to ensure recommendations contained sufficient detail, the full list of recommendations was reviewed for clarity and to determine if they were “actionable” or “non-actionable.” Fifty-seven items were identified as non-actionable (i.e., lacking enough detail to be sufficiently interpreted and acted upon). Examples of non-actionable items included recommendations like “require training” or “promote student agency.” The remaining 225 recommendations were coded with one of 31 codes from a code list generated by the lead researcher. Example codes included “teacher training” and “assessment.” Using these codes, similar recommendations were grouped and merged, yielding 95 recommendations. These 95 recommendations were edited by the lead researcher for grammar, syntax, punctuation, and clarity.

Round Two

The 95 recommendations derived from Round One served as the basis of the Round Two questionnaire. All 15 participants from Round One were emailed an invitation to participate in the online questionnaire for Round Two. In total, 12 people participated in Round Two. Recommendations with a median score below three were

removed, leaving 63 recommendations. To prepare the questionnaire for the third and final round, all recommendations were rank ordered by mean within their respective domain, and three were identified as having high variability (i.e., an interquartile range above one).

The final two items in the Round Two questionnaire asked participants to rate their agreement with the following statements using the same four-point scale: (1) “my recommendations from Round 1 were well incorporated into the recommendations provided in Round 2,” and (2) “the process by which my recommendations from Round 1 were edited and combined with others in Round 2 did not fundamentally change the original meaning of my recommendations.” Across participants, both statements had median scores of four. The first statement mean was 3.58, and the second statement mean was 3.42.

Round Three

All 12 participants from Round Two participated in Round Three. All 63 recommendations rated by participants in Round Three had a median of 3 or above. In support of pursuing consensus across participants, seven recommendations with an interquartile range above one and were removed from consideration. The remaining 56 recommendations were rank ordered by mean and split into two groups: the foremost recommendations provided by participants (i.e., the chief output associated with the research question driving this study) and all remaining recommendations. Table 4.2 provides the top five recommendations from each domain of practice for a total of 30 recommendations. The remaining 26 recommendations have been provided in Table 4.3.

With means ranging from 3.3 to 4.0, the top 30 recommendations provided in Table 4.2 are discussed in relation to their content and scope in the section that follows. Seven critical recommendations had a mean of 3.8 or higher including three with a mean of 4.0. These items with means of 4.0 were “provide students with IEPs with opportunities to make choices, provide input, and use supported decision-making from elementary school onward,” “require training on self-determination, adult decision-making supports, the limitations of guardianship, and alternatives to guardianship for special education professionals,” and “provide information on alternatives to guardianship that is accessible and in plain language for teachers, students, and families.” The remaining 26 recommendations provided in Table 4.3 were not identified as part of the foremost recommendations provided by participants in the study, but they still met the inclusion criteria and ranged in mean scores from 2.8 to 3.5. Notably, as detailed in Table 4.3, there were no additional recommendations in the domain of research and nine additional recommendations listed in both the domain of education and instruction and the domain of coordination and collaboration.

At the end of the Round Three questionnaire, participants used the same four-point scale to indicate their degree of agreement with the following two statements: (1) “the way in which my input in Round 2 influenced this questionnaire was clear” and (2) “overall, I’m satisfied with how my input has influenced the questionnaire for Round 3.” Across participants, both statements had median scores of four and mean scores of 3.6. To aid in understanding the flow of information across each of these three rounds of questionnaires, a visual supplement to the narrative descriptions of each round of this study has been provided here as Figure 4.1.

Discussion

The current study was driven by working with established professionals promoting alternatives to guardianship in a structured fashion to generate their collective recommendations for special education professionals to maximize student decision-making autonomy, independence, and dignity into adulthood. Its form and function were guided by a single research question: what are the foremost recommendations of established professionals in the use of alternatives to guardianship within special education practice in the areas of self-determination, assessment and planning, education and instruction, coordination and collaboration, policy and process evaluation, and research? A Delphi technique-driven study comprised of three rounds of online questionnaires functioned to solicit recommendations from participants, gather participant ratings of these recommendations, and affirm these ratings towards consensus. As a result, the study culminated in participants providing of 56 total recommendations in six domains meeting the inclusion criteria (median of 3 or above and an interquartile range of 1 or below). The top five recommendations from each domain were singled out in support of the research question guiding this study, providing a collection of 30 final recommendations (Table 4.2). This final list of critical priorities includes both novel ideas as well as recommendations that are represented in the literature base. Some of the implications of these recommendations, the limitations to the way they were derived, and directions for future research are outlined in the discussion that follows.

Self-Determination Recommendations

A cornerstone of Millar's Guardianship Alternative Model (GAM; 2014), the first five recommendations for special education professionals were organized into the domain of self-determination. Unlike the other five domains used to collect participant recommendations about general aspects of special education (e.g., research), this was the only content specific domain. While self-determination as a content area is markedly broad, its importance for people with disabilities is a hallmark of arguments in support of alternatives to guardianship (e.g., Martinis & Blanck, 2019; Shogren & Wehmeyer, 2015). Moreover, self-determination has been consistently identified as a predictor of postschool success for students with disabilities (Mazzotti et al., 2016; Mazzotti et al., 2021; Test et al., 2009).

Self-determination recommendations had means that ranged from 3.7 to 4.0. Each recommendation, in its own way, spoke to the need for providing students with self-determination related opportunities. The first self-determination recommendation was one of three in the entirety of Round Three with a mean rating of 4.0, indicative of perfect agreement across all 12 participants. This recommendation was to "provide students with IEPs with opportunities to make choices, provide input, and use supported decision-making from elementary school onward." The notion of providing students with disabilities with opportunities for choice and input is a general thread of import from across the literature on self-determination, but scholars have also warned against confusing the mere provision of choice making opportunities with people living truly self-determined lives (Agran et al., 2010). True choice, choice that improves the quality of people's lives, must involve both frequent opportunities for choosing and a breadth of

options from which one can choose (Brown & Brown, 2009). This recommendation highlights the need for an important word of caution about the implementation of this and the other recommendations gleaned from this study.

More than items on a checklist, these recommendations offer windows into things for which there are many interpretations. As such, each recommendation may bring with it a potentially large gradient of rigor across different loci of implementation. A helpful starting place for considering the ways in which recommendations in this domain may be implemented are the interventions that have been found to be causally linked to an increase in the self-determination of students with disabilities. Of the four of five recommendations offered in this domain that related to student opportunities to build self-determination skills, all four are clearly linked to the student support offered through the Self-Determined Learning Model of Instruction (SDLMI; Wehmeyer et al., 2000).

The SDLMI is an evidence-based instructional model for teachers to support students to engage in self-directed and self-regulated learning (Hagiwara et al., 2020; Wehmeyer et al., 2000; Wehmeyer et al., 2012). As a model of instruction, the SDLMI serves as an instructional guide that has been used for students with and without disabilities and tested across many instructional settings and curricular areas (Shogren et al., 2021). As an evidence-based practice, it serves to reason that the SDLMI should be considered as one the best available means for affecting positive student outcomes (Cook & Odom, 2013). Therefore, when considering recommendations that might increase student opportunities for making choices, directing their own educational pathways and futures, engaging in self-regulation, and effectively utilizing support, there is a

compelling case to be made for considering the SDLMI as a vehicle for implementing some of the recommendations provided here.

Assessment and Planning Recommendations

The five recommendations in the domain of assessment and planning had mean scores ranging from 3.3 to 3.9. In short, they relate to special education professionals (a) better attending to the transition planning process for students with IEPs, (b) incorporating decision making assessments and skill building into student IEPs, and (c) planning with the most current information available to support adult decision-making support and alternatives to guardianship. The recommendations offered here show a striking resemblance to Millar's provided alongside the domain of the same name in the GAM (2014). Like Millar's guidance, the most highly ranked recommendation, and most of the subsequent recommendations in this domain affirm, transition planning should "include and prioritize less restrictive alternatives to guardianship." Thoughtfully expanding the transition planning process to better address these issues was one of the chief pieces of guidance provided by Lindsey and colleagues in their 2001 position paper on age of majority in special education.

Transition planning has been a fixture of the special education landscape since it was first alluded to by the IDEA in 1990. Although it was not formally defined by the law in 1990 or subsequent reauthorizations of the IDEA, the concept of transition planning captures the mandates that do exist for (a) student and family involvement in the development of a student's postschool goals and (b) the coordination of transition services (Shogren & Plotner, 2012). Practitioners, administrators, and policy makers

alike, when considering how to best implement the recommendations provided in this domain, would do well to consider transition planning processes. This may mean better attending to issues related to adult decision-making support in transition assessments, transition services, and in communication with students and families.

More than just a recommendation for progressive practice, a failure to address adult decision-making support within transition planning processes places SEAs and LEAs in conflict with the IDEA (Kanter, 2015; Rood et al., 2014). Nevertheless, such approaches likely depend upon special education professionals that understand the existential threat posed by undue and overbroad guardianship for the postschool outcomes of students with disabilities. Moreover, such practices may need to be codified within the IDEA to ensure that this type of shift occurs in the field (Raley et al., 2020).

Education and Instruction Recommendations

With mean scores ranging from 3.5 to 4.0, recommendations on education and instruction covered (a) adult decision-making and self-determination related professional development and (b) schoolwide instructional support for self-determination. With a mean score indicative of perfect agreement across participants in Round Three, the most highly ranked recommendation was to “require training on self-determination, adult decision-making supports, the limitations of guardianship, and alternatives to guardianship for special education professionals.” Echoed in some fashion throughout four of the five recommendations in this domain, the need for such support for special education professionals is a resounding message from this study. It is a need that has been similarly echoed through the literature on this topic for quite some time now (e.g., Millar,

2003; Shogren et al., 2018). In their survey of 117 professionals in special education leadership positions, Plotner and Walters (2022) found that less than half reported having received training in the last three years on topics like self-determination, supported decision making, and assessments relevant to adult decision-making support. In a national sample of special education teachers, Walters and colleagues (2023) found even lower rates of self-reported access to training on these same topics. Special education administrators and policymakers should consider heeding this recommendation by ensuring that special education professionals at the state and local level have incentivized access to robust and ongoing training opportunities on these issues.

Coordination and Collaboration Recommendations

Coordination and collaboration recommendations ranged in mean scores of 3.6 to 4.0. With a score indicative of perfect agreement across participants in Round Three, the first recommendation suggests that special education professionals “provide information on alternatives to guardianship that is accessible and in plain language for teachers, students, and families.” Like many of the others provided, this recommendation provides a simple, low cost means for action at the state, local, or classroom level. Its provision intimates a current reality in which something so simple might not already be happening. Other recommendations offered in this domain speak to coordination and collaboration across schools and districts as well as between schools and outside agencies. Prior research suggests that special education professionals themselves may not have a sufficient knowledge base in supporting students through alternatives to guardianship (Millar, 2007; Millar, 2008; Plotner & Walters, 2021; Walters et al., 2021). Implementing

recommendations that provide clear suggestions for leveraging the expertise of others within or outside a LEA may be a sensible solution to this dilemma.

Policy and Process Evaluation Recommendations

In the GAM, suggested actions in the domain of policy and process evaluation are driven by four guiding questions: First, what is the extent of education and training opportunities provided to and accessed by stakeholders? Second, are policies and procedures known and followed? Third, are alternatives to guardianship being discussed in transition planning conversations? Fourth, what is the rate and nature of guardianship appointments? (Millar, 2014). Policy and process evaluation in the GAM served, as the name suggests, an evaluative function to ensure that the rest of the model was being implemented. Some recommendations provided by participants in this study appear to have been offered to similar ends, but most offer actual suggestions for special education policy *and* evaluation. Policy and process evaluation recommendations ranged in mean scores of 3.3 to 3.8. Each of the five recommendations provide logical extensions of recommendations provided in previous domains. The most highly rated recommendation suggests that SEAs and legislatures, “issue policy and guidance that promotes supported decision-making and other alternatives to guardianship.” It is a sentiment echoed throughout the other four recommendations provided and offers, a straightforward imperative for special education policy makers. With the recognition of the need for such approaches to policy, Raley and colleagues (2020) have offered a framework for a potential amendment to the IDEA. There is a resounding value in this framework for

policy efforts at the state and local level that provides a starting place for special education policymakers that recognize the need for such reform.

Research Recommendations

Research, the sixth and final domain in which recommendations were organized, is the only domain retained that was not previously present in Millar’s practitioner-focused GAM. With mean scores ranging from 3.4 to 3.5, the five recommendations in this domain serve to both affirm previous calls to action and suggest priorities that may be slightly more novel. The first and most highly rated recommendation urges the field to “develop research-based instructional materials for teachers to use to assess and support decision-making and self-determination skills, targeting life domains typically associated with guardianship for students with IEPs.” Initial development efforts to forward assessments such as the Supported Decision Making Inventory System (Shogren et. 2017b) have been conducted, yet it is not clear how well known such tools are to the field at large. When used in tandem with established means for supporting the self-determination of students with disabilities (e.g., the SDLMI) such assessments may provide promising directions for future exploration. In so doing, special education administrators, policymakers, and researchers alike, should consider, as other recommendations in this domain urge, the impact of such interventions on the postschool outcomes of youth with disabilities and the rate of guardianship in a defined geographical area. In sum, recommendations in this domain, as the name suggests, provide a host of implications for worthwhile, future research.

Limitations and Implications for Future Research

There are several limitations to this study that merit recognition both for the necessary context they provide for the findings of this study and the implications that such limitations hold for future research. First, it is important to acknowledge the fact that none of the 30 final recommendations for special education professionals come with directions on how to implement them. While some are clearer than others, each of these recommendations carry with them a high degree of interpretation when considering their use. To increase the utility of this study's findings, future research should unpack these recommendations in a fashion that supports their meaningful and practical use in the field.

Second, this study's framing of participant expertise, an integral element of the Delphi technique, was a somewhat complicated issue to navigate. Content expertise on avoiding undue and overbroad guardianship in special education contexts is a unique niche. Setting criteria for the nomination and participation of *established professionals* hearkens to the dilemma inherent to identifying people with such content expertise. Out of an abundance of caution from the lead researcher, the label of established professional was used instead of *expert* to avoid overextending claims about participant knowledge (Trevelyan & Robinson, 2015). More elegant solutions likely exist for identifying and referring to the subject matter expertise of professionals in similar, future efforts.

Third, future research should also consider the many ways in which expertise on this topic may be derived or conceptualized. Like so many studies on issues related to youth and young adults with disabilities, the expertise of lived experience that can only come from disabled people themselves is noticeably absent here. Replication of this study

or similar endeavors would do well to tap into the expertise of young adults with disabilities, even though this may mean even more complicated interrogations of the term “expert” in relation to this complicated topic. Other stakeholders with important insights abound. Future research should also consider the input of family members of young adults that have themselves navigated the transition to legal adulthood. Tapping into the knowledge of professionals from a common discipline like special education might also provide a fruitful foundation for future inquiry.

Finally, the sheer number of recommendations provided in Round One and the way in which many were consistently rated highly across Rounds Two and Three provided an unforeseen challenge. 56 recommendations ultimately met the inclusion requirements as an output of Round Three. To practically clarify this output, the top five recommendations in each domain were isolated and discussed. The remaining 26 recommendations, however, had mean scores that were only marginally lower than the 30 most highly rated recommendations. Despite the practicality of this treatment of recommendations, it is potentially misleading to negate the importance of some recommendations meeting the inclusion criteria of this study while elevating others. Future research should consider alternative treatments of these data and other means for communicating the important messaging behind all 56 recommendations.

Conclusion

There is a stark incongruence between a societal reliance on guardianship as a frontline for supporting adults with disabilities and the ethical, legal, and practical mandates of special education (Rood et al., 2014). To proactively address its active and

passive roles in students with disabilities being placed under undue and overbroad guardianship, the field must do more than simply comply with the age of majority mandates of the IDEA. These mandates alone, professionals have long been warned, may themselves serve as prompts for parents to pursue guardianship (Lindsey et al., 2001). The recommendations collected here represent the collective wisdom of some of the foremost leaders of thought and practice in less restrictive decision-making support for young adults with disabilities. They provide many promising directions for state and local policy, future research, and improvements to the business of supporting positive postschool outcomes. If quality of life and community integration are indeed the intended, long-term consequences of special education, the field must take action and demand sustainable, meaningful change.

Table 4.1 Demographic information for participants by round

Demographic Category by Response Option*	Round 1 % (n)	Rounds 2 and 3 % (n)
State		
District of Columbia	7% (1)	8% (1)
Indiana	7% (1)	8% (1)
Kansas	20% (3)	25% (3)
Kentucky	7% (1)	8% (1)
Maryland	13% (2)	8% (1)
Maine	7% (1)	8% (1)
Michigan	7% (1)	8% (1)
Minnesota	7% (1)	8% (1)
New York	7% (1)	0% (0)
South Carolina	13% (2)	17% (2)
Vermont	7% (1)	0% (0)
Gender Identity		
Female	87% (13)	83% (10)
Male	13% (2)	17% (2)
Agency Affiliation		
College or university	46.5% (7)	50% (6)
Non-profit	46.5% (7)	42% (5)
State agency	7% (1)	8% (1)
Educational Attainment		
Bachelor's degree	7% (1)	8% (1)
Master's degree	40% (6)	42% (5)
Doctoral degree	33% (5)	33% (4)
Juris doctorate	20% (3)	17% (2)
Formal Training		
Special education	27% (4)	33% (4)
Law	33% (5)	25% (3)
Rehabilitation counseling	13% (2)	17% (2)
Other	27% (4)	25% (3)
Years' Experience		
6-10	40% (6)	25% (3)
11-20	33% (5)	42% (5)
More than 25	27% (4)	33% (4)
Years in Current Role		
Less than 2	13% (2)	8% (1)
2-5	27% (4)	25% (3)
6-10	33% (5)	34% (4)
11-15	7% (1)	8% (1)
21-25	7% (1)	8% (1)
More than 25	13% (2)	17% (2)

* Note: Only response options selected by one or more participant have been included here

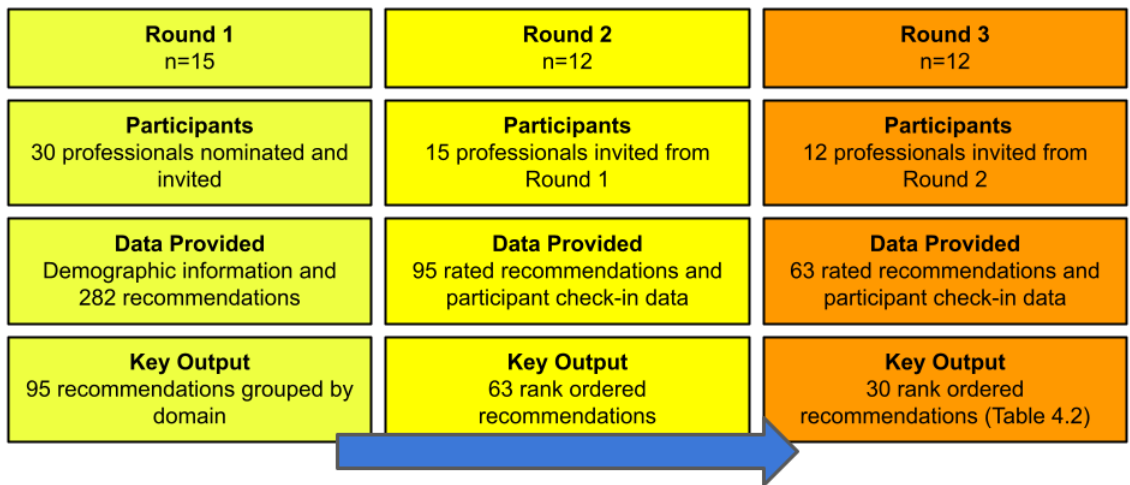


Figure 4.1. Visual depiction of key information from each study round

Table 4.2 Final recommendations rank ordered by mean

Recommendations by Domain	n	Mean
Self-Determination		
1. Provide students with IEPs with opportunities to make choices, provide input, and use supported decision-making from elementary school onward	12	4.00
2. Work with parents to help students with IEPs to designate a decision-making support network	12	3.83
3. Provide explicit opportunities for students with IEPs to learn and practice self-determination skills	12	3.75
4. Provide students with IEPs with the tools and support they need to engage in directing their own education planning and honor their choices	12	3.67
5. Support students to see themselves as decision-makers by teaching them how decisions are made, "mapping" their decisions, and promoting intrinsic motivation to be a decision-maker, including responsibility for consequences	12	3.67
Assessment and Planning		
1. Require transition planning to include and prioritize less restrictive alternatives to guardianship (e.g., supported decision-making, health care proxies, etc.)	12	3.92
2. IEPs at all grade levels should include decision-making skill development and information about how students will make decisions as adults	12	3.58
3. Ensure that special education professionals are using consistent and accurate information in age of majority discussions, meeting the requirements of the IDEA, and avoiding explicit or implicit support of parent petitions for guardianship	12	3.58
4. Engage in an ongoing process to identify student skills and growth areas in decision-making. If a student is not able to engage in skill-building, identify existing supports, or potential supports, that can be utilized into adulthood	12	3.33
5. Decision-making-related transition assessments should be strengths-based and track student opportunities to learn and practice skills, not highlight student deficits	12	3.33
Education and Instruction		
1. Require training on self-determination, adult decision-making supports, the limitations of guardianship, and alternatives to guardianship for special education professionals	11	4.00
2. Establish schoolwide initiatives to prioritize self-determination for all students	11	3.73
3. All special education professionals should receive training on how to support decision-making and best practices for including decision-making skill development in the curriculum for all students	11	3.64
4. Provide educators and administrators with information about all modes of decisional support for people with disabilities (e.g., supported decision-making, powers of attorney, medical directives, HIPAA and FERPA information, and the realities of guardianship)	11	3.54
5. Provide professional development opportunities that expose special education teachers to best practices and new, innovative ideas in adult decision-making support	11	3.54

Recommendations by Domain	n	Mean
Coordination and Collaboration		
1. Provide information on alternatives to guardianship that is accessible and in plain language for teachers, students, and families	11	4.00
2. Require schools to provide families of students with IEPs with information, referrals, and support to navigate less restrictive alternatives to guardianship as part of the transition IEP process	11	3.82
3. Seek input from disability-led organizations to promote student rights, autonomy, and self-determination skills	11	3.64
4. Partner with disability-led organizations to provide opportunities for students with IEPs to connect with other youth with disabilities that can provide mentorship related to adult decision-support	11	3.64
5. Coordinate (a) within schools and (b) between school districts and their state education agency to ensure correct and consistent messaging about self-determination, dignity of risk, and building supports to avoid the use of guardianship	11	3.55
Policy and Process Evaluation		
1. Within state education agencies and legislatures, issue policy and guidance that promotes supported decision-making and other alternatives to guardianship	10	3.80
2. Create state-level policies that emphasize self-determined learning for all students, with a particular focus on schools with large populations of students from marginalized groups	10	3.70
3. Issue policy, guidance, and regulations (and, if necessary, propose legislation or executive action) to support student decision-making and alternatives to guardianship such as SDM. Identify incentives for compliance with these mandates and sanctions for failures to do so. Ensure that all stakeholders (e.g., students and parents) participate in the process to generate such policies and have an opportunity to be heard	10	3.50
4. Base policy and practice on principles like autonomy, self-determination, and the human right of legal capacity rather than on protectionism and fear of liability	10	3.40
5. Monitor schools, classrooms, and interdisciplinary IEP team-level interactions to ensure a consistent approach to age of majority for students with IEPs, and intervene as necessary if coordination and collaboration break down	10	3.30
Research		
1. Develop research-based instructional materials for teachers to use to assess and support decision-making and self-determination skills, targeting life domains typically associated with guardianship for students with IEPs	11	3.55
2. Ensure that classroom-level special education personnel have access to research on best practices in adult decision-making support and are trained on how to implement these practices to support independent decision-making and alternatives to guardianship	10	3.40
3. Fund evaluation and research on the impact of teaching decision-making on postschool community inclusion, employment, use of adult services, and overall health	11	3.36

Recommendations by Domain	n	Mean
4. Investigate the rate of guardianship per county in comparison to census data to identify pockets of excellence and where more education is needed. Such research should include more robust sample sizes than similar efforts conducted to-date	11	3.36
5. Reach out to universities to connect with those conducting adult decision-making support research as well as other stakeholders in a position to fund or suggest areas in which research is needed. Provide needed funding for this research. Make sure that under-resourced schools receive incentives (including funding and personnel) to implement these research-supported practices	11	3.36

Table 4.3 Remaining recommendations rank ordered by mean

Recommendations by Domain	n	Mean
Self-Determination		
1. Emphasize student decision-making across instructional areas, including the Transition from parent/caregiver control to student choice	12	3.50
2. Implement student self-determined learning strategies across grades and content areas	12	3.42
3. Special education professionals should affirm dignity of risk for students with IEPs and promote self-determination and autonomy over protection	12	3.42
Assessment and Planning		
1. Offer opportunities for professional planning on fostering self-determination towards the implementation of research-based supports for decision-making	12	3.25
2. Assess the self-determination of students with IEPs and use assessment data to guide self-determination interventions and supports	12	3.25
3. Facilitate planning for adult decision-making support that always includes the student and serves as the culmination of multiple, robust transition assessments over a period of time	12	3.16
Education and Instruction		
1. Support students and special education professionals in learning about disability rights and available networks of support	10	3.40
2. Special education professionals serving to coordinate services (e.g., case managers) for students with IEPs should receive regular training on adult decision-making support to promote a seamless transition	11	3.36
3. Provide training on transition planning to ensure compliance with the spirit of the IDEA and to affirmatively and materially promote the address of self-determination in the IEP process	11	3.36
4. Include instruction in decision-making and asking for and receiving support as part of the curriculum and/or transition planning	11	3.27
5. Provide evidenced-based professional development on guardianship, supported decision-making, Universal Design for Learning, and differentiated instruction	11	3.27
6. Provide training on adult decision-making supports and related topics to school-based behavioral health professionals	11	3.18
7. Implement and monitor school-wide policies on independent student decision-making and alternatives to guardianship such as supported decision-making	11	3.18
8. Identify protocols and training materials that can assess student decision-making in a systematic manner, and develop plans (with timelines and identification of responsibilities) to implement best practices in decision-making	11	2.82
9. Adopt and universally implement a standardized curriculum for K-12 in decision-making skill development		
Coordination and Collaboration		
1. Develop consistent special education professional language and talking points to ensure that conversations with students, families, and other	11	3.45

Recommendations by Domain	n	Mean
professionals do now presume the need for guardianship but rather, identify available resources to help support the student into adulthood		
2. Begin discussing the topic of supported decision-making and alternatives to guardianship with families at all age levels from early elementary onward	11	3.36
3. Coordinate with state agencies to ensure supported decision-making is protected and upheld within systems serving students with IEPs and their families	11	3.36
4. Encourage collaboration with state social services, Medicaid waiver programs, Vocational Rehabilitation, and postsecondary education programs on the principles of decision-making supports in adulthood	11	3.36
5. Meaningfully involve students with IEPs and their family members in educational planning and create structures to ensure accountability in facilitating their involvement	11	3.27
6. Advocate for state-level legislation to provide a process for the transfer of educational decision-making rights for students with IEPs	11	3.27
7. Increase coordination and collaboration between general education teachers and special education teachers to ensure proper accommodations and modifications are being made to promote access for students with IEPs	11	3.18
8. Coordinate with statewide collaborative networks for professionals (e.g. WINGS) and self-advocates (e.g., CYVYC) that are building capacity for supported decision-making	11	3.18
9. Develop documents and communication strategies for age of majority communications in the IEP process along with requirements for the adoption of these tools in planning for special education transition services	11	3.09
Policy and Process Evaluation		
1. For students with IEPs at the school and district level, evaluate the outcomes of interventions to promote self-determination, supported decision-making, and the establishment of systems of support	10	3.30
2. Provide explicit policies and commensurate interventions that support the use of strengths-based approaches to age of majority and self-determination	10	3.20

CHAPTER FIVE

CONCLUSION

Each of the three interior chapters assembled here were written as standalone articles. In simple terms, Chapter Two and Chapter Three both serve as in-depth empirical inventories of the barriers keeping special education professionals from supporting youth with disabilities and their families through less restrictive alternatives to guardianship. Towards better understanding the landscape of the affirmative responsibility of special education professionals, Chapter Four is replete with constructive actions the field can consider as it looks to more ethical, responsible practice in the support of young adults with disabilities. Together, these chapters provide a window into both *problem* and *solution*. As is the case with many articles prepared for peer-reviewed journals, however, context on their creation is sacrificed to meet page limit requirements. It is this context that I hope to leave you with in this concluding word on this body of work.

Some of my most influential formative years as a professional were spent working for a college program for students with intellectual and developmental disability. At that time, such programs were not yet typical on college campuses. A grand experiment, of sorts, my colleagues and I were learning as we went about what it meant to support our students through life in college, an experience that in years prior they would have been

categorically denied access to. Watching disabled students thrive through the challenges associated with living away from home for the first time made an indelible mark on me. I learned, among many other things, that it wasn't one's inherent or perceived ability to succeed when faced with the demands of college life that mattered, it was whether they were given the opportunity to do so.

Trials like making friends, managing finances, and staying on top of busy schedules were the great equalizer. I watched as our students navigated these challenges in real time just as their peers without disabilities navigated them, too. And just like their peers without disabilities, certain failures were somewhat frequent. Instances of ignored wake up alarms resulting in missed classes and work shifts, unrequited romantic advances, disputes with roommates, and the like, were all commonplace. Rather than signs that something was drastically wrong in the lives of our students, such failures were signs that something was going right. Failure indicated the presence of opportunity. Through the guidance of the director of our program, we were taught that our job was never to insulate our students from these challenges but rather, to partner with them to determine the support they needed to be successful.

It was in this work that I learned one of the most valuable lessons of a career that has ever since involved supporting young adults with disabilities. Get out of the way. One of the most important and developmentally appropriate things you can do for a young adult is to simply move out of their way and let them experience life. This is not a denial of the very real support needs that young adults with and without disabilities have, nor is it a dereliction of a professional responsibility to provide that support. It is, rather, a clarification of priorities. I would go on to learn that while I had come to this

understanding organically through my work and the mentorship of the director of that program, it was not exactly a novel concept. Decades before I learned about the need to get out of the way through my own trial and error, Robert Perske advanced the concept of *dignity of risk* (1972). He asserted that professionals supporting people with disabilities are often “overzealous in their attempts to ‘protect,’ ‘comfort,’ ‘keep safe,’ ‘take care,’ and ‘watch’” (1972, p. 25). Such overprotection, he argued, keeps one from the very risk essential to their growth and development. Such overprotection may be one of the most predictable drivers of programs and systems supporting young adults with disabilities.

In this landscape of well-intentioned professionals insulating disabled young adults from the very opportunities they need to thrive, the three studies assembled here speak to a particularly troubling reality; as this concluding passage is being written, and even as it is being read, youth with their entire lives before them are having their legal capacity to direct their futures taken from them through guardianship. With the stroke of a judge’s pen, a young adult may be forever insulated from opportunity, from the very risk they need to learn, grow, and thrive. It is a tragic story, yet it would appear that in most cases, it is not a story villains and bad actors. Nevertheless, like so many complicated issues, this is one that runs a high risk for being reduced to two opposing sides. Such diametrically opposed positions include ones like guardianship vs. supported decision making and self-determination vs. paternalism. If we are being completely honest, such reductive binaries are often easier to employ than a discourse that captures the complication, the nuance, the shades of grey. In my attempts to illustrate the basic building blocks of these issues, I am increasingly aware that I have fallen into this very

trap in my writing. If one's takeaway from this work is simply guardianship = bad, supported decision making = good, I have done something terribly wrong.

The fact is that, over the years, I've met disabled young adults under guardianship living full, self-determined lives. Their parents have, almost exclusively, told me the same story over and over again; at some point as their son or daughter approached the age of legal adulthood, someone they trusted told them that obtaining guardianship was a necessary measure. Although they have guardianship orders in place, I've met many of these parents as they've searched for ways to get those orders revoked and support their adult children to live their lives to the fullest.

I've also met disabled young adults that, while not living under guardianship, had their every movement dictated by parents, teachers, or support workers. As offered from one of the special education administrators interviewed in Chapter Two, there are people that simply assume that their adult children must, by way of their dependence on them, follow their dictates. I've met adults my own age with their legal capacity for decisions fully intact that have learned they must ask other adults for permission before leaving a room to use the bathroom. In short, issues at the intersection of age of majority, special education, and adult decision-making support are not simply issues of a single right approach vs. the wrong approach.

The packaging of these three studies together here was highly intentional. I wanted to show a progression of my efforts to empirically document both problems and potential solutions related to the address of undue and overbroad guardianship in special education. In so doing, however, there is a real and present danger of painting a picture that attempts to edit the complicated reality of these issues. The work collected here is

nothing but a simple offering, an investment in an area of special education that has gone highly under researched. I trust that you, dear reader, have consumed this work in good faith and can balance that which has been oversimplified with this complicated reality. I trust also that somewhere in the middle of these two things, we will find ourselves together as professionals, as humans committed to ensuring that nobody needlessly experience their ability to choose being taken from them or their voice ignored.

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APPENDIX A: PERMISSION TO REPRINT CHAPTER TWO

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Mary Lynn Boscardin <mlboscardin.umass@gmail.com>

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Professor
[Editor, Journal of Special Education Leadership, CASE](#)
[Special Education Administration & Leadership](#)
[College of Education](#)
W253 Furcolo Hall
813 North Pleasant Street
University of Massachusetts Amherst
Amherst, MA 01003
Voice: 413-545-1193
Email: mlbosco@umass.edu

APPENDIX B: PERMISSION TO REPRINT CHAPTER THREE

RE: Current JoR Issue In Press

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To: Walters, Charles <WALTERC5@email.sc.edu>

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Executive Director, Sonoran Center for Excellence in Disabilities

Professor, Department of Family & Community Medicine

Editor, *Journal of Rehabilitation*

1521 E. Helen Street (mailing)

1533 E. Mabel Street (physical)

Tucson, AZ 85721

wparentjohnson@arizona.edu

520-626-0080 Office

785-764-2472 Mobile

APPENDIX C: ROUND ONE INSTRUMENT FOR CHAPTER FOUR

An Introduction to Round 1

Thank you for your interest in participating in this important study on age of majority and adult decision-making support within the context of special education. The purpose of the current study is to work with established professionals promoting alternatives to guardianship to generate and establish consensus on recommendations for special education professionals to maximize the decision-making autonomy, independence, and dignity of students with disabilities. As a nominated professional with expertise in these issues*, gathering your recommendations on this topic is central to the purpose of this project. This is the first of three, online questionnaires. It should take you no more than 20 minutes to complete. For those that participate, a link to the Round 2 questionnaire will be sent within 2-3 weeks.

This questionnaire is broken up into two sections. The 1st section will be used to collect information about you as a participant in this study. The 2nd section will be used to collect your recommendations to better support the autonomy and decision-making of young adults with disabilities in special education settings.

Your participation in this round and future rounds of questionnaires is completely voluntary. You should also know that the source of individual responses along with any other means for potentially identifying individual responses will be kept completely confidential. For those who complete both this round and the two subsequent rounds of questionnaires, you will be provided with the option of receiving a \$50 gift card to compensate you for the time you've spent contributing to this study.

On behalf of the research team conducting this independent project at the University of South Carolina, thank you for your important contribution to this project.

Charlie Walters, Study Lead and Ph.D. Candidate at the University of South Carolina
walterc5@email.sc.edu

*Note: To gather input from the professionals most familiar with this topic, I worked with leaders of supported decision-making capacity building efforts to gather nominations of professionals that: are (a) working within a professional role that involves advocating, building capacity, and/or researching in special education contexts for least restrictive adult decision-making supports; (b) conducting this work at the state- or national-level; (c) working primarily in the United States; and who have been (d)

working in this domain for at least three years. If these criteria do not apply to you, you can indicate that in the very first item of this questionnaire.

Section 1: Participant Information

To complete Section 1, please answer the following questions about yourself.

Do you meet the criteria for this study? These criteria specify that to participate in this study, you are (a) working within a professional role that involves advocating, building capacity, and/or researching in special education contexts for least restrictive adult decision-making supports; (b) conducting this work at the state- or national-level; (c) working primarily in the United States; and (d) working in this domain for at least three years.

- Yes
- No

In which U.S state or territory are you currently working? (dropdown menu)

Which option best describes your gender?

- Male
- Female
- Non-Binary
- Prefer not to answer
- Other (write-in option below)

Which option best fits your current age?

- 17-years-old or younger
- 18 to 25-years-old
- 26 to 30-years-old
- 31 to 40-years-old
- 41 to 50-years-old
- 51 to 60-years-old
- More than 61-years-old
- Prefer not to answer

Which option best describes your race/ethnicity?

- White/European American
- Black/African American
- Latino/Hispanic
- First Nations/Native American/Indigenous American
- Asian American
- Pacific Islander
- Prefer not to answer
- I identify as (write in)

Do you identify as a person with a disability and/or as disabled?

- Yes
- No
- Prefer not to answer

What type of agency do you work for?

- College or University
- State agency (not a college or university)
- Federal agency
- Health care agency (e.g., hospital or clinic)
- Non-profit organization
- Public school system (PK-12)
- Private PK-12 school
- Other (write-in)

What is your job title? (Write-in)

How many years have you been professionally involved in supporting young adults with disabilities?

- Less than 2
- 2-5
- 6-10
- 11-20
- 21-25
- More than 25

How many years have you worked in your current role?

- Less than 2
- 2-5
- 6-10
- 11-15
- 16-20
- 21-25
- More than 25

What is your highest level of education?

- High school diploma or GED
- Bachelor's degree
- Master's degree
- Doctoral degree
- Other (write-in)

In what professional domain(s) have you been formally trained? (e.g., law, special education, non-profit administration, education research methods, edu.)

What is your preferred email address? *Please note: Your email address is necessary for communication regarding participation in this study. Your identity will be known only to*

the lead researcher of this study, and your responses will remain completely anonymous to all other parties.

Section 2: Recommendations

In this final section, you'll see six areas of practice in special education: (1) self-determination, (2) assessment and planning, (3) education and instruction, (4) coordination and collaboration, (5) policy and process evaluation, and (6) research. A 7th area labeled "Other" is provided for any recommendations that might not fit well within the other six areas. Please use the spaces provided within each area to list your recommendations for special education professionals to better support the autonomy and decision-making of young adults with disabilities at the classroom, school, district, and/or state level. Specifically, these recommendations should serve to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship for young adults with disabilities.

Recommendations may be derived from promising approaches that you've seen implemented or simply approaches you anticipate might be helpful given your professional wisdom. It is also perfectly acceptable to not provide recommendations in a given area or within a given level or practice if you do not have any recommendations to provide. Moreover, please feel free to repeat recommendations that may apply in more than one area or level of practice. The following outline depicts each of the prompts in the remainder of this questionnaire that will collect your recommendations on practice in special education that limits undue and overbroad guardianship:

- (1) Self-determination
 - Classroom-level recommendation
 - School-level recommendation
 - District-level recommendation
 - State-level recommendation
- (2) Assessment and planning
 - Classroom-level recommendation
 - School-level recommendation
 - District-level recommendation
 - State-level recommendation
- (3) Education and instruction
 - Classroom-level recommendation
 - School-level recommendation
 - District-level recommendation
 - State-level recommendation
- (4) Coordination and collaboration
 - Classroom-level recommendation
 - School-level recommendation
 - District-level recommendation
 - State-level recommendation
- (5) Policy and process evaluation

- Classroom-level recommendation
- School-level recommendation
- District-level recommendation
- State-level recommendation

(6) Research

- Classroom-level recommendation
- School-level recommendation
- District-level recommendation
- State-level recommendation

(7) Other

- Classroom-level recommendation
- School-level recommendation
- District-level recommendation
- State-level recommendation

Recommendations on Self-Determination

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of self-determination? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Recommendations on Assessment and Planning

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of assessment and planning? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Recommendations on Education and Instruction

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of education and instruction? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Recommendations on Coordination and Collaboration

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of coordination and collaboration? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Recommendations on Policy and Process Evaluation

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of policy and process evaluation? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Recommendations on Research

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in the area of research? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

Other Recommendations

What are your top recommendations to ensure that no professional action or inaction is supporting the use of undue or overbroad guardianship in any other area that has not yet been covered? Reminder: Recommendations may (a) come from your own personal practice, observations, or professional expertise and (b) be repeated, if needed, across multiple areas or levels of practice. If you have no recommendations to offer at a given level or practice, you may simply leave that prompt blank.

Recommendation(s) at the classroom level

Recommendation(s) at the school level

Recommendation(s) at the district level

Recommendation(s) at the state level

APPENDIX D: ROUND TWO INSTRUMENT FOR CHAPTER FOUR

Welcome to Round 2

Thank you for your continued participation in this important study on age of majority and adult decision-making support within the context of special education. This is the 2nd of 3, online questionnaires. In this round, you will respond to each of the recommendations provided by the small group of people that participated in Round 1 (n=15).

Recommendations have been grouped according to the following 6 categories: Self-Determination, Assessment and Planning, Education and Instruction, Coordination and Collaboration, Policy and Process Evaluation, and Research.

Across these 6 categories, you will find 95 total recommendations and a corresponding place to rate each of them (Strongly Disagree, Disagree, Agree, and Strongly Agree). Please note, you will likely agree in principle with many of these recommendations, but the purpose of Round 2 is to identify the recommendations that are most important for special education professionals. Your level of agreement signifies your belief that a recommendation should be carried forward as a critical priority for special education systems. At the end of this questionnaire are 2 items to check in with you as a participant about how well your input in Round 1 was carried into Round 2.

Your participation in this questionnaire is completely voluntary. You should also know that the source of individual responses along with any other means for potentially identifying individual responses will be kept completely confidential. Update: For those who complete all 3 rounds of questionnaires, you will now be provided with the option of receiving a 2, \$50 Visa gift cards to compensate you for the time you've spent contributing to this study.

On behalf of the research team conducting this independent project at the University of South Carolina, thank you for your important contribution to this project.

Charlie Walters, Study Lead and Ph.D. Candidate at the University of South Carolina
walterc5@email.sc.edu

What is your preferred email address? Please note: Your email address is necessary for communication regarding participation in this study. Your identity will be known only to the lead researcher of this study, and your responses will remain completely anonymous to all other parties

Self-Determination Recommendations

Please rate your agreement with each of these recommendations as critical priorities for

special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
Support all students with IEPs to lead and/or direct their own IEP meetings				
Provide students with IEPs with the tools and support they need to engage in directing their own education planning and honor their choices				
Provide students with IEPs with opportunities to make choices, provide input, and use supported decision-making from elementary school onward				
Work with parents to help students with IEPs to designate a decision-making support network				
Special education professionals should affirm dignity of risk for students with IEPs and promote self-determination and autonomy over protection				
Emphasize student decision-making across instructional areas, including the transition from parent/caregiver control to student choice				
Support students to see themselves as decision-makers by teaching them how decisions are made, "mapping" their decisions, and promoting intrinsic motivation to be a decision-maker, including responsibility for consequences				
Implement student self-determined learning strategies across grades and content areas				
Set clear expectations for growth in self-determination for students with IEPs				
Observe student decision-making and offer guidance to those students who need assistance				
Provide explicit opportunities to students with IEPs to learn and practice self-determination skills				

Assessment and Planning Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
Require transition planning to include and prioritize less restrictive alternatives to guardianship (e.g., supported decision-making, health care proxies, etc.)				
Support students with IEPs to complete a Positive Personal Profile to outline their hopes and dreams for their lives after school				

Use strengths-based language in student assessment reporting and descriptions of student support needs in the context of decision-making				
Use data-based decision-making to develop systems and supports for providing resources schools need to promote self-determination				
IEPs at all grade levels should include decision-making skill development and information about how students will make decisions as adults				
Offer opportunities for professional planning on fostering self-determination towards the implementation of research-based supports for decision-making				
Support students, families, and teachers to create authentic person-centered plans				
Establish independent living as a key part of transition planning, provide structured independent living skill development, and develop measures to track how student independent living skills are being supported				
Ensure that special education professionals are using consistent and accurate information in age of majority discussions, meeting the requirements of the IDEA, and avoiding explicit or inexplicit support of parent petitions for guardianship				
Assess the self-determination of students with IEPs and use assessment data to guide self-determination interventions and supports				
Engage in an ongoing process to identify student skills and growth areas in decision-making. If a student is not able to engage in skill-building, identify existing supports, or potential supports, that can be utilized into adulthood				
Facilitate planning for adult decision-making support that always includes the student and serves as the culmination of multiple, robust transition assessments over a period of time				
Decision-making-related transition assessments should be strengths-based and track student opportunities to learn and practice skills, not highlight student deficits				

Education and Instruction Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
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Train special education professionals on promoting intrinsic motivation through competence, autonomy, and relationships				
Special education professionals serving to coordinate services (e.g. case managers) for students with IEPs should receive regular training on adult decision-making support to promote a seamless transition				
All special education professionals should receive training on how to support decision-making and best practices for including decision-making skill development in the curriculum for all students				
Provide professional development opportunities that expose special education teachers to best practices and new, innovative ideas in adult decision-making support				
Require training on self-determination, adult decision-making supports, the limitations of guardianship, and alternatives to guardianship for special education professionals				
Provide training on adult decision-making supports and related topics to school-based behavioral health professionals				
Provide educators and administrators with information about all modes of decisional support for people with disabilities (e.g., supported decision-making, powers of attorney, medical directives, HIPAA and FERPA information, and the realities of guardianship)				
Provide evidenced-based professional development on guardianship, supported decision-making, Universal Design for Learning, and differentiated instruction				
Provide training on transition planning to ensure compliance with the spirit of the IDEA and to affirmatively and materially promote the address of self-determination in the IEP process				
Provide professional training to address professional bias and student accommodations to ensure effective communication				
Provide training to special education professionals on effective transition planning and the role of transition assessments.				

Require training for special education professionals to support transition-age students to lead their own IEP meetings				
Support special education professionals to ensure that creative approaches for accommodating and supporting student skill development take priority over assumptions about student decision-making capacity and deficits				
Include instruction in decision-making and asking for and receiving support as part of the curriculum and/or transition planning				
Establish schoolwide initiatives to prioritize self-determination for all students				
Adopt and universally implement a standardized curriculum for K-12 in decision-making skill development				
Support students and special education professionals in learning about disability rights and available networks of support				
Reduce the use of self-contained programming and demonstrate a commitment to providing more professional development for classroom teachers on Universal Design for Learning and differentiated instruction				
Facilitate inclusion with fidelity across academic and non-academic domains for students with IEPs supported by Universal Design for Learning, differentiated instruction, opportunities for extensive collaboration for all school-level professionals, and data-driven goals				
Provide teachers and staff with evidence of how truly inclusive environments benefit all students in the classroom				
Implement and monitor school-wide policies on independent student decision-making and alternatives to guardianship such as supported decision-making				
Introduce a school-level decision-making curriculum on a pilot basis and evaluate results. Scale up from school-level pilot by providing support (including materials and funding) for school districts that serve a disproportionate number of students from marginalized groups.				
Provide students with IEPs with greater access and more meaningful engagement with assistive technology through strengths-based evaluations				
Identify protocols and training materials that can assess student decision-making in a systematic manner, and develop plans (with timelines and				

identification of responsibilities) to implement best practices in decision-making				
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Coordination and Collaboration Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
Develop documents and communication strategies for age of majority communications in the IEP process along with requirements for the adoption of these tools in planning for special education transition services				
Coordinate (a) within schools and (b) between school districts and their state education agency to ensure correct and consistent messaging about self-determination, dignity of risk, and building supports to avoid the use of guardianship				
Update teacher credentialing and preparation programs to ensure all teachers understand how to support students through Universal Design for Learning and differentiated instruction				
Meaningfully involve students with IEPs and their family members in educational planning and create structures to ensure accountability in facilitating their involvement				
Provide time for teachers to meet and collaborate to design ways to promote self-determination				
Advocate for state-level legislation to provide a process for the transfer of educational decision-making rights for students with IEPs				
Partner with disability-led organizations to provide opportunities for students with IEPs to connect with other youth with disabilities that can provide mentorship related to adult decision-support				
Provide information on alternatives to guardianship that is accessible and in plain language for teachers, students, and families				
Require schools to provide families of students with IEPs with information, referrals, and support to navigate less restrictive alternatives to guardianship as part of the transition IEP process				
Develop consistent special education professional language and talking points to ensure that conversations with students, families, and other professionals do not presume the need for guardianship but rather, identify available				

resources to help support the student into adulthood				
Begin discussing the topic of supported decision-making and alternatives to guardianship with families at all age levels from early elementary onward				
Facilitate the mapping of community resources and networks within school districts that support families to navigate alternatives to guardianship				
Collaborate with Parent Training and Information Centers and Family to Family Health Information Centers for training opportunities and transition resource fairs				
Establish opportunities for teacher collaboration with other teachers, state agencies, and families to ensure their practice supports self-determination for students with IEPs				
Offer state-wide conferences, guided by broad stakeholder input, on independent decision-making and alternatives to guardianship (e.g., supported decision-making)				
Coordinate with state agencies to ensure supported decision-making is protected and upheld within systems serving students with IEPs and their families				
Coordinate with statewide collaborative networks for professionals (e.g. WINGS) and self-advocates (e.g. CYVYC) that are building capacity for supported decision-making				
Encourage collaboration with state social services, Medicaid waiver programs, Vocational Rehabilitation, and postsecondary education programs on the principles of decision-making supports in adulthood				
Foster collaboration between SPED and CTE and encourage work-based learning experiences				
Work with special education personnel to speak with one voice on age of majority-related issues. Meet as necessary to facilitate developing a consistent approach				
Seek out legal advocates (from law school clinics, P&As, legal services offices) and solicit their input on issues related to age of majority and adult decision-making support				
Increase coordination and collaboration between general education teachers and special education teachers to ensure proper accommodations and modifications are being made to promote access for students with IEPs				

Prohibit school personnel involvement in assisting with obtaining guardianship and providing legal recommendations				
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Policy and Process Evaluation Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
Within state education agencies and legislatures, issue policy and guidance that promotes supported decision-making and other alternatives to guardianship				
Base policy and practice on principles like autonomy, self-determination, and the human right of legal capacity rather than on protectionism and fear of liability				
Provide explicit policies and commensurate interventions that support the use of strengths-based approaches to age of majority and self-determination				
Establish and monitor policies to promote self-determination and agency for students with IEPs, including conducting surveys and focus groups with students with IEPs and their parents				
Create state-level policies that emphasize self-determined learning for all students, with a particular focus on schools with large populations of students from marginalized groups				
Issue guidance to local districts to assist them in ensuring that their current policies and procedures for age of majority align with the IDEA and related state regulations				
Issue policy, guidance, and regulations (and, if necessary, propose legislation or executive action) to support student decision-making and alternatives to guardianship such as SDM. Identify incentives for compliance with these mandates and sanctions for failures to do so. Ensure that all stakeholders (e.g., students and parents) participate in the process to generate such policies and have an opportunity to be heard				
Promulgate guidance and regulations emphasizing the goal of interagency collaboration and coordination related to age of majority to enhance student decision-making and identify and promote alternatives to guardianship (e.g., supported decision-making)				

Monitor schools, classrooms, and interdisciplinary IEP team-level interactions to ensure a consistent approach to age of majority for students with IEPs, and intervene as necessary if coordination and collaboration break down				
For students with IEPs at the school and district level, evaluate the outcomes of interventions to promote self-determination, supported decision-making, and the establishment of systems of support				
Evaluate student IEPs to measure the number of students with self-determination and independent living goals and progress made toward these goals				
Manage up (recommendations to relevant state officials) and down (to schools) to ensure that education policies are supportive of values aligned with supported decision-making				
Survey students with IEPs about their satisfaction with opportunities for input into their transition goals				

Research Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree

	Strongly Disagree	Disagree	Agree	Strongly Agree
Develop research-based instructional materials for teachers to use to assess and support decision-making and self-determination skills, targeting life domains typically associated with guardianship for students with IEPs				
Evaluate the intermediate and long-term effects of interventions to promote self-determination, student decision-making, and related domains of student support				
Investigate the rate of guardianship per county in comparison to census data to identify pockets of excellence and where more education is needed. Such research should include more robust sample sizes than similar efforts conducted to-date				
Prioritize participatory action research on topics related to self-determination and decision-making for students with IEPs				
Ensure that classroom-level special education personnel have access to research on best practices in adult decision-making support and are trained on how to implement these practices to support				

independent decision-making and alternatives to guardianship				
Reach out to universities to connect with those conducting adult decision-making support research as well as other stakeholders in a position to fund or suggest areas in which research is needed. Provide needed funding for this research. Make sure that under-resourced schools receive incentives (including funding and personnel) to implement these research-supported practices.				
Solicit views of individual school personnel regarding gaps they perceive in available adult decision-making support practices and the research they would like to see and communicate that information to relevant state officials. Provide these findings to ensure wide distribution, with particular attention to under-resourced schools				
Investigate student outcomes when disability rights and autonomy are a part of the classroom curriculum				
Fund evaluation and research on the impact of teaching decision-making on postschool community inclusion, employment, use of adult services, and overall health				
Support schools to create time and space to participate in research				

Participant Check-In

Please indicate the degree to which you agree with each of the following statements

	Strongly Disagree	Disagree	Agree	Strongly Agree
My recommendations from Round 1 were well incorporated into the recommendations provided in Round 2.				
The process by which my recommendations from Round 1 were edited and combined with others in Round 2 did not fundamentally original meaning of my recommendations.				

APPENDIX E: ROUND THREE INSTRUMENT FOR CHAPTER FOUR

Welcome to Round 3

Thank you for your continued participation in this important study on age of majority and adult decision-making support within the context of special education. This is the final questionnaire you will receive as a participant in this study. In this round, you will be asked to again rate recommendations for special education professionals to establish consensus among participants. Like Round 2, recommendations have been grouped within the following 6 categories: Self-Determination, Assessment and Planning, Education and Instruction, Coordination and Collaboration, Policy and Process Evaluation, and Research. Across these 6 categories, you will now find **63** total recommendations and a corresponding place to rate your agreement with each of them on a 4-point scale (Strongly Disagree, Disagree, Agree, and Strongly Agree).

Please note, you will still likely agree with many of these recommendations in principle, but the purpose of Round 3 is to identify the recommendations that are most important for special education professionals. Your level of agreement with each recommendation signifies the degree to which you think it should be carried forward as a critical need for special education systems. Towards the end of this questionnaire are 2 items to check in with you as a participant about how well your input in Round 2 was carried into Round 3.

Your participation is completely voluntary. You should also know that the source of individual responses along with any other means for potentially identifying individual responses will be kept completely confidential.

On behalf of the research team conducting this independent project at the University of South Carolina, thank you for your important contributions over the last 2 months.

Charlie Walters, Study Lead and Ph.D. Candidate at the University of South Carolina
walterc5@email.sc.edu

What is your preferred email address?

Please note: Your email address is necessary for communication regarding participation in this study. Your identity will be known only to the lead researcher of this study, and your responses will remain completely anonymous to all other parties.

Self-Determination Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Provide students with IEPs with the tools and support they need to engage in directing their own education planning and honor their choices (Mean: 4)				
Provide students with IEPs with opportunities to make choices, provide input, and use supported decision-making from elementary school onward (Mean: 3.9)				
Provide explicit opportunities to students with IEPs to learn and practice self-determination skills (Mean: 3.9)				
Work with parents to help students with IEPs to designate a decision-making support network (Mean: 3.8)				
Support students to see themselves as decision-makers by teaching them how decisions are made, "mapping" their decisions, and promoting intrinsic motivation to be a decision-maker, including responsibility for consequences (Mean: 3.8)				
Implement student self-determined learning strategies across grades and content areas (Mean: 3.6)				
Special education professionals should affirm dignity of risk for students with IEPs and promote self-determination and autonomy over protection (Mean: 3.5)				
Emphasize student decision-making across instructional areas, including the transition from parent/caregiver control to student choice (Mean: 3.5)				

Assessment and Planning Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (**from left to right**) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Require transition planning to include and prioritize less restrictive alternatives to guardianship (e.g., supported decision-making, health care proxies, etc.) (Mean: 4)				
IEPs at all grade levels should include decision-making skill development and information about how students will make decisions as adults (Mean: 3.7)				
Engage in an ongoing process to identify student skills and growth areas in decision-making. If a student is not able to engage in skill-building, identify existing supports, or potential supports, that can be utilized into adulthood (Mean: 3.7)				
Decision-making-related transition assessments should be strengths-based and track student opportunities to learn and practice skills, not highlight student deficits (Mean: 3.6)				
Facilitate planning for adult decision-making support that always includes the student and serves as the culmination of multiple, robust transition assessments over a period of time (Mean: 3.5)				
Use data-based decision-making to develop systems and supports for providing resources schools need to promote self-determination (Mean: 3.4)				
Offer opportunities for professional planning on fostering self-determination towards the implementation of research-based supports for decision-making (Mean: 3.4)				
Ensure that special education professionals are using consistent and accurate information in age of majority discussions, meeting the requirements of the IDEA, and avoiding explicit or inexplicit support of parent petitions for guardianship (Mean: 3.4)				
Assess the self-determination of students with IEPs and use assessment data to guide self-determination interventions and supports (Mean: 3.4)				

Education and Instruction Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (**from left to right**) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree

Require training on self-determination, adult decision-making supports, the limitations of guardianship, and alternatives to guardianship for special education professionals (Mean: 3.9)				
All special education professionals should receive training on how to support decision-making and best practices for including decision-making skill development in the curriculum for all students (Mean: 3.8)				
Provide educators and administrators with information about all modes of decisional support for people with disabilities (e.g., supported decision-making, powers of attorney, medical directives, HIPAA and FERPA information, and the realities of guardianship) (Mean: 3.8)				
Establish schoolwide initiatives to prioritize self-determination for all students (Mean: 3.8)				
Adopt and universally implement a standardized curriculum for K-12 in decision-making skill development (Mean: 3.6)				
Provide evidenced-based professional development on guardianship, supported decision-making, Universal Design for Learning, and differentiated instruction (Mean: 3.6)				
Special education professionals serving to coordinate services (e.g. case managers) for students with IEPs should receive regular training on adult decision-making support to promote a seamless transition (Mean: 3.5)				
Provide professional development opportunities that expose special education teachers to best practices and new, innovative ideas in adult decision-making support (Mean: 3.5)				
Provide training on adult decision-making supports and related topics to school-based behavioral health professionals (Mean: 3.5)				
Support special education professionals to ensure that creative approaches for accommodating and supporting student skill development take priority over assumptions about student decision-making capacity and deficits (Mean: 3.5)				
Include instruction in decision-making and asking for and receiving support as part of the curriculum and/or transition planning (Mean: 3.5)				
Implement and monitor school-wide policies on independent student decision-making and alternatives to guardianship such as supported decision-making (Mean: 3.5)				

Identify protocols and training materials that can assess student decision-making in a systematic manner, and develop plans (with timelines and identification of responsibilities) to implement best practices in decision-making (Mean: 3.4)				
Provide training on transition planning to ensure compliance with the spirit of the IDEA and to affirmatively and materially promote the address of self-determination in the IEP process (Mean: 3.4)				
Support students and special education professionals in learning about disability rights and available networks of support (Mean: 3.4)				
Provide teachers and staff with evidence of how truly inclusive environments benefit all students in the classroom (Mean: 3.4)				
Reduce the use of self-contained programming and demonstrate a commitment to providing more professional development for classroom teachers on Universal Design for Learning and differentiated instruction (Mean: 3.3; High Variability)				
Facilitate inclusion with fidelity across academic and non-academic domains for students with IEPs supported by Universal Design for Learning, differentiated instruction, opportunities for extensive collaboration for all school-level professionals, and data-driven goals (Mean: 3.2; High Variability)				

Coordination and Collaboration Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Provide information on alternatives to guardianship that is accessible and in plain language for teachers, students, and families (Mean: 4)				
Coordinate (a) within schools and (b) between school districts and their state education agency to ensure correct and consistent messaging about self-determination, dignity of risk, and building supports to avoid the use of guardianship (Mean: 3.8)				
Require schools to provide families of students with IEPs with information, referrals, and support to navigate less restrictive alternatives to				

guardianship as part of the transition IEP process (Mean: 3.8)				
Seek input from disability-led organizations to promote student rights, autonomy, and self-determination skills (Mean: 3.7)				
Partner with disability-led organizations to provide opportunities for students with IEPs to connect with other youth with disabilities that can provide mentorship related to adult decision-support (Mean: 3.6)				
Begin discussing the topic of supported decision-making and alternatives to guardianship with families at all age levels from early elementary onward (Mean: 3.6)				
Coordinate with statewide collaborative networks for professionals (e.g. WINGS) and self-advocates (e.g. CYVYC) that are building capacity for supported decision-making (Mean: 3.6)				
Coordinate with state agencies to ensure supported decision-making is protected and upheld within systems serving students with IEPs and their families (Mean: 3.5)				
Develop documents and communication strategies for age of majority communications in the IEP process along with requirements for the adoption of these tools in planning for special education transition services (Mean: 3.5)				
Encourage collaboration with state social services, Medicaid waiver programs, Vocational Rehabilitation, and postsecondary education programs on the principles of decision-making supports in adulthood (Mean: 3.4)				
Advocate for state-level legislation to provide a process for the transfer of educational decision-making rights for students with IEPs (Mean: 3.4)				
Develop consistent special education professional language and talking points to ensure that conversations with students, families, and other professionals do not presume the need for guardianship but rather, identify available resources to help support the student into adulthood (Mean: 3.4)				
Increase coordination and collaboration between general education teachers and special education teachers to ensure proper accommodations and modifications are being made to promote access for students with IEPs (Mean: 3.4)				
Meaningfully involve students with IEPs and their family members in educational planning and create				

structures to ensure accountability in facilitating their involvement (Mean: 3.3)				
Prohibit school personnel involvement in assisting with obtaining guardianship and providing legal recommendations (Mean: 3.3)				
Provide time for teachers to meet and collaborate to design ways to promote self-determination (Mean: 3; High Variability)				

Policy and Process Evaluation Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Within state education agencies and legislatures, issue policy and guidance that promotes supported decision-making and other alternatives to guardianship (Mean: 3.8)				
Base policy and practice on principles like autonomy, self-determination, and the human right of legal capacity rather than on protectionism and fear of liability (Mean: 3.8)				
Create state-level policies that emphasize self-determined learning for all students, with a particular focus on schools with large populations of students from marginalized groups (Mean: 3.6)				
Provide explicit policies and commensurate interventions that support the use of strengths-based approaches to age of majority and self-determination (Mean: 3.5)				
Issue policy, guidance, and regulations (and, if necessary, propose legislation or executive action) to support student decision-making and alternatives to guardianship such as SDM. Identify incentives for compliance with these mandates and sanctions for failures to do so. Ensure that all stakeholders (e.g., students and parents) participate in the process to generate such policies and have an opportunity to be heard (Mean: 3.5)				
Monitor schools, classrooms, and interdisciplinary IEP team-level interactions to ensure a consistent approach to age of majority for students with IEPs, and intervene as necessary if coordination and collaboration break down (Mean: 3.5)				
For students with IEPs at the school and district level, evaluate the outcomes of interventions to promote self-determination, supported decision-				

making, and the establishment of systems of support (Mean: 3.5)				
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Research Recommendations

Please rate your agreement with each of these recommendations as critical priorities for special education systems by indicating (from left to right) Strongly Disagree, Disagree, Agree, or Strongly Agree.

	Strongly Disagree	Disagree	Agree	Strongly Agree
Fund evaluation and research on the impact of teaching decision-making on postschool community inclusion, employment, use of adult services, and overall health (Mean: 3.6)				
Develop research-based instructional materials for teachers to use to assess and support decision-making and self-determination skills, targeting life domains typically associated with guardianship for students with IEPs (Mean: 3.5)				
Investigate the rate of guardianship per county in comparison to census data to identify pockets of excellence and where more education is needed. Such research should include more robust sample sizes than similar efforts conducted to-date (Mean: 3.5)				
Ensure that classroom-level special education personnel have access to research on best practices in adult decision-making support and are trained on how to implement these practices to support independent decision-making and alternatives to guardianship (Mean: 3.5)				
Reach out to universities to connect with those conducting adult decision-making support research as well as other stakeholders in a position to fund or suggest areas in which research is needed. Provide needed funding for this research. Make sure that under-resourced schools receive incentives (including funding and personnel) to implement these research-supported practices (Mean: 3.4)				

Participant Check-In

Please indicate the degree to which you agree with each of the following statements

	Strongly Disagree	Disagree	Agree	Strongly Agree
My recommendations from Round 1 were well incorporated into the recommendations provided in Round 2				

The process by which my recommendations from Round 1 were edited and combined with others in Round 2 did not fundamentally original meaning of my recommendations				
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