

Abstract:

New York State guardianship law for individuals with intellectual and developmental disabilities is not built for the spectrum of needs of the population. There are various resources available to assist individuals for whom it may be detrimental to have a guardian; unfortunately, in New York, these alternatives to guardianship are not yet legal. Using a qualitative phenomenological approach, this study examines how advocates came to their decision on guardianship including what motivated them to make their decision, why they felt guardianship was the best decision or not, who provided guidance towards their supportive role, as well as determining the advocates' understanding of guardianship and its alternatives. The results found and discussed explore how the participants came to their decisions on guardianship, their motivations, and their level of knowledge surrounding guardianship and its alternatives.

*Life, Liberty, and the Pursuit of Happiness for Individuals with Intellectual and
Developmental Disabilities: A Qualitative Study*

by
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DISSERTATION
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Dedication:

This work of love, for a population I have treasured getting to know, is dedicated to my friends, professors, colleagues, individuals, and most importantly, my family. I would not have been able to complete this without your ongoing support and guidance.

It has meant the world.

What's next?

“L'fum tzara agra, according to the effort is the reward.”

Ben Hei Hei, Pirkei Avot, 5:26

I have the honor to be, your obedient servant,

R. Minkoff

Table of Contents

Chapter One: The Proposal Overview	1
Chapter Two: The Study Problem	7
Chapter Three: Literature Review	30
Chapter Four: Theoretical Framework.....	52
Chapter Five: The Research Question	59
Chapter Six: Methodology	60
Chapter Seven: Results	64
Chapter Eight: Discussion.....	99
References.....	109
Appendix A.....	115
Appendix B.....	117

“It was ability that mattered, not disability, which is a word I'm not crazy about using.”

Marlee Matlin

Chapter One: Dissertation Overview

This study aimed to identify the motivations for selecting legally defined guardianship or its alternatives and the observed mental health characteristics of the individual thereafter. Why do advocates choose a specific avenue of support, and what mental health outcomes are seen as a result of that choice? Further, information was sought to determine what supports and alternatives are being offered to those who do not have the full cognitive ability to make decisions independently and do not meet the criteria for requiring a full guardian and therefore have their rights restricted. It was also sought to determine if any psychosocial harm was derived from inappropriate guardianship appointment. Currently, New York State guardianship law is black and white. However, the spectrum of developmental disabilities is not, and there are various resources to assist the individuals who it would be detrimental to have a guardian that are not yet legal alternatives.

This study utilized a qualitative phenomenological approach. The phenomenological approach appeared to be the most valid as guardianship decisions are a shared experience of a unique population (Creswell, 2013). Data was gathered using Zoom-based interviews where participants were asked open-ended research questions. After data collection, the recorded audio files were uploaded to Amazon Transcription services and transcribed into text. It was then coded using QDA Miner Lite and reviewed for emerging themes. This study planned to have approximately 10-15 participants and totaled 11 participants. Parents and

other advocates were asked to participate in a qualitative interview. This sample was reached through listservs of parent support groups as this population can be difficult to reach; this also accounts for the sample size. All participants were presented with an informed consent before beginning the interview and were reminded that participation was optional.

Study limitations include having a small sample size, making these results non-generalizable. Further, due to the nature of guardianship law being variable from state to state, this study focused solely on New York State law and only sampled within New York State. Therefore, this will render the results even less generalizable. However, since New York is a large state and the statute is contained to this state alone, the results continue to stand to have an impact.

Background

As per the 2010 census, there are approximately 1.2 million adults with an intellectual disability and 944,000 adults with other developmental disabilities. There are also 1.7 million children living with an intellectual and/or developmental disability (I/DD, or hence forth referred to as developmental disabilities) (Brault, 2012). Prior to the age of 18, like any typically developing child, parents make the decisions for their child. However, those with developmental disabilities may lack decision-making capabilities and will need someone to continue making appropriate decisions for them after they reach adulthood. Despite misconceptions, legally, parents cannot continue to make decisions for their child simply because they have a developmental disability and may lack the capacity to do so for themselves. There is a court process that awards someone guardianship over the person with the developmental disability, should the court find a guardian is necessary.

Currently, guardianship is seemingly very black and white; either you need a guardian, or you do not. However, there are many individuals with I/DD who, would there be another option available would not be so restricted, yet they slip between the cracks and are assigned a full guardian and have their rights removed. Rather, guardianship should be on a spectrum – full guardianship, supported decision-making, or no guardianship. Additionally, more thorough assessments (i.e. functional skills) should be done to see where individuals fall on a skills spectrum and ability to make appropriate decisions as IQ does not always measure accurately or appropriately when it comes to independent living and decision-making.

In New York, while there are two major routes for obtaining guardianship of an individual with an I/DD, the most common, and easiest, route is through the Surrogates Court to obtain Article 17-A Guardianship. Guardianship grew during a time when parents and advocates were looking to deinstitutionalize individuals with I/DD; at that time, guardianship was the only, and best, alternative (Massad & Sales, 1981). The idea for this specific form of guardianship started when parents and advocates of people with I/DD stated the need for a simpler form of the guardianship process; the “assumption being that the [developmentally disabled] were perpetual children, such that the legal powers all parents had over persons under eighteen should simply be extended indefinitely for the parents of the [developmentally disabled]” (Andreasian, et al., 2015, p.288). In response to this, the New York State Legislature signed the Surrogate’s Court Procedure Act, Article 17-A (SCPA17A) into law in 1969 (Andreasian, et al., 2015).

SCPA17A guardianship is specifically for people with I/DD and begins with a petition to the court (“Guardianship of a Person,” n.d.). This can be done with or without a lawyer and all forms can be found online. Any person over the age of 18 can petition the

court; this can be a parent, a social service agency, or any adult. This petition is a written request for the court to appoint a guardian for the individual (“Guardianship Case,” n.d.). Along with the petition, the petitioner must submit certification from a physician and from a psychologist (or two physicians, including a psychiatrist) certifying that the individual has a disability and is “not able to manage his or her affairs because of intellectual disability, developmental disability or a traumatic head injury” (“Guardianship of a Person,” n.d., para. 3). Guardianship under SCPA17A can happen one of three ways: the petitioner can petition for (1) guardianship of the property, (2) guardianship of the person, or (3) guardianship of both the person and the property (“Guardianship of a Person,” n.d.). As the New York Court system describes it “Article 17-A Guardianship is very broad and covers most decisions that are usually made by a parent for a child, such as financial and healthcare decisions” (“Guardianship of a Person,” n.d., para. 4). Following a submission of a petition, there will be a court hearing where the petitioners will present evidence of why they believe guardianship is necessary. If a guardian is appointed, the judge will issue papers outlining the specifics of what a guardian can do, these are called letters of guardianship (“Guardianship Case,” n.d.).

The New York State guardianship statute is relatively simplistic and has been unchanged for several decades. Due to this, it can be considered antiquated as the disabilities field is constantly changing. The purpose of this study is to make recommendations to the standard practice based on interviews of those who have made guardianship decisions for people with I/DD. Advocates are the best source of information, aside from those subject to guardianship, as they make the decision regarding what path of guardianship to choose.

Relevance to the field of social work

One of the ethical concerns in guardianship is the lack of autonomy and self-determination offered to the individual during the guardianship process and that continues even once they have a guardian. Guardianship is plenary, and once a guardian is placed, the individual no longer has any decision-making rights over any facet of their life. Social workers place a high value on self-determination; the NASW Code of Ethics (2017) states that we should work to promote a client's right to self-determination; we should support the client in identifying their own goals and assist them in achieving them. That said, a social worker should also use professional judgment when limiting self-determination when a client is putting themselves or others in harm (NASW, 2017). Practitioners are potentially put in an ethical conundrum when the topic of guardianship comes up; they both want to advocate for the autonomy of the individual but ensure their safety as well (Campigotto & Hilburn, 2016). When this is the case, it is the practitioner's duty to explore all support options available, SCPA17A and Article 81 included, to determine what is in the best interests of the client.

Social workers also value the dignity and worth of the person. This fits into supporting the client's right to self-determination; a social worker should support the client in "enhancing their capacity" (NASW, 2017, Ethical Principles Section, para. 4) and supporting them in identifying and addressing their own needs (NASW, 2017). McManus (2006) makes a valid point in stating that, "autonomy and independence do not grow out of being told what to do and when to do it. It is only by having his needs considered, by becoming a participant in the decision-making process, that a [person] develops the capacity for autonomy" (p. 591). McManus (2006) suggests a system called therapeutic-jurisprudence (TJ), a psycho-social-legal theory. In this system, a person with more mild limitations is included in the decision-making process. Through this involvement, they obtain a feeling of control and satisfaction

with their choices. They also have both the negative and positive consequences of their choices. Additionally, the individual is more likely to comply with the decision when included in the decision-making process; the idea here being to minimize the anticipated negative therapeutic consequences attached to guardianship and the decision-making control it comes with (McManus, 2006). Understanding the differences in functioning levels of I/DD individuals is key in developing the right type of support for them; however, SCPA17A does not take this into consideration and, if the individual has any limitations to the court's standards, a guardian will be assigned (Monthie, 2016).

As advocates for this population, we should be aware of alternatives to guardianship as well as of the current practices. We must be able to appropriately advocate for our clients and be knowledgeable of options across the field. This question is of particular interest as social workers are often not a part of this process, nor do we give any type of written statement as to our clients' ability to make decisions when the case does go to court. However, we are there to deal with the potential fallout should the individual have a negative reaction to losing their decision-making capability. We have the ability to work with individuals and families before a guardianship hearing and to advocate for alternatives to guardianship *before* the potential negative effect can occur. As social workers, we also have the ability to work within the system and with the added knowledge from study, we can advocate for changes to the current statute.

Chapter Two: The Study Problem

The research below shows that legal guardianship can have a detrimental effect on individuals with I/DD and that alternatives to guardianship can bring forward more positive outcomes for the individual (Davidson et al., 2015, Kohn et al., 2013). In New York State, there are various alternatives to guardianship that are in use, some legally binding, and others not. However, that leaves one to question how parents and other advocates choose the particular support path that they do and what mental health outcomes they see as a result of that decision.

While there are two major routes to consider when obtaining guardianship of an individual with an I/DD in New York State, the most common, and easiest, route is through the Surrogates Court to obtain Article 17-A Guardianship. Guardianship grew during a time when parents and advocates were looking to deinstitutionalize individuals with I/DD. At that time, guardianship was the only, and best option to maintain decision-making control for a person with a perceived limited capacity (Massad & Sales, 1981). The idea for this specific form of guardianship started when parents and advocates of people with I/DD stated the need for a simpler form of the guardianship process; the "assumption being that the [developmentally disabled] were perpetual children, such that the legal powers all parents had over persons under eighteen should simply be extended indefinitely for the parents of the [developmentally disabled]" (Andreasian, et al., 2015, p.288). In response to this, the New York State Legislature signed the Surrogate's Court Procedure Act, Article 17-A (SCPA17A), into law in 1969.

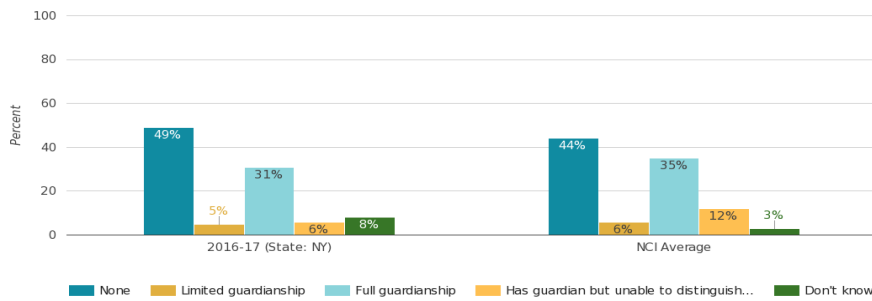
Guardianship under SCPA17A can be granted in one of three ways: the advocate can petition for (1) guardianship of the property, (2) guardianship of the person, or (3) guardianship of both the person and the property. Guardianship of both the person and the property is most common, shown by the data in Figure 1 (NCI, 2017). The reason for this being that it is plenary, or all-encompassing (A. Cohen, personal communication, Nov., 2017). However, this form of guardianship removes the rights of the individual completely and the guardian is henceforth responsible for all the decision-making. Guardianship is obtained through a court proceeding; the individual can be excused if the advocate argues, and the court deems, that the process would be detrimental to their wellbeing. The individual is often not assigned legal counsel unless the individual objects to the guardian, or the court finds it necessary for someone to speak on the individual's behalf. Either case would result in guardian ad litem being assigned, this is a court-appointed representative who is familiar with the process of guardianship. The guardian ad litem works either on the individual's behalf or the court's, to discover the concerns of the case and then makes recommendations to the court. Following this, a decision is made (A. Cohen, personal communication, Nov., 2017).

Figure 1 is from the National Core Indicators, a primarily state-funded research group aimed at looking at performance and outcome measures of people with I/DD across the United States (38/50 States participate) and is used to improve services and supports (NCI, 2017). The below table shows the percentages of the total types of guardianships in New York State and the average nationally between 2016 and 2017 (NCI, 2017). In New York, 49 percent of people have no guardian, 5 percent have limited guardianship, 31 percent have full guardianship, 6 percent have a guardian, but are not able to distinguish between limited and full, and 8 percent are not sure if they have a guardian or not. Nationally, those who have full

guardianship are at 35 percent, which is slightly higher than New York as well as 12 percent for those unable to distinguish the type (NCI, 2017). This data shows that, of those who have a guardian, full guardianship is the most common route, both in New York and nationally.

Figure 2 shows that, compared to Figure 1, rates of guardianship have gone up significantly, even between 2015-16 and 2016-17 (National Council on Disability, 2019).

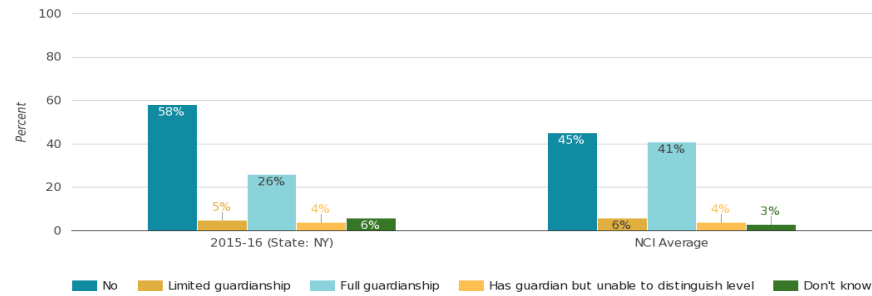
Figure 1.
Guardianship



Total Respondents: 530
State(s): NY

Additional Info:
Total Number of Respondents = 530
National Core Indicators. Chart Generator 2016-17. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved on 02/01/2020 from the National Core Indicators Website: <http://www.nationalcoreindicators.org/charts/>.

Figure 2.
Guardianship



Total Respondents: 495
State(s): NY

Additional Info:
Total Number of Respondents = 495
National Core Indicators. Chart Generator 2015-16. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved on 02/01/2020 from the National Core Indicators Website: <http://www.nationalcoreindicators.org/charts/>.

Figure 2, from the National Core Indicators (NCI, 2016) shows the percentages of the total types of guardianships in New York State and the average Nationally between 2015 and 2016 (NCI, 2016). These numbers show a sharp jump in the percentage of full guardianship cases from 26 percent in 2016 to 31 percent in 2017 in New York State while the national average decreased from 41 percent in 2016 to 35 percent in 2017 (NCI, 2016, NCI, 2017).

While changes were made to SCPA17A in 1989 to include developmental disabilities other than mental retardation, further proposed changes were suggested in the early 1990s as the field of I/DD was changing and the treatment and rights on these individuals were being taken into consideration (post-Willowbrook, etc.). Out of these propositions came Article 81 Guardianship (under Mental Health Law (Article 81)), and little change has been made to SCPA17A Guardianship as of 2018 (Andreasian, et al., 2015). (It should be noted that the law still uses the terminology "mental retardation" when intellectual and/or developmental disability is the common verbiage (Bailly & Nick-Torok, 2011).) A continuing issue between the separation of SCPA17A and Article 81 is that SCPA17A is "diagnosis driven" as it is only for people with developmental disabilities. Since Article 81 is for individuals with developmental disabilities, the aged, and those with mental health issues, it focuses more on their functional limitations (Campigotto & Hilburn, 2016). Table 1 breaks down the differences between the two statutes.

Table 1.
Differences Between the Two Statutes

	Article 17A	Article 81
What Guardianship Covers	Provides guardianship of the person, the property, or both.	The court decides what decisions will be made by the guardian and which by the individual through a court evaluation; guardianship is tailored and individualized.
Court Protection for the Individual	Will provide a guardian ad litem if the individual requests one, disagrees with guardianship, or at the court's discretion.	Judge will automatically appoint a court evaluator.
Court Check-Ins	No check in after guardianship awarded.	Yearly check-ins with the court.
Certifications required	Requires one evaluation from a physician and one from a psychologist (or two physicians).	The evaluator meets with the individual and does an investigation as to whether guardianship should be awarded or not. They write a report and discuss what powers the guardian should have.
Designed for	People with intellectual disabilities, developmental disabilities, or those with a traumatic brain injury.	People defined as an incapacitated Person (i.e. a person with an intellectual disability, developmental disabilities, mental illness, or dementia, etc.)

(Guardianship of an Incapacitated, n.d. and Guardianship of a Person, n.d.)

Article 81 guardianship tends to be a more complex and time-intensive process. It also becomes more difficult for the guardian to make decisions on the individual's behalf without court support; due to this, many guardianship petitioners will go the 'easier' route and use the Surrogates Court for SCPA17A guardianship. Article 81 guardianship is more customizable and is tailored to the needs of the individual, which are determined by a court evaluator. This evaluator meets with the individual and determines whether a guardian

should be appointed, and if so, what decisions they are responsible for ("Guardianship of an Incapacitated," n.d.). Despite its all-encompassing nature, SCPA17A guardianship continues to be the most used route for guardianship proceedings. As the field of I/DD continues to develop and grow, so does the need for a change in the proceedings of guardianship. Some have spoken out for the need to merge the two Articles of guardianship, but advocates for people with developmental disabilities continue to champion the need for a separation between Article 17A and Article 81 guardianship. Advocates of SCPA17A guardianship cite the fact that people with varying degrees of disabilities need different levels of support, the lower costs of the proceeding, and the ease of the proceedings as defining factors for the continued need for a separation of the two different court proceedings. Additionally, there was also an eight-year lag between the addition of end-of-life decision-making capabilities for the guardian (first given to people with SCPA17A guardianship and then Article 81), which was an extra incentive to pursue SCPA17A guardianship during that time (Bailly & Nick-Torok, 2011). Despite the call for change through the years, there has been no change to the statute or alternatives to guardianship given legal standing.

Why This Matters

At the time the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (2000) was passed, there were somewhere between 3,200,000 and 4,500,000 individuals with developmental disabilities in the United States alone. Studies at that time were showing that individuals with developmental disabilities comprised between 1.2 and 1.65 percent of the United States population (Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000). This still held true at the time of the most recent Diagnostics and Statistical Manual of Mental Disorders (DSM) publication in 2013 where it was stated

that intellectual disability has a population prevalence of 1% and rates vary by age. Severe intellectual disability is approximately 6 in 1000 of those diagnosed. Rates of comorbidity with mental, neurodevelopmental, medical, and physical conditions are three to four times higher than the general population (APA, 2013).

Table 2.
Definitions of Key Constructs within guardianship of people with developmental disabilities

Term/Key Concept	Author(s)	Definition
Advocate Role	Barker, 1999	“Speaking out on behalf of the client to achieve changes in the conditions that contribute to the client’s problems and securing and protecting a client’s existing right or entitlement” (p. 11).
Autonomy	Lee, 2011	The freedom to make decisions for one’s self.
Best Interests	Menikoff, 2001	Deciding for a person with regard to what one believes is in the best interests of the person. This is typically a judge or an appointed decision-maker (in this case, a guardian) (p. 294).
Capacity	Millar, 2014	Has definitions in both clinical and legal settings. When referred to in the legal field, often refers to the mental health status of a person and their ability to make decisions on their own behalf or perform certain functions. A lack of capacity is critical evidence in a guardianship hearing.
Cognitive Ability	APA, n.d.	Level of functioning in the following areas: learning, memory, understanding, awareness, reasoning, judgment, intuition, and language.
Developmental Disability	Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000	A chronic disability caused by a mental or physical impairment, or a combination of the two diagnosed prior to the age of 22 that causes an impairment in three or more of the following areas (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, (7) economic self-sufficiency, and (8) a proved need for ongoing special supports and services that are individually planned and coordinated for the duration of their life.

Table 2. Continued

Term/Key Concept	Author(s)	Definition
Individualized Supports	Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000	Supports in place that enable the individual to be independent, productive, fully integrated, exercise self-determination, and be included in all aspects of the community. These supports are designed to provide the individual with the most independent life possible. They promote the least restrictive settings and allow the individual to work, learn, and live in the community. This includes a wide array of services and assistive technology.
Integration	Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000	Individuals have the same access to and ability to use the same community resources as those without disabilities.
Intellectual Disability	APA, 2013	Characterized as a disorder that has its onset during the developmental period (prior to the age of 18) that includes deficits in both intellectual and adaptive skills through conceptual, social, and practical areas. There are deficits in reasoning, problem-solving, judgement, and abstract thinking, etc. this is not necessarily defined by IQ scores, rather on adaptive functioning. Ranges from mild, moderate, severe, and profound.
Plenary	(A. Cohen, personal communication, Nov., 2017).	Full or total. In this context, guardianship over both the person and property.
Self-determination	Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000	Activities where the individual, with appropriate assistance, is (A) given the opportunity to make personal decisions, (B) given the opportunity to exercise control of the type and level of service, supports, and assistance they receive, (C) given control to obtain new or additional services, supports, and assistance, (D) provided “opportunities to participate in and contribute to their community,” and (E) is able to advocate for themselves financially, develop leadership skills, attend self-advocacy and other training, and participate in policy-making that affects individuals with developmental disabilities.

Table 2. Continued

Term/Key Concept	Author(s)	Definition
Substituted Judgment	Menikoff, 2001	Making a decision on behalf of a person when their wishes are known or can be determined and agreed upon by those that know them well but cannot be expressed at this time by the individual.

Unfortunately, many rights are removed from the individuals without explicitly being given to the guardian during the Article 17A guardianship court proceedings. This can include the right to marry, vote, drive, become and remain employed, sign contracts, sue in court, apply for government benefits, decide where to live, and decide whom to associate with (i.e. who to be friends with). Other rights that are explicitly given to the guardian include managing money and property and consenting to medical treatment. Other rights, which can be given to the guardian under specific court ruling include commitment to a treatment facility or institution, consenting to research, filing for divorce, consenting to the termination of parental rights, and consenting to sterilization or abortion (National Council on Disability, 2019).

The removal of rights to this extent is why guardianship is often lauded as a “civil death” as the person loses autonomy in areas related to their person (Shea & Pressman, 2018). With a guardian, the individual is “no longer permitted to participate in society without mediation through the actions of another if at all” (Dinerstein, 2012, p. 9). Further, guardianship is subject to the Americans with Disabilities Act (ADA). This is interpreted through the U.S. Supreme Court 1999 Olmstead Decision, which finds that individuals with disabilities must be provided with the least restrictive options to meet their needs in all areas of their lives (National Council on Disability, 2019). Justice Ginsburg held that isolating individuals would fundamentally change the nature of their services and therefore individuals

cannot be unjustly isolated. The plaintiffs in this case were discriminated against on the basis of their disability and were subject to institutionalization because of it, and not on the recommendation of their physicians. Due to the outcome of this case, states are now mandated to provide reasonable modifications for community living, typically referred to as the least restricted setting, which state programs currently provide through Medicaid (Olmstead v. L.C., 1999). Later interpretation comes out of “least restricted” in that individuals should be offered the least restricted option in all matters, when feasible. If the guardianship system is not considering less restrictive alternatives, such as supported decision-making or proxy decision-making, one can argue that they are violating the ADA and the Olmstead community integration mandate (National Council on Disability, 2019).

Further issue is found in states that have separate guardianship statutes for people with IDD; the current focus is on California, Connecticut, Idaho, Michigan, and New York. The National Council on Disability (2019) finds New York’s statute one of the “most striking” as they have two completely separate systems for guardianship, Article 17-A of the Surrogate Court’s Procedure Act, where guardian assignment is diagnosis driven and not functionality. The procedural requirements are also much less stringent than the other guardianship system, Article 81 of the Mental Health Hygiene Law. Often, the individual is not present in court, decisions are based on Best Interest standards rather than Substituted Judgment for decision-making on behalf of the individual and the guardianship cannot be limited in scope of capability (National Council on Disability, 2019). Substituted judgment is the preferred method in health care decision-making when the patient is unable to make decisions for themselves (i.e. in a vegetative state) as the patient has either previously expressed their wishes or their wishes are determinable by those who know them well.

However, the best interest model is used for guardianship, where the replacement decision-maker now makes all decisions in the assumed best interests of the individual (Menikoff, 2001); no determination has been made if a best interests of substituted judgment model should be used, i.e. to consult in the individual on their preferred outcome for decisions before making a choice on their behalf. In most other states, the guardian is given limited control, but in New York, the guardian is able to make “any and all health care decisions” (National Council on Disability, 2019, p.37).

A 2015 report from the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association found that the two separate New York guardianship statutes “discriminate against persons with intellectual and developmental disabilities, denies procedural and substantive due process to those for whom guardianship is sought, and over whom guardianship is imposed, fails to honor or promote autonomy, self-determination and dignity, and fails to protect persons under guardianship from abuse, neglect and exploitation” (Andreasian et al., 2015, p. 335). Adding to this, the Olmstead Cabinet, a New York State Cabinet created in 2012 to uphold the mandates of the Olmstead Act, came to similar findings and recommended guardianship reform to be more consistent with the Americans with Disabilities Act stating that,

“The Olmstead Cabinet also recommends reform to law governing guardianship over people with developmental disabilities. Community integration includes the ability of people with disabilities to make their own choices to the maximum extent possible. Guardianship removes the legal decision-making authority of an individual with a disability and should, consistent with Olmstead, only be imposed if necessary and in the least restrictive manner” (The Olmstead Cabinet, 2013, p. 27).

The Olmstead Cabinet goes further stating,

“Once guardianship is granted, Article 17A instructs the guardian to make decisions based upon the “best interests” of the person with a disability and does not require the guardian to examine the choice and preference of the person with a disability. In

contrast, Article 81 imposes guardianship based upon a functional analysis of a person's disability, requires a hearing, requires the presence of the person over whom guardianship is sought at the hearing, requires guardianship to be tailored to the person's functional incapacities, and requires the guardian to consider the person's choice and preference in making decisions. The Olmstead Cabinet recommends that Article 17A be modernized in light of the Olmstead mandate to mirror the more recent Article 81 with respect to appointment, hearings, functional capacity, and consideration of choice and preference in decision making" ((The Olmstead Cabinet, 2013, p.28).

To date, these recommended changes to modernize SCPA17A to be tailored to the functional limitations of the individual and not based on their disability have not been made.

Best Interests at Heart

In the matter of guardianship, the best interest of the individual can be called into question. That said, some legal scholars and advocates think that since the parent is typically the guardian and they can name their successor (alternate guardian), it is believed that the best interests of the individual are often well taken care of (Bailly & Nick-Torok, 2011). Bailly & Nick-Torok (2011) state that this process often provides parents with the "peace of mind" that someone they trust is taking care of their child for the rest of their lives. While this provides the parent peace of mind, it is unclear if the alternate guardian is someone who understands how to work with the individual, understands how they like their choices made or to include them, or will continue to act in the best interest of the individual once the parents are no longer able to provide care.

What about when a corporation or a non-parent is the primary guardian? In fact, any interested party over the age of 18 can apply to be a guardian, including an Office of People with Developmental Disabilities¹ (OPWDD) certified non-profit agency (Bailly & Nick-Torok, 2011). Outside of people, corporations serving as a non-profit and designated by the

¹ New York State office overseeing I/DD services and provider agencies

state to serve as a guardian can apply for guardianship of an individual (Surrogate's Court Procedure Act, 1969). Further, public organizations and banks can be guardians as well if deemed appropriate by the court (NAMI, n.d.).

These procedures lead one to question if these people have the same best interest in mind that a parent would. Even more noteworthy, the parents (or primary guardian(s)) are not reevaluated at any point to ensure they continue to act in the best interest of the individual. Bailly & Nick-Torok (2011) state that "the lack of standards can also present difficulties in determining whether a guardian's decisions are appropriate and in the best interest of the individual" (p. 824). SCPA17A lays out no standards about how any guardian (parent, alternate, corporation, etc.) should conduct themselves (Bailly & Nick-Torok, 2011). Additionally, there is no burden of proof required on behalf of the applicant to determine if they are acting in the best interests of the individual. Once awarded, a guardian remains in place permanently or until they are terminated by the court (Bailly & Nick-Torok, 2011). These are some of the many reasons why, in the matter of SCPA17A, periodic monitoring would be beneficial. Guardianship can also be extremely difficult to reverse (Andreasian, et al., 2015). With special care taken before placing a guardian, it is less likely that reversal will need to take place. However, with periodic monitoring, guardianship should become less restrictive and continue only so long as it suites the individual.

California sets a prime example of periodic monitoring. After guardianship is awarded, the court reevaluates the need for a guardian. This reevaluation occurs six months' post-appointment, one-year post-appointment, and annually after that to determine if amendments to the guardianship need to be made or if the guardianship needs to be terminated altogether (Andreasian, et al., 2015). In Michigan, guardianship is only awarded

in five-year intervals and the interested party must continue to reapply as needed; the person with the disability is also assigned counsel which is paid for by the state (Andreasian, et al., 2015). As these are persons with developmental disabilities, whose abilities are generally either progressing or regressing, it seems wise that guardianship is reevaluated to ensure that the individual is being met with the least restrictive care and the best support available.

Guardianship's Violations of Civil Liberties

As shown in the court cases outlined below, the constitutionality of SCPA17A is questioned on various occasions, usually based on due process. During the guardianship process, the individual is not offered nor given counsel, and can even be excused from the hearing; this is all before they are assigned a guardian and potentially stripped of their rights. However, when included in the hearing, the judge will explain what a guardian is and will ask the individual if they want a guardian (A. Cohen, personal communication, Nov., 2017). This is when the individual has an opportunity to object to a guardian and be assigned a guardian ad litem (A. Cohen, personal communication, Nov., 2017). This is an important opportunity for the individual to be included in the decision-making process that they are often excluded from.

As found in the Matter of Zhuo and the Matter of Leon, counsel could be provided free of charge when requested, as the deprivation of liberty is at stake. The right to counsel is a constitutional mandate, but is not provided for the individual at the onset of the guardianship hearing (Bailly & Nick-Torok, 2011). Should the individual have issues with the hearing or appointment of the guardian, they will often be assigned a guardian ad litem; however, this is not legal representation for the individual (A. Cohen, personal communication, Nov., 2017).

Monthie (2016) states that SCPA17A violates the Fifth and Fourteenth Amendments to the U.S. Constitution as the "termination of all decision-making rights" violate due process. In the guardianship case of Mark C.H., the court decided that guardianship was unconstitutional under due process, as an individual is deprived of liberty, as a guardian, under SCPA17A, does not have to make regular reports to the court on the care the individual is receiving. To rectify this, the court decided that Mark C.H. would be appointed a guardian under SCPA17A, but that the guardian would have to report to the court on an annual basis such as in Article 81 guardianship (Bailly & Nick-Torok, 2011). Furthermore, there have been various legal authorities who question the constitutionality of SCPA17A guardianship based on its violation of liberty, equal protection, as well as the overall restriction of rights.

Life, Liberty, and the Pursuit of Happiness

Monthie (2016) cites guardianship as an infringement on liberty, both in regard to the person and property, as it gives the guardianship control over decision-making for both the person and the property (when seeking total guardianship). The issues of due process and liberty are brought up in the Surrogate's Court in the Matter of Mark C.H. (2010). The court plainly states that the individual, when given a guardian, loses the ability to make medical decisions, to decide where to live, whom to associate with, if and when they can travel, if and where they can work, what programs to be enrolled in, if and whom they can marry, etc. The guardian imposes "virtually complete power over the ward, clearly and dramatically infringing on the ward's liberty interests" ("In the Matter of," 2010, p. 6). The court, in this case, cites a Supreme Court case where due process and liberty are defined; the constitution protects from the right to be restrained, but also "the right of the individual to contract, to

engage in any of the common occupations of life, to acquire useful knowledge, to marry, to establish a home and bring up children...and generally to enjoy those privileges long recognized at common law essential to the orderly pursuit of happiness by free men" (Meyer v. Nebraska, 1923 & Monthie, 2016 p. 691). In short, the constitution protects the liberty to pursue the things for typical people that guardianship takes away from individuals with I/DD.

Equal Protection

Monthie (2016) and McManus (2006) clearly outline the disparities between Article 81 guardianship and SCPA17A guardianship. Under Article 81, the court assesses the individual for the specific limitations and tailors the guardianship to ensure any "deprivation of rights and liberties" (Monthie, 2016 p. 948) are based on their limitations and not their general disability diagnosis. Additionally, under Article 81, the individual is granted an attorney during the process and is covered by other "procedural protections" that simply do not exist for the individual under SCPA17A (Monthie, 2016 p. 949). Contrastingly, under SCPA17A, the justification for a guardian is based on the diagnosis label, "uncontested medical certifications," the individual is not provided with counsel, and the individual is often not present during the hearing (Monthie, 2016 p. 949). In SCPA17A, guardianship is all-encompassing, regardless of the different levels of need from one individual to another. So long as they would benefit from a guardian on some level, they are given a guardian over some part of their life (Monthie, 2016).

Alternatively, when an Article 81 case is proceeding, the individual is always notified of the hearing and is informed that they can retain a lawyer if they would like. Additionally, the lawyer will be paid for if the individual cannot afford it. The court will also appoint a person to explain the court proceedings and what a guardian is to the individual during

Article 81 proceedings. Under SCPA17A, notice of the hearing is not legally required (Monthie, 2016), although some counties do provide notice (A. Cohen, personal communication, Nov., 2017). Interestingly, any notification that is sent out does not have to be formatted to ensure that the individual can cognitively understand it (Monthie, 2016). It is worthwhile to note that, while legal representation can be appointed in a SCPA17A proceeding, it is not offered at the onset and only given should the individual have objections to having a guardian or the court finds an issue with proceedings itself (A. Cohen, personal communication, Nov., 2017).

Bailly and Nick-Torok (2011) discuss the guardianship case of Derek, which focuses on the matter of patient-physician privilege; again, under the protection of due process. The SCPA17A guardianship application requires two affidavits, one from a treating physician and the second from a licensed psychologist who has examined the individual or from another treating physician. In the Matter of Derek, the court ruled that equal protection should be given under SCPA17A and Article 81 to give the protection of due process. The court stated that it is "arbitrary" that the individual can claim physician-patient privilege in one proceeding (Article 81) and not the other (SCPA17A) (Bailly & Nick-Torok, 2011).

McManus (2006) depicts why further exploration into the disability and the unique limitations of the individual should be explored during the SCPA17A hearing like they are in Article 81: "...because mere labels of diagnoses of mental disability do not necessarily provide meaningful information about an individual's ability to function autonomously" (McManus, 2006 p. 608). All individuals are different and therefore all forms of guardianship placed over the individual should be tailored to their specific level of needs.

Case One: Guardian for Michelle M.

A case referenced by the National Resource Center for Supported Decision-Making, *In the Matter of Michelle* focuses on alternatives to guardianship that parents can seek when a guardian is not warranted. In the matter of Michelle, both of her parents, together, petitioned the Surrogate's Court for guardianship. Michelle is described as a lively 34-year-old woman who lives in a supportive apartment in Brooklyn with two roommates. Michelle is diagnosed with Down Syndrome and an intellectual disability. Michelle reportedly "takes pride" in her cooking skills and enjoys going out into the community to go shopping. She has also held steady employment in the past. Michelle sees her doctors as needed, goes to the bank, keeps track of her money, travels, and manages her own medication. The court report states that Michelle regularly makes decisions about her employment, finances, health, relationships, safety, and living situation ("Guardian for Michelle M.," 2016).

The petitioners, while acknowledging Michelle's level of independence, state that she is unable to make medical decisions and "other decisions relating to her welfare" ("Guardian for Michelle M.," 2016 p. 1). Michelle, represented by Mental Hygiene Legal Services (MHLS), presented oral testimony during the hearing (her parents, the petitioners, were also represented by counsel). In addition to the testimony, the following paperwork was also presented: a certification from a treating physician, a certification from a psychologist, and Michelle's Individualized Service Plans (ISPs) from her Medicaid Service Coordination agency from 2012, 2013, and 2014. Michelle's Full-Scale IQ, as per the Stanford-Binet Intelligence Scale, was scored at 46, and her Vineland Adaptive Behavior Composite Standard Score was 33, both in the moderate range. The certifiers both stated that Michelle lacked the capacity to manage her day-to-day decisions and affairs due to her diagnosis and that she was incapable of "understanding and appreciating" the repercussion of her decisions,

specifically those related to health care (“Guardian for Michelle M.,” 2016). The MHLS testified that the petitioners are active in Michelle’s life and she consults with them on various decisions and that they would be appropriate guardians if the court felt a guardian was needed. However, she also testified that there were less restrictive options available to Michelle that would both protect Michelle and her family’s interest as well as provide Michelle with continued independence and autonomy; the court agreed (“Guardian for Michelle M.,” 2016).

The court stated that guardianship should not be awarded simply because a person is diagnosed with a developmental disability or has an intellectual disability; having a guardian should be in their best interests and be the least restrictive option. The court cited past decisions remarking that SCPA17A guardianship could not be tailored as Article 81 guardianship could be. SCPA17A is plenary and would give too much control to the guardians; this form of guardianship removes all decision-making rights on behalf of the individual and gives them to the guardian. The court stated that SCPA17A guardianship is the “most restrictive type of guardianship available under New York law” (“Guardian for Michelle M.,” 2016 p. 2).

The court determined that guardianship for Michelle would not be in her best interests, that it would limit her autonomy, and that it would be too restrictive to be awarded. The court stated that the petitioners had failed to prove Michelle was incapable of making her own decisions and that, like any typical person, Michelle had found a way to make her own decisions with support from those around her, including the petitioners. The court recommended alternatives to guardianship be explored, such as durable power of attorney

and health care proxy, but ruled that Michelle did not need a legal guardian under SCPA17A and dismissed the petition (“Guardian for Michelle M.,” 2016).

This case was one of the first guardianship cases in New York where alternatives to guardianship could and would be recommended by the court. This case is referenced to in various other New York Guardianship court cases. Case two further outlines when the court takes matters into its own hands.

Case Two: The Matter of Mark C.H.

The matter of Mark opens with the court questioning if SCPA17A meets "the constitutional standards in the absence of a requirement of periodic reporting and review" ("In the Matter of," 2010, p. 1). Mark and his brother were adopted when Mark was just five days old, and Mark was later diagnosed with Autism. Later, when his mother was diagnosed with cancer, Mark was placed in a residential facility; at the age of 14, Mark moved into a center for Autism. His mother subsequently passed away two years later, and Mark was left a sizable trust. Some two years after that, the family attorney, a designee on Mark's trust, petitioned for guardianship of Mark. Through the recommendations of his school and health care providers, Mark should not appear at the hearing, as it would be detrimental to his well-being. Mark is diagnosed with Autism, developmental delays, mental retardation, and a seizure disorder. Mark also displayed aggressive behavior towards himself and others, especially when in an unfamiliar situation. The initial hearing included the petitioner and the local Mental Health Legal Services attorney. The court revealed that the petitioner, Mark's mother's lawyer, who made a deathbed promise to the mother, had never been to visit Mark, had never been in touch with the facility regarding Mark's wellbeing or needs, and that none of the \$3 million trust has been spent on Mark's needs "despite the clear intention" that this is

what the trust was meant for. The lawyer was also a co-trustee with a bank ("In the Matter of," 2010, p. 2).

In response to the court's findings, a second hearing was scheduled. The court assigned Mark a guardian ad litem and requested the corporate trustee (the bank) send a representative to the hearing and to visit Mark, along with the petitioner. The bank pleaded a lack of institutional competence and admitted it had done nothing to follow up on Mark's needs. The guardian ad litem was assigned to ascertain if the residential school or Medicaid were aware of the trust. The trustees found a care manager to assess Mark's needs and she discovered several areas of Mark's life where the trust could be put to use. Through this court intervention and subsequent evaluations, the care manager was retained long-term and Mark was provided with the services and items that were identified and would "likely improve his quality of life" ("In the Matter of," 2010 p. 2). The court went on to state that, despite being left a sizeable trust, Mark lacked resources to "reach his best potential...as significant monies left to care for him increased, unspent in his trust, from which both trustees presumably took their annual commissions" ("In the Matter of," 2010). The court states that this demonstrates why a statute that gives total control over another person's life should include the "provision for period court review" ("In the Matter of," 2010 p. 3).

The court goes on to discuss the need for a review and revision of SCPA17A and reviews the history of the Article as well as how it has remained, largely, unchanged for most of its time. The court raises the issue, made by the present case, that has implications on the constitutionality of SCPA17A as well as having "human rights" implications; there is the absence of a reporting or review of the guardian once they have been established ("In the

Matter of," 2010). The court outlines the following reasons as to why periodic reporting and review are necessary for guardians of people with developmental disabilities:

Frist, the American Bar Association (ABA), in 1989, made recommendations for changes to SCPA17A, including instituting reporting and review of the guardian. They cite one judge stating that a guardian is an agent of the court, therefore, the ABA states that, this is a major reason the court should monitor the guardian, to ensure that the agent is acting properly in the court's name. Second, a person with a developmental disability's needs change over time, and this should be monitored. Third and fourth, the court can support the guardian in their role and gauge the effect of the court order. Lastly, the ABA states that monitoring can improve the court's image and bolster the public's confidence in the court. These recommendations were not fulfilled at the time and, the court, in this case, goes on the state that the pressing need for monitoring has only grown since the ABA has made these recommendations ("In the Matter of," 2010).

The Surrogates Court cites US Supreme Court rulings in which due process is protected for those involuntarily committed to mental hospitals and non-hospitalized mentally ill patients with involuntary treatment orders. In other words, their court orders are subject to periodic review. The court states that guardianship infringes on due process as liberty and property are at issue ("In the Matter of," 2010). The court discussed the definition of liberty as the Supreme Court and Constitution have defined it, as discussed above, but does take note that it cannot define liberty itself.

The court continues to review the process of guardianship in that the court is involved only to the point where the guardian is deemed necessary and, in the individual's, best interests. Beyond this, the guardian can remain in place for decades without the court ever

being involved. However, periodic monitoring will help reevaluate if a guardian is still necessary and if the "deprivation of liberty resulting from guardianship is still justified" ("In the Matter of," 2010, p.7), or if the individual has progressed to the point where a guardian is no longer required. Not monitoring could leave a guardian in place, infringing on liberty, when a person with a disability has progressed in such a manner that they no longer need one "which is a real possibility" ("In the Matter of," 2010 p. 7). Periodic monitoring also ensures that the guardian continues to act in the best interests of the individual, such as in the case of Mark C.H. ("In the Matter of," 2010). In the matter of Mark C.H., the court determined that Mark required a guardian to protect his interests and, since there were no other interested parties, awarded guardianship to the lawyer. In the end, the court required that the lawyer report to the court on an annual basis, providing the same information required by Article 81 guardianship ("In the Matter of," 2010).

Chapter Three: Literature Review

Introduction

People with intellectual and developmental disabilities (I/DD) have long been subject to guardianship mandates. Through these mandates, these individuals lose all or most of their legal rights which in turn can result in negative mental health outcomes. While some individuals benefit from a guardian, there are others that could suffer psychosocial detriment from having their rights and decision-making capability taken away from them. Through the literature, we seek to find out what damage, if any, has been seen, what changes to the system have already been explored, as well as what practices guardianship statutes have in place that creates systems of removing rights. Additionally, several discussions are occurring regarding alternatives to guardianship and how they can best support individuals in making appropriate decisions, but not removing all of their level rights. With the emergence of these alternatives to guardianship, there are now studies and law review articles addressing the efficacy of these practices and how they impact the individual. Guardianship law in the United States differs from state to state with no federal guidelines in place. However, in 2006 the United Nations met to address the legal needs of people with intellectual and developmental disabilities as well as their status in society (Brady et al., 2019, Houseworth et al., 2019, Lee, 2011).

Due to the nature of this subject matter, both social science and legal perspectives were reviewed. Social workers and other advocates for this population should be aware of the

process of guardianship, alternatives to guardianship, as well as the potential negative effects guardianship can have on the individual.

Method

The research below was completed using a Boolean search with the terms “Guardianship” AND “developmental disabilities or intellectual disabilities or mental retardation” AND “impact or effect or influence or outcome or result or consequence.” It was completed using the PsychInfo, Social Work Abstracts, and HeinOnline databases. The inclusion criteria was set to include articles that were peer-reviewed and from the United States, or that included discussion about the United States, as definitions of developmental disabilities would be different across countries, nevertheless the laws. PsychInfo and Social Work Abstracts were selected as a social services resources and HeinOnline as a law and policy resource; this was done in order to have a good balance of information from legal and psychosocial perspectives and frameworks on guardianship for people with developmental disabilities and its influence. Exclusion criteria included articles that were found but did not pertain to people with developmental disabilities, guardianship, and articles that were considered out of date based on their content (i.e. systems and technology referenced in the paper rendered the information contained in the article out of date). Further exclusions included articles that were from other countries and that did not include relevant information to the United States or were specific to a state that was not New York. There was a total of 54 references found; 11 were included. The references included in the selected articles were reviewed for any relevant literature not identified in the database searches.

Results

Throughout this review, several themes emerged across the literature. This includes the current status of guardianship, the school's role, the United Nation's mandates, autonomous decision-making, supported decision-making, familial knowledge of alternatives to guardianship, opposing systems, and changing guardianship before reaching the courts. These themes highlight various issues, knowledge, and alternatives to the current guardianship standards. The following sections will be organized according to these themes.

Zhang et al. (2019) inform us that modern guardianship law in the United States hails from the Task Panel on Legal and Ethical Issues of the President's Commission on Mental Health in 1978. From this panel, the following went into effect regarding guardianship law across the United States; (1) there are various procedural protections for the individuals; (2) there has to be a clearly-defined incompetency related to the individual's functional abilities; (3) the powers of the guardian should be limited to ensure the least restrictive option; and (4) there should be a form of limited guardianship for individuals who are capable of making decisions in some areas of their lives and guardianship is only covering where they are incapable of "acting independently" (Zhang et al., 2019, p.1809)

Kohn and Blumenthal (2014) note that, oftentimes, it is the parents making decisions for the individual, but when they pass away, the decision-making system that had been put in place can become destabilized. This is a reason why people feel the need to petition for guardianship. Guardianship is typically the option when the legal competency of the individual is in question. The areas of competency have been found to be (1) the right to make decisions and have control over one's life, (2) it is understood that not every individual has the capacity to make all decisions in their lives, (3) the basis for a legal system to provide mechanisms for those considered incapacitated is needed, and (4) when someone is

considered legally incapacitated, it justifies and/or obligates the state to intervene so ensure the welfare of the person (Millar, 2014). However, while guardianship has been created to protect those with limited capacity and who are therefore considered vulnerable, it also results in a substantial loss of rights and often does not even “address the issues of concern that prompted a guardianship appointment in the first place and have often appeared to have benefited the guardian more than the [individual]” (Millar, 2014, p.172). Guardianship is also hard to reverse, especially considering the court process it requires and the support an individual would need to navigate this (Houseworth et al., 2019).

How Guardianship Currently Occurs

Many states have made guardianship an easy and “streamlined” (Millar, 2013, p.1116) process. More forms of guardianship are available for people with developmental disabilities than for those with other disabilities and, due to this, there are “less barriers to obtaining guardianship and can also encourage the use of plenary guardianship” (Kohn et al., 2013, p. 1116). Further, some caregivers are encouraged to apply for guardianship so that they can oversee benefits, especially for their children who have reached the age of 18 but are still in school; provisions in the Individuals with Disabilities Education Act (IDEA) recommend to the parents that doing this gives them more control over their child’s public education benefits (Kohn et al., 2013). Millar (2013) goes farther in stating that the IDEA mandates in Section 615 transfer all decision-making rights to the student once they reach the age of majority unless the student is deemed incompetent by state law. Therefore, when incompetence is “in question” (p. 291), the state then has proceedings to assign someone to take over the education responsibilities for the student. It is at this time that guardianship is

raised, especially when the Individualized Education Plan (IEP) meetings are taking place (Millar, 2013).

Often, guardianship is incorporated as a typical part of service planning. Due to this, guardianship is being overused by people who simply do not know that there are less restrictive alternatives available. When guardianship is applied inappropriately, it infringes on the civil rights and civil liberties of the individual. Kohn et al. (2013) state that guardianship should be used as a “last resort, applied only when an individual lacks the capacity to make decisions” (Kohn et al., 2013, p. 1117). However, many believe that guardianship is often applied without “sufficient evidence of their decision-making incapacity” (Kohn et al., 2013, p. 1117). Additionally, the overuse of the plenary status of many guardianship laws across the United States may actually violate the American’s with Disabilities Act (ADA) as individuals are not “provided with reasonable, less restrictive alternatives to guardianship” (Kohn et al., 2013, p. 1119), with the least restrictive option being the goal; and beyond that, are often being treated differently due to their disability. Millar (2013) seconds the need for all less restrictive forms of support to be explored before guardianship is assigned. It should be noted, in many states, there aren’t many legal options other than health care proxy and representative payee. In discussing how the cases proceed in court, Millar (2013) makes an astounding remark, guardianship hearings last about seven minutes and that, almost always, guardians are appointed.

Kohn et al. (2013) feel and fear that simply having a diagnosis of a disability is being used as a justification for awarding guardianship. Zhang et al. (2019) add that society does not view people with disabilities as individuals or able to make their own decisions. Therefore, the system is not set up to support each person as the individual that they are.

Kohn et al. (2013) further state that leaving the individuals out of the decision-making process leaves them feeling isolated and lonely. This can lead to stunted development outside of their already established disability. Additionally, overuse of guardianship can “undermine” (p. 1120) the individual’s psychological health as they now have a lack of control over their own lives. As others put it, this is a “state sanctions removal of personhood” and a “form of civil death” (Kohn et al., 2013, p. 1120). Zhang et al. (2019) remark that guardianship “segregates a person from social economic, and civil life and violates Title II of the Americans with Disabilities Act” (p.1803) which is the Title that requires the most integrated and least restrictive setting and option in any program or service provided by local or state government. Guardianship can also lead to abuse since guardians only need to file paperwork with the courts once a year (Zhang et al. 2019); nevertheless, under SCPA17A, once guardianship is awarded, the guardians never have to follow up with the court again, making the potential for abuse even greater.

Some states and U.S. Territories follow at least some of the guidelines in the proposed Uniform Guardianship and Protective Proceedings Act (UGPPA) created in 1997 and even fewer have enacted the followed up proposed Act from 2017; New York has not enacted either (“*Guardianship and Protective Proceedings Act,*” n.d. & “*Guardianship, Conservatorship, and Other Protective Arrangements Act,*” n.d.). This Act made recommendations related to all aspects of guardianship law; however, there is too much variability in how states determine guardianship. One major area this Act addresses is how competence and capacity are determined (Millar, 2014). The UGPPA defines the need for a guardian being that “the respondent lacks the ability to meet essential requirements for physical health, safety, or self-care because the respondent is unable to receive and evaluate

information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision-making; and (B) the respondent's identified needs cannot be met by a protective arrangement instead of guardianship or other less restrictive alternative" (National Conference of Commissioners on Uniform State Laws, 2018, p. 69). The least restrictive options should be explored if supports can be put in place for that option to be successful. Guardian petitioners, in good faith, should look at the alternatives to guardianship and consider the preferences and values of the individual before a determination of guardianship is made. Further, advocates argue that everything possible should be done to "negate the need" for a guardian (Millar, 2014, p. 178).

Advocates in several states requested assessments determining daily living skills, which include decision-making capabilities, be continued through the guardianship term as part of an annual review. It is important to remember why guardians are needed, for both the elderly and those with developmental disabilities, it is usually due to how much support they require in various areas including living safely at home, managing money, and tending to their medical and health care. Notably, daily living skill assessments are typically not performed as part of the guardianship process and when they are, are "vague and subjective" and include wording like "is incapable of taking care of himself" (Millar, 2014, p. 179).

When guardianship is being considered, it is important to not only consider the individual's disability, but also their social support and the environmental factors. Their own personal attributes and skills should also be considered during this assessment (Millar, 2014). Currently, only psychiatric and/or clinical assessments are being used during this assessment period and do not usually address capacity and competence. Therefore, it would be wiser to use testing that assesses functional abilities and behaviors (Millar, 2014).

The School's Role in Guardianship

Approximately 10 million school-aged students were identified as having an intellectual disability between the years 2006 and 2008. At least one in six students were found to have autism, a cognitive impairment, a traumatic brain injury, or another developmental disability and this number is only on target to increase (Millar, 2014b). Too often, guardianship is being planned in school during transition planning, when an individual is still developing. School assessments play a large role in the guardianship process. During transition assessments, students' decisions on the determination of guardianship are not always taken into consideration as they should be. While they cannot always be followed, it is important to consider the values, vision, and preferences of the individual, especially when looking at their capacity and if an alternative to guardianship can be of use (Millar, 2014).

The Individuals with Disabilities Education Improvements Act of 2004 (IDEA) is the mandate behind transition planning services. The transition process must begin at age 16, but can begin earlier if needed, for those receiving special education services. The idea behind this planning is to identify the next steps for the individual after school. This can range from college to employment to day habilitation services as well as to various living arrangements. This planning is based on the needs of the student while also considering their strengths and interests. When the student reaches the age of majority, which in New York is 18, IDEA mandates that the rights be given to the student i.e. the student now maintains all decision-making control. This happens regardless of the nature and severity of the disability. Due to this, the question of guardianship is often raised at these transition meetings, so the rights never transfer to the student and remain with the parent (Millar, 2014b).

Millar (2014) makes an interesting point in that we give students opportunities to try, fail, or succeed, and therefore learn in school, work, and home settings. With that in mind, we should do the same with alternatives to guardianship. As part of the transition and planning process, the individual and their families should try alternatives to guardianship and determine if any of them can suit the individual before accepting full guardianship as the only option (Millar, 2014).

United Nations Convention on the Rights of Persons with Disabilities

In 2006, The United Nations presented a human rights treaty called the Convention on the Rights of Persons with Disabilities (CRPD) (Brady et al., 2019, Houseworth et al., 2019, Lee, 2011). The CRPD met and drafted a document that focuses on policies regarding people with disabilities around the world. They also focus on the inclusion and independence of individuals with I/DD in society. It was adopted by the United Nations in 2006 and ratified by 167 countries to date, not including the United States as the “CRPD delineates legal rights beyond current U.S. law to ensure more complete civil and political rights, adding the important realms of economic, social, and cultural rights” (Houseworth et al., 2019, p.2). At this convention, supported decision-making was discussed as was the need to provide people with disabilities the support they require to make decisions and continue to exercise their legal capacity (Davidson et al. 2015, Lee 2011). This convention also instituted Article 12 which requires that people with disabilities “enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations, 2008, p.10, Zhang et al., 2019, p.1809) and that all signatories have a universal legal capacity, support decision-making being a model for this (Brady et al., 2019).

Article 12 focuses on equal recognition before the law for people with I/DD and includes five subarticles. They affirm that individuals have equal recognition as persons before the law, they should have legal capacity on an equal basis in all aspects of life, and that safeguards should be put in place so the individual can exercise their legal capacity as needed. In the United States, this Article presented an issue as guardianship law deems the person incapable of making decisions and the guardian replaces in the individual in the decision-making role. Many researchers agree that the “intention” of Article 12 is being violated by guardianship and other substituted decision-making mandates in the United States and across the globe (Houseworth et al., 2019, p.2).

Glen (2018) discusses, in her law review article, how Article 12 of the CRPD highlights this new human right, the concept of legal capacity, and how it can be brought into practice in the United States. While Glen (2018) notes that legal capacity is a human right, mental capacity is linked, but different and independent. Therefore, when found incapacitated, it is of mental capacity, not legal capacity. The author ties legal capacity into dignity and value and is key for participation in society, which should never be removed from a person. Mental capacity is related to decision-making skills, which, as guardianship stands, can be removed. Article 12 of the CRPD makes it clear that regardless of the profoundness of the disability, legal capacity should not be removed from a person. As it stands now when a functional assessment of abilities is performed for mental capacity and decision-making skills are removed, that individual’s status before the law is also lowered (Glen, 2018).

To that end, various nations have had different responses to these measures. Some already had policies like ones requested by the CRPD in place and revised them, such as

Canada. While others, such as the United States and Australia, began implementing these models as a result of the CRPD; unfortunately, guardianship law differs from state to state which can make a widespread change difficult (Brady et al., 2019). While the United States signed the treaty, they have yet to ratify it. (Brady et al., 2019; Zhang et al., 2019). The United States continues to have more restrictive guardianship measures in place across the country despite the notion that most states require the least restrictive options to be explored before a guardian is put in place and only “when an individual lacks the capacity to make decisions” (Brady et al., 2019, p. 1079).

In Saskatchewan, the court appoints a co-decision-maker for personal and/or property decisions specifically for individuals who require assistance to make decisions. This person must defer to the individual in decision-making matters so long as a “reasonable person” would have made the same decision and the person would not have a loss “to their estate” (Kohn et al., 2013, p. 1124). Further, “co-decision-makers are explicitly required to maximize the participation of the person they assist in decision with which they are assisting” (Kohn et al., 2013, p. 1124).

In Sweden, a person who serves a role similar to a guardian but acts more as a mentor (roughly translated to “good man”) is appointed by the municipal government. The “good man” does not reflect the legal capacity of the individual. Despite the intentions, the “good man” holds a confusing stature. They are not to act without the consent of the individual and are limited in their scope based on that consent, but can be put in place without that same consent. Further, they can serve their role for an individual who lacks the ability to provide any consent (cognitively) (Kohn et al., 2013).

When it comes to the future of guardianship law following Article 12 mandates, mental and legal capacity need to be separated, as this would protect people lacking mental capacity (Glen, 2018). This would require major changes to legal systems which brings philosophical, legal, and political backlash. Supported decision-making (SDM) has been a positive derivative of the concept of legal capacity. A fear faced is that SDM may become a billable service for provider agencies to market and will therefore fail as a form of maintaining legal capacity for those lacking mental capacity. There have been various pilot projects in the United States, and while New York has had the largest one, SDM continued to not be a legal alternative to guardianship. Supported Decision Making New York's (SDMNY) main focus is to prevent individuals from receiving guardianship if not necessary and to restore rights to individuals currently under guardianship (Glen, 2018).

The American Bar Association has recommended that attorneys consider SDM as an alternative to guardianship. In New York, legislation to amend the guardianship statute has been sitting for a number of years. This new legislation cites Article 12 of the CRPD and the right of legal capacity, which uses a human rights lens when approaching guardianship (Glen, 2018). To date, this legislation has not passed and guardianship law in New York remains unchanged (Glen, 2018). As signatories on the CRPD doctrine, the "antiquated dualistic conceptions of guardianship and autonomy are potentially challenged" (Lee, 2011, p. 396). However, no changes in the law need to be made until, and if, the United States ratifies these mandates. After that, states will need to change their guardianship statutes to comply with the standards that the CRPD set forward (Lee, 2011).

Using the National Core Indicators Adult Consumer Survey (NCI-ACS) Houseworth et al. (2019) did a quantitative study focusing on the extent to which people with I/DD

already exercise their rights specifically those outlined by the CRPD. The researchers further looked to determine the impact of guardianship on the rights of these individuals. The NCI-ACS survey is a project across the United States that measures various outcomes of adults with I/DD, many related to their rights. This survey is either conducted with the individual or with the assistance of a reliable reporter and focuses on their experiences in various areas of life including work, community, health, and their rights. This research aimed to assess if the NCI-ACS study could be a potential measure of rights. This study used secondary data from the 2013-2014 NCI-ACS data collection. 15,525 adults (18 and over) with I/DD from 29 states and one sub-state entity participated with 15,248 responses being calculated. Participants were randomly sampled from individuals receiving some sort of related service i.e. home and community-based services (Houseworth et al., 2019).

Houseworth et al. (2019) hypothesized that individuals who have a guardian do not exercise their rights to the same extent that people without a guardian do. Recent NCI-ACS (2016) data showed that 42% of participants had a legal guardian; the rates varied across the states as policies in each state differ. The researchers found that those with a guardian had lower levels of community employment and/or goals to reach employment. Conversely, this did not hold true for budgetary agency. Overall, the researchers found that those under guardianship had access to fewer rights in some areas, but not others. In addition to lower levels of employment, there were also lower levels of social privacy, or, the ability to “engage in activities alone and with people of the person’s choosing” (Houseworth et al., 2019, p. 9). Overall, people with I/DD show varying levels of access to their rights as outlined by the CRPD depending on the issue. The researchers did find that the NCI-ACS tool was a good indicator of access to rights (Houseworth et al., 2019).

Autonomous Decision-Making

The literature discusses the need for different approaches to guardianship and recognizes that the current model, across the United States and internationally, is outdated. Kohn, Blumenthal, and Campbell (2013) note that advocates for people with developmental disabilities seek to promote self-determination and that employing full guardianship is the opposite of this. Millar (2013) agrees, stating that we seek to ensure autonomy while also striving to protect the individual, going so far as to say guardianship should be used as a “last resort” (Millar, 2013, p. 292). Davidson et al. (2015) further surmise that decision-making is a spectrum spanning from autonomous decision-making to substitute decision-making. Too often, “law, policy, and practice” focus too much on the ends of the spectrum and “approach decision making as if people are either globally capable or incapable” (Davidson et al., 2015, p.61).

Supported Decision-Making

Davidson et al, (2015) and Kohn, et al. (2013) are proponents of supported decision-making, a model that provides a person to support the individual in making their own decisions rather than a court-appointed guardian to make decisions on the individual’s behalf like that of guardianship. As Kohn et al. (2013) put it, this model is supported rather than surrogate decision-making. While Kohn et al. (2013) note that people with developmental disabilities can and do lack certain decision-making capabilities, some are a result of their diagnosis, and others are a result of their social environment. Since they have not been given the chance to develop the skills to make decisions, they now lack this skill. If taught and encouraged to participate in decision-making, the individual may be able to better make decisions. Millar (2013) takes note of the “internal conflict” (p.292) to both protect

individuals and provide autonomy, but ultimately individuals should be allowed to learn from their decisions. Davidson et al. (2015) adds to this stating, “the central question should no longer be ‘does this person have the capacity to make that decision?’ but rather, ‘what supports are needed to ensure that this person can best exercise [their] rights?’” (p.62).

Kohn et al. (2013) and Kohn and Blumenthal (2014) advocate for supported decision-making in place for guardianship for those individuals who are able to make decisions on their own behalf. However, they note that little testing has been done on the efficacy and longevity of this model. This model comes about, in part, from the United Nations Convention on the Rights of Persons with Disabilities and many advocates are calling for the implementation of this model or one like it. In this model, the person with the disability identifies their support(ers) who can either be someone they already have a relationship with, or someone new added to their life for the purpose of support in decision-making, the most commonly cited model being one from British Columbia (Kohn and Blumenthal, 2014). The individual seeks assistance and advice in making decisions as they see fit but retain all decision-making control (Kohn et al., 2013). There is a “minimal capacity requirement to execute a standard Representative Agreement,” which is the agreement in which the individual contracts with the support person regarding their role (Kohn and Blumenthal, 2014, p. S40).

A large negative factor in this model is the potential for abuse, most notably financial abuse and manipulation (Kohn et al. 2013, Kohn and Blumenthal, 2014). There is also the potential for the supporter to influence decisions, but knowingly and unknowingly. Where SDM is now in use, there is no data on rates of abuse or corrupted influence on decision-making (Kohn and Blumenthal, 2014). Millar (2013) makes an interesting point in that

people, regardless of if they have a disability, often seek advice from friends and/or family when facing significant decisions, so why should people with disabilities be denied those same opportunities? Additional issues with this model are the lack of empirical evidence supporting it. Even researchers who spend time discussing it, have no data to back up their support of the model. There is “insufficient information to know whether SDM is achieving its goals or how to develop effective evidence-based SDM practices, but also because it means that policy changes regarding SDM will be made without the benefit that insight from empirical research can provide” (Kohn and Blumenthal, 2014, p. S41). At this time, even the rate of use is unknown, as is the number of people eligible for such an option (Kohn and Blumenthal, 2014).

Davidson et al. (2015), in their literature review, concluded to some potential benefits to society from supported decision-making including a better understanding of the needs and rights of people with disabilities and a more inclusive society. Further, when included in the decision-making process, individuals are less likely to disagree or reject the outcome of the decision; the individual is also less likely to feel “coerced and dissatisfied” and therefore more likely to engage in the deciding result i.e. participate in the service (Davidson et al., 2015, p.62). This model also empowers and engages the person with the disability (Kohn and Blumenthal, 2014, p. S41).

Millar (2013) advocates on behalf of this population stating that those most often working with them, “educators, lawyers, judges, social workers, and other service providers” (p. 302) need to be better educated on the needs of people with I/DD, how to interact with them, and how to advocate for them; Millar (2013) goes a step further to say that this responsibility lies with their “preparation programs” (p. 302). Those working with, and for,

people with I/DD need to be learning about “the nature of disabilities, strategies to prevent stereotypes, laws that address and protect the rights of individuals who have disabilities, the philosophy of inclusion, equal access, and accommodation, and the complex community, state, and federal supports, resources, and services systems” (Millar, 2013, p.302).

Specifically, those involved in the legal side should be aware of alternatives to guardianship.

Zhang et al. (2019) add that “there is a responsibility of organizations and societal institutions to reduce barriers against people with disabilities” (p. 1804).

Regarding the model of supported decision-making, the person providing this support can either be from a “pre-existing relationship” or “may be a new relationship created for the purpose [of providing support]” (Kohn et al., 2013, p. 1121). A secondary format of this is a circle of support or a microboard. These are groups of people who come together and meet on a regular basis, with the individual, with the goal to assist and support the individual in achieving their goals. A circle of support is typically friends and family while a microboard typically consists of non-profit workers. In both cases, “the person with a disability directs its actions” (Kohn et al., 2013, p. 1123).

The biggest drawback of supported decision-making is the fear that individuals will just be subjected to “coercion” from the support person. In the ideal model, supported decision-making would look like “(1) the individual retains legal decision-making authority; (2) the relationship is freely entered into and can be terminated at will; (3) the individual actively participated in decision-making; and (4) decisions made with support are legally enforceable” (Kohn et al., 2013, p.1128). While this is a model, there is no empirical evidence supporting it. With thought, if these guidelines are followed, should the individual feel coerced, they can and should terminate the relationship. This relationship may work

better if the support person is new to the individual and/or not a family member who can easily coerce the individual (Kohn et al., 2013).

Familial Knowledge of Alternatives

Brady et al. (2019) provide a qualitative analysis of 10 participants, the adult siblings of people with developmental disabilities. The authors surveyed the participants on their knowledge and perspective of guardianship and its alternatives. Brady et al. (2019) found that many siblings are on the trajectory to care for their sibling with an I/DD and that existing research has found that they lack information about medical, legal, and financial resources. They have also found that parents often are unaware of alternatives to guardianship and are therefore likely to seek guardianship without first exploring alternatives. With this knowledge, Brady et al. (2019) sought to find out if siblings had a different knowledge base as compared to their parents and what their perspectives were (Brady et al., 2019).

Brady et al. (2019) found older siblings tended to have more knowledge while the younger siblings generally had less as they were not as involved in the process, but could share what their parents had gone through. When asked what guardianship was, the siblings overall shared that it meant that they would be making decisions for their sibling; four of the siblings did note that it would mean making these decisions on a legal basis while another four were unclear in their understanding of guardianship. Other participants were under the impression that the individual had to be living with them in order for guardianship to be in effect. As for alternatives to guardianship, the participants reported little to no known information. Five participants stated that they knew of no alternatives to guardianship. The other five knew of one to two alternatives including power of attorney and limited guardianship; none of the participants could define these alternatives. When presented with a

list of options, nine of the participants had heard of many of the alternatives, while only three were familiar with supported decision-making (Brady et al., 2019).

When asked if guardianship was necessary, all ten participants stated that it was. Even when presented with the alternatives, all of the participants continued to state that full guardianship was the option for their sibling. When asked why this was the case, the siblings stated that their brother/sister lacked decision-making capabilities, but did note that the alternatives could work for other individuals with I/DD who did not have the same limitations as their siblings. When supported decision-making was discussed specifically, the siblings found taking part in this alternative to be too difficult, especially with their lack of knowledge and would choose to defer to guardianship as planned (Brady et al., 2019).

When it comes to the guardianship process, there are many systems involved, including education, agency service providers, and the judicial system. Unfortunately for the families and individuals, none of these systems use consistent language or philosophies, which can make it increasingly difficult for families to navigate this system, nevertheless its alternatives. Further, “interaction and integration” between these systems are necessary to ensure appropriate services for the individual, which does not typically exist (Millar, 2014, p. 174).

It is worthwhile to note that an individual and family’s race, ethnicity, culture, and religion may impact their values and preferences when it comes to the guardianship process, especially when capacity is called into question (Millar, 2014).

Opposing Systems

OPWDD calls for person-centered planning, but then the court removes the individual from decision-making; both actions are state-sanctioned. Supported decision-making keeps

the individual involved and keeps the person in the center. This approach is in line with choosing the least restrictive option and therefore having guardianship be “the last resort” (Kohn et al., 2013, p. 1125). However, how can guardianship be the last resort if there are no alternatives? (Kohn et al., 2013). Yes, Article 81 guardianship does exist and can be less restrictive than SCPA17A, but if SCPA17A continues to be easier, faster, and the less expensive route people will always gravitate towards that approach. Supported decision-making has already been made a legal alternative in the District of Columbia, Alaska, Delaware, Indiana, Kansas, Maine, Maryland, Missouri, New Mexico, Ohio, Rhode Island, Texas, and Washington. Other states, such as Wisconsin and North Carolina have proposed legislation that did not pass (Brady et al., 2019).

It is understood that individuals with developmental disabilities typically need more support when it comes to making appropriate decisions than their typically functioning counterparts (Kohn et al., 2013). With the presence of alternatives to guardianship, more individuals can be provided support, especially those who do not require a guardian but could still benefit from guidance and support in decision-making matters. Moreover, having an alternative to guardianship will open avenues for borderline cases where it is unclear if a guardian should be placed or not. The need for a guardian is reflective of the disability at hand, but it also stands to reason that if never given the chance to make decisions, the individual will never learn (Kohn et al., 2013).

The Idea of Changing Guardianship Practices Before Reaching the Courts

While there are several issues with the standard form of guardianship, if the current format were to remain in place, advocates have raised several issues for how guardianship is determined. Specifically, how exactly competency is determined has been an issue for

advocates of this population for some time (Millar, 2014, p.172). Millar (2014) raises the idea of a Guardianship Alternative Assessment Template (GAAT) as a preventative for guardianship. This assessment combines education, mental health, and judicial practices and addresses five areas to determine if the individual needs a guardian. These five areas are: “(1) vision, (2) values and preferences, (3) cognitive functioning, (4) risk of harm and least restrictive guardianship alternatives, and (5) opportunities to enhance capacity” (Millar, 2014, p.172). The idea here being to not only assess IQ but to “facilitate communication” about other areas of the individual’s life that affect decision-making capacity and how they can be addressed. It also offers guardianship alternatives that could be used to address any areas of concern that arise from this evaluation. The GAAT aims to provide information on areas the individual needs to develop skills for them live more independently as well as outlining strengths. Millar (2014), notes that assessments should be ongoing and involve several modalities.

Discussing assessments, many are not based on functional skills. Instead, they are standard psychological tests (Millar, 2013). Further, these assessments often don’t focus on the individual’s ability to live safely and independently in the community and their ability to complete daily living tasks (Millar, 2014). If discussing one’s competence and capacity, these factors should be considered, not just disability status and IQ scores.

Summary

The discussion above leads us to understand that there are various alternatives to guardianship available, but that they are not yet legally viable, at least not in New York State. All the while, full legal guardianship is causing potential harmful mental health outcomes for the individuals subject to it as, “under guardianship, the decisions of many people with

disabilities are commonly disregarded or ignored. These individuals are denied rights to make their own decisions (e.g. voting and marriage) because their guardians make the final decisions” (Brady et al., 2019, p.1078). While it is understood by those writing on the subject that New York’s guardianship statutes are antiquated and even the U.N. has made worldwide recommendations for the support of this population, the literature shows that no change has been made to the statutes in New York in several decades.

The most notable limitation is that only one of the above articles discussed in the course of this systematic literature review is research-based. This shows a clear gap in the knowledge base, but also concludes that the literature above is opinion, and not research, based. The results above are lacking in original research. The one study that was located is based on sibling knowledge of alternatives to guardianship. While valuable information, it does not prove the efficacy of these alternatives. Researchers Kohn and Blumenthal (2014) share these same concerns. They note that little research has been done in this field and that, with the concerns around supported decision-making, most notably the potential for abuse with no oversight, the need for data on these alternatives is significant.

Due to this, there is no way to know what is actually happening within the legal system as many researchers are theorizing at this point or state that these options are being utilized, while not yet a legal alternative. Due to the fact that these options are not yet legal alternatives and/or had not been options for a significant length of time at the time of many of the above publications, the research has yet to be done. Therefore, this study addressed the research gap by answering the question: What are the motivations for selecting legally defined guardianship or its alternatives, and what are the observed mental health characteristics of the individual thereafter?

Chapter Four: Theoretical Framework

What theoretical orientation guides the study?

Theories in research guide the way in which we look at the questions being examined to answer as well as our methodologies. Due to this, the theoretical framework is fundamentally important to research. In turn, research helps further develop theories and therefore they are interconnected. As we look for rigor in research and wider acceptability of our work, the basis of a shared theory roots our work (Johnston, 2014). In the case of this study, we look to Self-Determination Theory.

Self-Determination Theory (SDT), which relates to choice and human autonomy, was developed by Deci and Ryan in 1985. SDT is a macro-theory that looks at basic human issues such as personality development, self-regulation, life goals, and universal psychological needs (Deci & Ryan, 2008). SDT relates to culture and the impact of the environment on motivation, affect, behavior, and wellbeing (Deci & Ryan, 2008). SDT holds by the concept that people are truly autonomous when they are the only ones behind their actions and decisions. This is typically when a person finds something interesting or important. The opposite of being autonomous is being controlled. This is when someone acts because there is pressure, which can be direct and indirect. Even when people are being controlled in their choices, they can be agreeable and even highly motivated, but studies have shown that the “quality of the experience and performance is not as good in general when people are controlled than when they are autonomous” (Moller, Ryan, & Deci, 2006, p. 104).

Furthermore, controlled decisions have a history of being linked with lower psychological well-being (Moller, Ryan, & Deci, 2006, p. 104).

Moller, Ryan, & Deci (2006) also highlight the different motivations when making a decision and focus on the type of motivation rather than the amount of it (Deci & Ryan, 2008). There is intrinsic (inner) motivation, making a decision because the activity is enjoyable and/or satisfying (leisurely activities) or extrinsic (outside) motivation, making a decision because there will be a consequence that can be either positive or negative (i.e. receiving payment or punishment); extrinsically motivated decisions, therefore, being the less autonomous of the two (Moller, Ryan, & Deci, 2006). When people have different types of motivation, either autonomous (intrinsic and extrinsic motivation where activities have value), controlled (externally regulated motivation by reward or punishment), or amotivated, this will often be a predictor of their performance and well-being (Deci & Ryan, 2008).

When individuals are given choices and are free from rewards and punishments that affect decisions, studies have shown that autonomy is “enhanced” (Moller, Ryan, & Deci, 2006, p. 105). Additional studies have shown that simply having the ability to select from options can elevate feelings of autonomy. For participants who are not provided any pressure, they reported to engage in their choice longer than those who had their choices controlled. From the SDT perspective, the number of options available when making a choice is inconsequential of it being an autonomous choice; even as low as one option, choosing from that would still be autonomous. In fact, having fewer options available has resulted in less overwhelming decision-making. It should be noted that when forced to make a decision, this is not considered a choice. This enacts pressure or a feeling of being forced that takes away the experience of choice (Moller, Ryan, & Deci, 2006).

As Moller, Ryan, & Deci (2006) summarize, having the ability to make autonomous choices leads to “maintained behavior change, effective performance (especially when flexibility or insight is required), and psychological well-being” (Moller, Ryan, & Deci, 2006 p. 107). Deci and Ryan (2008) further state that this theory looks at social conditions that will either enhance or diminish motivation and therefore the psychological need for autonomy. This theory also examines how one’s life goals are impacted by intrinsic or extrinsic motivation and therefore how one’s performance towards these goals and psychological health are related (Deci & Ryan, 2008).

Self-Determination and Mental Health

Self-determination has mainly positive attributes with the removal of self-determination having negative ones. Many find that autonomy is a basic human right and links directly to freedom. Autonomy also supports healthy behavior changes, effective functioning, as well as psychological and physical well-being (Moller, Ryan, & Deci, 2006). As Zhang et al. (2019) put it: “self-determination is a fundamental need in people” (p.1805). Research has found that those who participate in self-determination have better physical and mental health outcomes. “The perception of control has a positive impact on the individual whereas perceptions of a lack of control have detrimental effects” (Zhang et al., 2019, p.1805). When included in the decision-making process, people are less likely to disagree or reject the outcome of the decision; the individual is less likely to feel “coerced and dissatisfied” and therefore engage in the deciding result i.e. a proposed service (Davidson et al., 2015, p.62).

Deci & Ryan (2008) have found that there are some basic and universal psychological needs to maintain functioning and psychological health; one of these being autonomy and in

the case of guardianship, this is decision-making control. Guardianship removes decision-making control from the individual and therefore nullifies any choices the individual makes on their own behalf and defers them to another; thereby, removing autonomy. Kohn et al. (2013) corroborate this is saying that “guardianship may also undermine wards’ physical and psychological wellbeing by reducing their sense of control over their own lives” (p.1120). Additionally, overuse of guardianship can “undermine” (p. 1120) the individual’s psychological health as they now have a lack of control over their own lives (Kohn et al., 2013). When guardianship is awarded, the individual’s participation in society is now restricted. Supported decision-making models allow for the individual to be more integrated in society and to maintain their “human rights” (Zhang et al., 2019, p. 1804).

In studies with students with I/DD, students who are given the opportunity to be autonomous are more likely to have a successful transition into adulthood. They have better outcomes with regard to education, employment, and independent living. These studies further show that individuals who had a guardian did not improve in the areas that necessitated the guardian, but potentially would have improved if the guardian had never been placed. Typically, the guardianship appointment is more so to benefit the guardian than the person it is over. With some participants of the National Council on Disability (2019) stating “[Guardianship is] never going to allow the person [subject to it] to really become integrated to [the] community because [others are] going to have to be always checking with the guardian, not the person” (p. 34).

Bound by their Code of Ethics (2017), Social workers are mandated to respect the dignity and worth of a person. Within that, social workers strive to “promote clients’ socially responsible self-determination” (NASW, 2017, para. 17). While we must work to keep

clients safe, we also work to encourage self-determination. We are mandated to support our clients in addressing their own needs, making their own choices, and enhancing their capacity (NASW, 2017). Further, the New York State Office for People with Developmental Disabilities (OPWDD), an independent cabinet-level state agency overseeing state services for people with I/DD, mandates that their employees, especially at the most basic level, support self-determination for the individuals through the National Association of Direct Support Professionals (NADSP) Code of Ethics. Stating “I will assist the people I support to direct the course of their own lives” (“The NADSP Code,” 2016, para. 13), further highlighting the importance of self-direction for the individuals. Those working for OPWDD work to support individuals in making self-determined physical, intellectual, emotional, and spiritual choices. These mandates, for social workers and those working with the I/DD population in general, both set a stark contrast to the guardianship statutes which effectively remove self-determination from an individual.

OPWDD also recognizes the individual’s right to assume risk, when well-informed. Additionally, those working for OPWDD are mandated to recognize that each individual is capable of growth and learning throughout the lifespan (“The NADSP Code,” 2016). This all lends to the same idea set forth by the California Court system in that individuals continue to grow and change as they get older and therefore if a guardian is assigned at some point, it should be reevaluated to ensure it is still needed as the individual has continued to change (Andreasian, et al., 2015).

As we see from Self-Determination Theory (SDT), the ability to make choices for oneself is key in one’s growth and development. Therefore, how an individual is meant to grow and develop *and* practice self-determination (as outlined by NASW and NADSP) when

there is a guardian in place making decisions for them becomes an essential question. While decision-making is necessary for growth, it is understood that support may be required to make appropriate decisions for problem-solving, goal setting, for appropriate self-awareness, and self-advocacy (Curryer et al., 2019).

There is also the need to protect from harm and abuse. Parents are often in a good place to provide this assistance as they know the individual well and already have an established, trusted relationship. In spite of this, parents may also have a difficult time knowing when and how to intervene. This is due to several factors, including perceived decision-making capabilities of the individual, their vulnerability, the potential risk, and a familial sense of safety for the individual. There is also the desire for decisions to align with family values (Curryer et al., 2019). With that in mind, models such as supported decision-making are a proper alternative to guardianship to ensure safety for the individual, but also autonomy.

Theory in Data Analysis

As we looked to determine if the presence of an unduly placed guardian can have a detrimental effect on an individual with an intellectual and/or developmental disability, and much of the research shows that guardianship takes away all decision-making capabilities from the individual, self-determination theory was uniquely suited to aid in this inquiry. The ability to make decisions for one's self is, in essence, being self-determined. With guardianship in place, the individual loses this ability. This theory shares the idea of the importance of self-determination, at any age, and why having the ability to make decisions is crucial to development.

As per Ryan & Deci (2000), when self-determination is promoted, there is enhanced motivation and psychological wellbeing, and when it is removed, there is diminished motivation and wellbeing. This is an important factor in the psychosocial health of the individual with I/DD. The question of guardianship's role in the psychosocial health of this population in relation to self-determination is at the forefront of this study.

This theory informed the approach I used in all aspects of research. I chose a qualitative approach as I wanted to know how and why these decisions were being made, and how they were affecting self-determination and to what degree. This theory also informed the method used as the survey tool focused on the level of self-determination that the individual had and how guardianship affected that. SDT has also informed my method of sampling. I chose to sample guardians and other advocates as they had the most information regarding how much autonomy the individuals had, especially concerning the decision-making and the observed mental health of the individual.

The theory of self-determination affected the whole study as we sought to determine what leads an advocate to choose the type of support they did, how guardianship or its alternatives influenced the self-determination the individual has, and in turn, the effect on the individual's mental health. Individuals themselves may not have been able to answer the research questions regarding their self-determination due to their possible communication and comprehension limitations and may not have gotten permission to participate. Therefore, the advocates who are providing this support and observe their mental health served as the sources of information.

Chapter Five: The Research Question

This study aimed to investigate what the motivations were for selecting legally defined guardianship or its alternatives, and what the observed mental health characteristics of the individual thereafter were. As this was a qualitative study, there was no hypothesis. However, sub-questions that guided the scope of the study are as follows: (1) Why are advocates choosing one path of support over another? i.e. legal guardianship over non-legal options (2) What alternatives to guardianships are advocates aware? (3) To what extent do advocates seek guidance from mental health professionals before moving forward with guardianship proceedings or other formal support measures? (4) To what extent is the mental health of the individual affected by guardianship decisions? (5) What role does the advocate play in the individual's life once holding a guardianship or guardianship-alternative role? (6) What decisions do advocates make on behalf of the individual? (7) Finally, in what ways do they consult the individual prior to making these decisions?

Chapter Six: Methodology

Procedures

This study focused on how advocates came to the decision to pursue their particular advocate role, their observations of the individual's mental health since taking their role, as well as the individual's role in decision-making. This study also explored the impact of guardianship and other support methods on an individual's mental health. Due to the nature of the sample required, I used a non-probability volunteer and purposive sampling method to collect participants. In this case, all of the participants were required to be parents or other advocates for people with intellectual and/or developmental disabilities who act in the guardianship role or provide other support as an alternative to guardianship. There was a limited number of participants to pool from, and even more limited by focusing on New York State.

To complete this sampling, solicitation letters were sent to several private practitioners in various fields, as well as 39 non-profit social service agencies that report to working with individuals with developmental disabilities throughout New York State. To protect the anonymity of participants, the agency names are not provided. Additionally, the solicitation was posted on Reddit and Facebook to garner interest in the study.

I collected the contact information for each of these practitioners and organizations and solicited them (letter in appendix A) to share this study with their list-serves. The total number of their subscribers is unknown. Subjects were also asked to share the study information with peers that they thought would be interested in participating. The goal was to

survey at least 10-15 participants; this is an appropriate sample size due to the unique nature of this population. The purposive sampling method is useful when attempting to contact participants who share a similar attribute or characteristic that represent a population as well as have a shared lived experience; this method was determined to be most useful for this research study (Berg, 2009).

Due to the need for contacting advocates across the state, a Zoom interview format was used to collect participant information. The interviews were recorded and once the recording was transcribed into text, the interview and all identifying data were deleted. The subjects were issued pseudonyms to protect their anonymity. All subjects expressed that they were eager to participate as they felt the rights of this population are of great importance. Interviews were conducted and transcribed by December of 2020. At the start of the session, the participants were refreshed on the informed consent they had signed prior to participating, as well as the purpose of the study. They were reminded that the study was voluntary and were thanked for their time and participation.

Measures

As this is a qualitative study, validity and reliability could not be accounted for due to the nature of open-ended questions. A solicitation letter (Appendix A) was sent out to providers through email which included contact information to schedule an interview. The interview (Appendix B) included questions on demographics as well as open-ended questions on the types of support being provided, the individual's role in decision-making, and the observed mental health of the individual.

Data Analysis

The recorded audio file from the Zoom interviews was uploaded to a secure platform on the Temi website to create text files. Once that was done, the audio files and recorded interviews were deleted. I used QDA Miner Lite to analyze and code the data through open, axial, and selective coding for themes. I knew that saturation had been achieved when at least 5-25 participants had been surveyed, as recommended by the phenomenological approach (Creswell, 2013). I aimed for 10-15 participants, and a criterion sample, which was also required based on the nature of this study. Moreover, we knew saturation had been achieved when all of the relevant themes had been extrapolated from their responses.

A Phenomenological Theory approach was used here as this study revolves around a particular shared experience – a decision on guardianship. A phenomenological approach looks to “understand the essence of the experience” which I looked at through this study (Creswell, 2013, p. 104). Further, the lived phenomenon here, for all participants, is the time when a choice regarding guardianship for an individual with an intellectual and/or developmental disability was made and the time thereafter. This study collected data through virtual interviews for participants to report observations and experiences. This approach sought to describe these experiences, in this case, of the advocates and the effects of the guardianship order or guardianship alternatives, which was information I hoped to gain from this study.

Coding started with open and then axial and selective coding to ensure theme saturation. Several overall themes were found in the first level of coding and additional themes were found in the second level of coding that produced various data and significant statements which helped to understand the experience of the individuals and their advocates.

Protection of Human Subjects

First and foremost, this study was given an exemption status by an Institutional Review Board (IRB) in order to protect the rights of the participants. Informed consent was provided to each participant prior to the interview and reviewed at the start of the interview. All participants were made to understand that their participation was voluntary (Appendix B). The language in the informed consent was in a basic language that could be understood by most if not all who participated. The subjects who were asked to participate are not a protected class. Risks and benefits were explained during the consent process; the consent also asked the participants to certify that they are ages 18 or older.

All information will be kept confidential and participants were made aware of this. All potential identifying information was deleted once the interviews were transcribed and pseudonyms were assigned to each study participant. Limited demographic questions were asked (i.e. location, age, time as a guardian, etc.). All questions were voluntary.

Chapter Seven: Results

Below are the findings of the analyses of the data recorded based on interviews of 11 advocates of people with I/DD regarding their role as an advocate. The researcher explored how the individual is involved in decision-making, if the individual desires to be involved in decisions, and the advocates' observations of the mental health of the individual since the advocate took on their role. Throughout the course of the data analysis, several themes emerged. During the first level of coding, the major themes were Guardianship, Mental Health, and Decision-Making. However, as the coding progressed to the second and third levels, more specific themes emerged regarding each of these areas.

The study participants consisted of 11 advocates in total. All of the participants were assigned pseudonyms to aid in the storytelling process. All of the participants, but one, were female. Ten were parents of the individuals and one was the older sister of the individual. Four of the mothers were single parents. The mean age of the participants was 58.36 years. All of the individuals discussed were 18 years and older as this is the age of majority in New York State and therefore the youngest age guardianship could take effect. The mean age of the individuals at this time was 27.91 years old. The mean age when someone took a formal advocate role could not be determined as some did not know the exact age they took their role and others were still in the process of formalizing their role. Seven of the participants held legal guardianship and two were in the process of obtaining guardianship. One was the representative payee and in the process of obtaining limited power of attorney and one was the health care proxy; neither plans to pursue guardianship. 10 participants were Caucasian,

one was Asian; all were from different religious backgrounds. The disabilities for all of the individuals discussed varied, however, eight were diagnosed with Autism as one of their diagnoses. The functioning level of all of the individuals varied and the Full-Scale IQ (FSIQ) was not known for all of them. Table 3 shows the demographics of the participants and the individual they are the advocates for.

Table 3.
Demographics

Participant ID	Lisa	Jenny	Peggy	Melanie
Relation to Individual	Mother	Mother	Mother	Sister
Age of Participant	50	51	45	69
Location	Upper New York	Upper New York	Upper New York	New Jersey (Holds New York Guardianship)
Race	Caucasian	Caucasian	Caucasian	Caucasian
Religion	Jewish	Christian	Jewish	Lutheran
Employment Status	Self-Employed	Full Time	Other (Disabled)	Retired
Living Arrangement of Individual	Guardian's Home	Group Home	Family's Home	Group Home
Diagnosis of Individual	Autism, ADHD	Autism, Bipolar Disorder	Autism, ADHD, Major Depressive Disorder, Anxiety Disorder, Traumatic Brain Injury, Epilepsy	Cerebral Palsy, Brain Damage, and Epilepsy
Functioning Level	Severe	Moderate	Mild	Profound
FSIQ (if known)	40	Unknown	92	Unknown
Age of Individual Now	18	22	22	62
Age of Individual at Onset of Support Type	18	18	22	21 (Sister has been guardian for 23 years after mother passed)
Sex of Individual	Female	Male	Female	Male
Type of Support Provided	Article 17A Guardianship	Article 17A Guardianship	Representative Payee, in process for Limited Power of Attorney	Article 17A Guardianship

Table 3. Continued

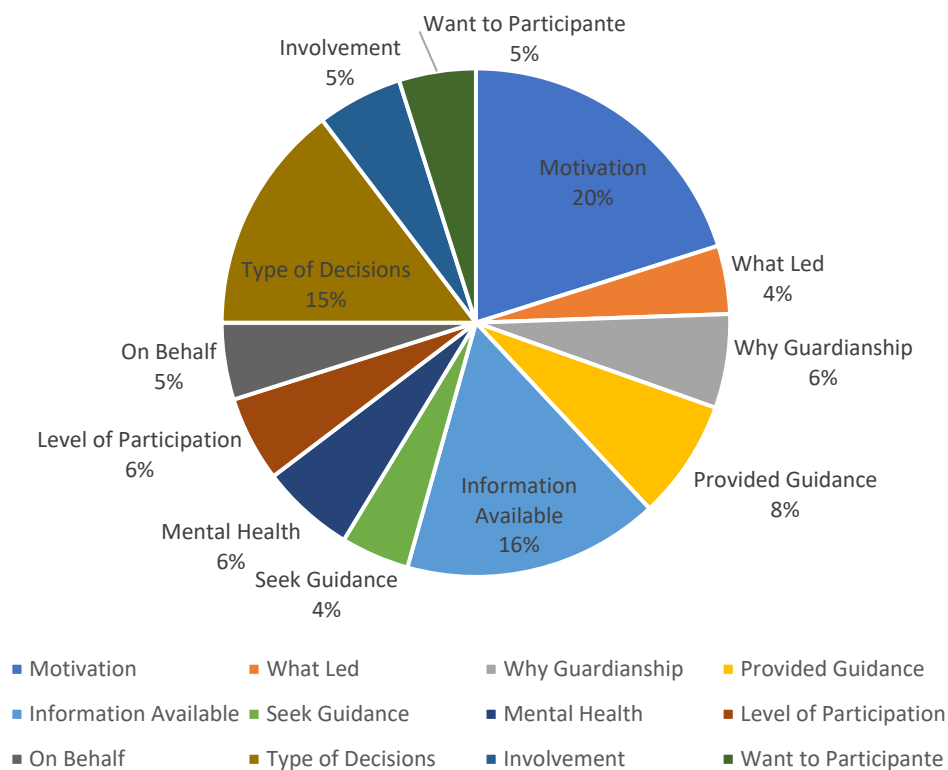
Participant ID	Caryn	Fanny	Kevin	Donna
Relation to Individual	Mother	Mother	Father	Mother
Age of Participant	52	58	56	64
Location	Upper New York	Upper New York	New York City	New York City
Race	Caucasian	Caucasian	Asian	Caucasian
Religion	Catholic	Jewish	Christian	Jewish
Employment Status	Full Time	Full Time	Full Time	Full Time
Living Arrangement of Individual	Residential School	Guardian's Home	Guardian's Home	Own Apartment (Self-Directed, Mother is Landlord)
Diagnosis of Individual	Intellectual Disability and Autism	Autism	Autism, ADHD	Spina Bifida, Hydrocephalus, and Arnold-Chiari II Malformation Pseudo-Seizures
Functioning Level	Severe	Severe	Mild/Moderate	Mild
FSIQ (if known)	Low 60s	Unknown	93	79-100
Age of Individual Now	18	21	20	32
Age of Individual at Onset of Support Type		18	18	On and off since 18
Sex of Individual	Female	Male	Male	Male
Type of Support Provided	In Process of Article 17A Guardianship	Article 17A Guardianship Representative Payee	Article 17A Guardianship	Health Care Proxy

Table 3. Continued

Participant ID	Mary	Angelica	Caryl
Relation to Individual	Mother	Mother	Mother
Age of Participant	68	68	61
Location	Long Island	Long Island	Long Island
Race	Caucasian	Caucasian	Caucasian
Religion	Jewish	Jewish	Jewish
Employment Status	Retired	Self-Employed Full Time	Part Time
Living Arrangement of Individual	Own House (Self-Directed)	Family's Home	Own Apartment (Self-Directed)
Diagnosis of Individual	Phelan-McDermid Syndrome	Autism	Autism, Learning Disabilities, Hydrocephalus, Anxiety Disorder, and Depression
Functioning Level	Moderate	"High Functioning"	Mild-Moderate
FSIQ (if known)	40	80-140	>100
Age of Individual Now	34	28	30
Age of Individual at Onset of Support Type	Mid-20's		19-20
Sex of Individual	Female	Male	Male
Type of Support Provided	Article 17A Guardianship, Representative Payee	In Process of Article 17A Guardianship. Stated has Power of Attorney, Representative Payee, and Healthcare Proxy	Article 17A Guardianship; only the Person. Power of Attorney

Figure 3 shows a representation of the data collected. As shown below, the motivation to seek a formal role as an advocate was highly discussed by the participants. Different types of information available was also major topic of discussion; this includes an understanding of guardianship, its alternatives, and if the advocate finds guardianship to be the right choice for their loved one. Additionally, the types of decisions that the individual participates in was heavily discussed by the participants which can link the relationship between disability and decision-making as shown in the results below.

Figure 3.
Data Collected



Guardianship

This study examined how advocates came to their decision on guardianship including what motivated them to make their decision, why they felt guardianship was the best decision or not, who provided guidance towards their support role, as well as determining the advocates' understanding of guardianship and its alternatives. These themes explore how the participants came to their decisions on guardianship as well as their motivations and level of knowledge around the subject.

Motivation

These findings reveal what motivated the participant to seek their role as guardian or to provide another form of legal support.

Familial Obligation. All participants were family members of the individuals. Nine were mothers, one a father, and one was an older sister. Familial obligation is discussed as the family member being interviewed having a sense of obligation and responsibility to take on this role for the individual. Peggy, a single mother, stated “I've been the only parent since she's like four years old. So, you know, it's kind of the default relationship. It was never, there was never a consideration of someone else being the one responsible.”

Melanie, the older sister of her brother with Cerebral Palsy, stated she always knew she would care for her brother, even from a young age saying “it was something I always knew I would do. I'm the oldest of five, so I never had to have my own kids cause I had plenty of practice with taking care of them. And um, I remember when I was 12, you're gonna make me cry, but it was Father's Day. I said to my father, don't worry. I'll always take care of James. He's my baby. So, it was never optional.” When discussing how she took on the role of guardian, Melanie went on to say “that was an automatic because my mother was the guardian and I was the successor guardian. Implying that rather than having an older family member or family friend as the backup guardian, Melanie's family had her in line to take over the care of her brother.

Donna, the mother of a young man with Spina Bifida, Hydrocephalus, Arnold-Chiari II Malformation, and Pseudo-Seizures simply stated, in reference to her role as health care proxy, “that's what, that's what a mother does.” While Angelica, the mother of a young man with Autism went deeper stating that she has been her son's guardian for “28 years since he's been born, I've been the person who's been legally and doing everything for him. So, I mean, only when he turned 18, things switched around, but I'm still doing everything that's necessary.” Adding, “he's my child. I love him. I am his mama.”

Would Not Be Safe Otherwise. The advocates interviewed felt that since their relatives with a disability benefited from guardianship or other forms of support as they would be left in unsafe situations otherwise, specifically in medical and financial scenarios. Lisa, the mother of an 18-year-old young woman, described as having a severe disability shared “cause she's not going to make medical decisions on her own or financial decisions on her own.” She went on to say “you just have to do it, okay. For their safety.”

Jenny, a single mother, who described an abusive ex-husband, specifically cited safety concerns for her son shared “...the biggest reason for me was making sure my son was safe and that person could not come in and have any type of interaction with him. Cause my son is very vulnerable and could probably be talked and to having interactions with the person who's very dangerous.”

Peggy, the mother of a young woman with Autism and several mental health diagnoses, has chosen not to pursue guardianship as her daughter would not benefit from having someone take this role. Instead, she is the representative payee for her daughter and is in the process of obtaining limited power of attorney. She has chosen this route as her daughter was in an accident and will be receiving a sizable settlement. In describing why she is involved in only the finances and medical decisions said “I would say the biggest thing is the, the estimated settlement size of the settlement. The money someone needs to help her manage.”

Fanny simply stated that they did not feel their son could make decisions, therefore guardianship was the only option for him. “Obviously, we didn't feel like he could make decisions on his own, so we decided to pursue the guardianship.” Caryn shared similar sentiments stating “She has no ability to make decisions. She needs to be supervised

24/7...She can't make her needs known because she's nonverbal. She wouldn't know what to do if she was sick, she wouldn't be able to talk to a doctor.” Angelica shared a similar feeling regarding healthcare, “That's when he ages out, when he turned to an adult and there are things that he is very difficult with such as if he hurts himself, he won't tell you He's broken his arm and he wouldn't say anything to anybody and we had to fight with him to get him to the hospital.”

Kevin, whose son he described as mild to moderately functioning currently has guardianship but would like to encourage his son's independence to one day remove it. As to why he currently has guardianship Kevin stated, “Even if the future that even he looks, I have a normal IQ and he has normal, little normal communication skills, but his judgment basically is very, very off compare with even a little kid... his cognitive judgment basically is his own understanding. We always have this problem that I cannot fully [be] comfortable [with] his own judgment, especially when he was not informed.” Kevin adds, “But when you put, in a situation, which is some people intentionally try to trick him, try to fool him, try to, you know, take advantage of him. He's defenseless. He's, he's, he's no way he can see other people intention. He [has] no way to defend himself... I said, you know, of course we'll protect you. The guardianship basically is, is a one-way last defense. We protect you.”

Mary shared a similar sentiment regarding the judgement and vulnerability of her daughter with Phelan-McDermid Syndrome stating “She really does not have judgment about things. She's just, she's not safe. Um, plus she's and you know, this isn't something I really thought about then, but I think about now is that she is really very malleable in the right hands. She's a pleaser. And if you know, someone, you know, just wanted to manipulate and they certainly could, I mean, it's not hard to manipulate her... this is a no brainer, you know,

for her really, she just does not have the understanding of the world, um, to be able to make those kinds of decisions... I think about that I, that I'm doing this for her health and safety and really not to try to dictate how her life is. And I'm really conscious of this.”

Caryl specifically has guardianship over the person only for her son due to healthcare concerns stating “he doesn't realize what he doesn't understand. That's very frustrating and concerning.” Caryl further details the specific instance which led to the decision for seeking guardianship “...because he tried to kill himself, because he was in over his head on college campus and wasn't reaching out to us, wasn't telling us and was doing things that he knew he shouldn't, but he, because he's so vulnerable and naive and gullible, he was doing drugs, smoking pot, and he was drinking and things that his neurosurgeon told him he should never do. And he was doing that, and he tried to kill himself. And we realized at that point that he really needed support making decisions.”

Does Not Want Anyone Else Making Decisions. In addition to not wanting their relatives in unsafe situations, several advocates also noted that they did not want anyone else coming in to take the guardianship role or to be making decisions without their input. Further, they also wanted to ensure that the appropriate needs of their relatives were being met and to the individual's liking; they wanted to make sure the individual's likes and dislikes were considered.

As Jenny stated, “it was really important for me to make sure he was safe and protected and that his wishes were, um, met...I'll let him actually articulate what his wishes and desires were...I wanted to make sure that he had the life the way he wanted it. So, I feel like it was an extension of his voice. And I actually had him to go to the meetings with me. He actually participated in the guardianship.” Peggy added “we didn't plan for any of this

other than the rep payee for the SSI, any of the other stuff wasn't planned for at all until she had her accident and the issue became you know, the money.” It was important to this mother that improper financial decisions not be made with her daughter’s money, either by her daughter or by other people involved in her life.

Donna noted that in healthcare situations, both she and her son did not want anyone else to intervene as he has several healthcare issues that have come up in the past, “I guess it was, you know, more the, the combination of the health issues and, and also that, uh, I don't want, I don't want him to be, uh, anything to be done to him that he wouldn't want to be done to himself, because as we know, there's, there's, uh, a hierarchy, a priority list. If, if someone is incapacitated, then, then the hospital goes down a list of, uh, whatever who's, who can make the decision, you know, and the, you could, you could end up with, with somebody, the, whatever, the, the doesn't have the same ethical, uh, basis or religious basis.”

Mary shares a similar feeling, but instead is planning for the potential and for a future without her presence stating, “It was just knowing that this is what was going to eventually be that, you know, that, you know, with like, if she was in the hospital, you know, whatever, we need to be able to, you know, do what we need to do, and then hopefully to take the next step after we're gone for someone else to be her guardian.”

Became Legal Adult. Another major motivation for seeking guardianship or an alternative was that the individual had become a legal adult and therefore able to make decisions independently, regardless of their disability. As noted in the demographics, several of the advocates sought guardianship at the age of 18 or 17.5 so that there would be no gap in their decision-making control. Jenny commented on the need for guardianship at this age: “Well, I know that when he turned 18 that the, in the eyes of the law, he's technically an

adult, but he's very vulnerable. And so, I wanted to be sure that, um, something should happen to him that guardianship would, I think in some ways, protect him.” Peggy shared a similar sentiment on her feelings of the importance of timing and guardianship: “well, her becoming a legal adult definitely led to formalizing it.”

Fanny added that a reason to do it before the age of 18 was that her son would not have to attend the court hearing sharing “if you, um, you completed it prior to the age of 18, that he didn't need to be present at the hearing.” Lisa shared that her thoughts on why the guardianship for her daughter needed to be done at the age of 18 “that's when you're supposed to do it.” Kevin, who sought guardianship when his son was 18, cited a concern for legal reasons, “we started the guardianship probably after he is 18...the reason you was that, you know, after he [became] 18, he supposed to make a decision himself. So, so whatever you sign the paper, which is a legal after. So that's a big concern.” Mary, who became the guardian of her daughter when her daughter was in her mid-20's knew she needed guardianship when her daughter turned 18, but did not seem to be in a rush to complete the process. Mary stated “we knew we were going to die someday, so we need to. I knew since she was 18, I knew we needed to do it, so I'm not, it was something we were going to do at some point we got to, we just did it when we got around to it, essentially.”

What Led You to Your Support Choice?

Following the theme of motivation, the advocates also described what led them to providing support in a legal form.

It Is What You Do/To Do List. Several participants shared a feeling that, as the parent of a child with special needs, that there is a list of things you need to do at different stages and that guardianship is what you do at age 18. Lisa simply put her decision to seek

guardianship for her daughter, “it's just what you do.” Lisa added that no one made her seek guardianship for her daughter, but that it was more just a part of the to do list of a special needs parent. “So, it's nothing like, no one's knocking on your door to arrest you if you don't do it. And I'm just saying, it's just more supportive to do it. And you know, it's one thing to check off your list...So it's something you have to check off your list and just this peace of mind, because you just never know.” Fanny shared a similar feeling in that guardianship was something you just needed to get done and over with when you have a child with special needs, “...just wanted to get it over with, you know, so we didn't have to worry about it.” Donna added a shared sentiment stating, “that's just the continuation, uh, of motherhood for, especially for a disabled individual.

Have to Do It/Right Thing to Do. Along with a sense of a to-do list, participants also shared that guardianship was simply the right thing to do or something they had to do for their loved one. Jenny stated that, although there are many things that need to be done as the parent of a child with a developmental disability, guardianship is a necessary step: “you can't ignore it or it's just the right thing to do.” Caryn shared a similar sentiment that there was a lack of choice when it came to taking the step of seeking guardianship “well, she's legally an adult now. So, I have no choice, it has to be done.” Caryl shared about the necessity to be involved in healthcare decisions for her son stating “the decision-making and healthcare and stuff like that, we needed to be involved. And he agreed.”

Melanie shared that guardianship for her was just going to court to update the paperwork after her mother's passing, there was never a question that she would be her brother's guardian “so, I just did my job and got the paperwork done. It was easy.” As she was placed in the paperwork long before she was the legal guardian, she always knew she

would eventually become the primary guardian at her mother's passing. Her father had passed away at a young age, and even though her other brothers care deeply for her brother, she has always had a sense of responsibility for him.

Why Choose Guardianship or an Alternative?

The themes here discuss why the advocates felt that the role they took was the right role for their loved ones.

Best Interest. The participants discussed their decision being in both the best interest of the guardian and the individual. As Lisa stated in regard to her best interests as the guardian "It just in your best interest," but later added the following about the best interest of her daughter "we have to make the decisions for her in her best interests...guardianship is the right decision. That's the only decision. But in the day in day out, we're making the decisions. We have legal rights to do that."

Jenny stated that part of her motivation for seeking guardianship was ensuring that her son would always be taken care of and that she would be able to adequately plan for his future without her through these proceedings. She explained, "the guardianship helped me set up a special needs trust. So I could give him equal amounts of my life insurance to my other children." In addition to his general need for support "well, his intellectual functioning means that he really does need that. He's very vulnerable, incredibly trusting. And I felt like that was really important for him to have that guardianship."

Angelica shared that her son will always need someone to assist him and due to that, having a guardian in place is in his best interest. Angelica stated "I realized that I was in his own world and you know, less now, but he had nothing to do with age. Just has to do with who he is, you know, and he expects me to be there to help him. He's never going to be able

to take care of himself... And I'm trying every day that is that he takes more responsibility for himself. But when it comes to deep down to anything that is necessary, he, he needs a guardian. He needs someone who's going to be there for him all the time... I mean, I have to, because I want the best for my child.” She went further sharing that all people with disabilities need a guardian for their best interests stating “No, they shouldn't be emancipated. It should be natural when you have a special needs person that they are under your guardianship, even if you don't ever use it, use it. And they are capable of doing whatever it is. They need help and you need to have legal, legal guardianship. They don't want to be bothered with talking to the insurance companies. They don't want to be bothered with talking with social, you know, social security. They need you to deal with it for them.”

Sense of Agency (Autonomy). On why Peggy did not seek guardianship for her daughter “really the only thing I don't have is guardianship. And I, I feel like what we have or what we have planned to be in place gives her some sense of autonomy. That guardianship would, would take away from her.” This statement goes beyond best interest and, as Peggy is one of the few participants to not have guardianship, she begins to discuss the concept of autonomy for her daughter. Donna, having health care proxy, wants to ensure autonomy for her son and has never sought guardianship. Donna shared that she wants to give her son the dignity of risk in his own decisions stating, “you know, the responsibility and the dignity of risk and allowing him to, to sometimes make mistakes and determine, you know, what he wants to do and how he wants to do it.”

Who Provided Guidance?

These themes explore who guided the advocates to their options, if anyone. As discussed in the results, there were several routes in which advocates gained information about guardianship, but little about alternatives.

Peers. Several participants, mainly those from Upper New York, shared that it was from their peers that they learned that guardianship was a necessary step for them to take. Lisa shared the following “My friends, basically my friends in the autism community, we have very close friends in the autism community... We're all in the same boat... we'll get together....who have children who are a year older, two years older and so forth. They told us...we help each other out.” Melanie shared a different way of learning to take on her role “I learned from my parents just to be a caregiver.”

Case Managers/Lawyers/Other Professionals. Jenny shared her experience working with her son’s case worker, stating that she would not have known about guardianship were it not for the case worker, but also stating that the case worker funneled her towards that decision. “...and the system is really kind of guiding all the parents through that guardianship. had I not been told that by his caseworker, I wouldn't have known about it. That's just, I'm learning as I went. they really helped direct me towards the guardianship and towards the group that I chose.” Peggy, whose daughter has a sizeable monetary settlement was guided towards limited power of attorney by their personal injury lawyer as a way to protect her financially shared that it “was at the recommendation of our personal injury attorney. It wasn't even on my horizon that these were necessary steps.”

School. Jenny also shared that her son’s school and group home were guiding her towards guardianship being the right choice and the only way to protect him. She explained, “the group home and his school and the caseworker all telling me that this is what you need

to do to ensure that you still have rights and say in his life once he's 18.” The school seemed to be a main contributor in sharing the idea of guardianship for participant Jenny: “...once your child starts heading towards 18, we always have them to go through this at the school.” Kevin shared a similar method of learning about guardianship stating “the reason I put the guardianship is that because this is a standard recommendation from the transition planning from the school.”

Self. Several participants researched guardianship and its alternatives on their own; those who did shared that they also work in related fields giving them added access to information and resources. Donna shared simply about who guided her, “no one really. I mean, I, I read a lot.” Mary also did her own research to guide her decision stating “I do a lot of research. I've been doing like a lot of advocacy and stuff since she's three. So I've, I had been to conferences and read about a bunch of stuff and kind of had decided just from reading that that's what made the most sense.” Angelica shared that no one guided her and that she made the decision entirely alone stating, “I said, I need to take guardianship of him the end.”

Information Available

These themes explore additional information the advocates would have wanted during the process of formalizing their roles as well as what information was available to them, including their level of knowledge of what guardianship means for the individual and knowledge of alternatives to guardianship.

Additional Information. In asking what additional information the advocates wished they had had during the process of formalizing their role, the advocates shared several feelings on the guardianship process. Jenny shared “I think at the time, I didn't realize I'd

have to go to court by myself... I was really surprised at how much it cost.” Caryn discussed how the process could be easier for children like her daughter, whom she thought clearly required guardianship without a hearing shared that “they can make it a little easier. I mean, for children like Nicole, it's kind of ridiculous. I have to go to court over it. There should be an easier process for, for the real easy cases.” Peggy felt that she was well informed, after sharing there were free courses on the subject at a local social service agency “so I really, I can't say that there was any more information that I would've hoped to have had.”

Kevin shared a desire for more supportive material during the process, specifically regarding what his options were “I want the lots of supporting material. Tell me how this situation, what's my option. What is good for that? What is bad that for that one?” Donna was looking for more information on alternatives to guardianship sharing “I would like more information about what the supportive decision-making will, will look like.” While Angelica shared a belief that guardianship is harder to obtain after the individual turned 18 and would have liked someone to share that with her as she is going through the process now with her 28 year old son, “like if someone had said to me when he was 18 or before he was 18, you need to take legal guardianship of him or else you're not going to be able to get guardianship of him. It's going to be a lot more difficult.”

Understanding of Guardianship. The researcher asked the advocates what their understanding of guardianship was regardless of their current role in their loved one’s life. Six participants shared a blunt understanding of guardianship which mainly revolved around their role as decision-makers for their loved ones. Lisa stated that “we have the legal backing to make decisions for our daughter who's over 18. It's, um, medical decisions, financial decisions...” Jenny further shared “I am still the person that would have the say in terms of

his residence choices, like what type of living arrangement he would have and end of life wishes would be, should he be hospitalized or incapacitated? I would be the person that would be making those decisions, um, in terms of his rights.” Caryl shared her understanding on the role the guardian takes with a key statement on the individual’s rights, “so it's for people, but you know, intellectual and developmental disabilities specifically, and it's an easy process. It's designed so that families have an easy way to step in and continue their role as advocate for their child. Once they turn 18 or older I don't believe it strips away their citizenship.”

Peggy, who was one of the few participants to not hold guardianship, stated “...you'll never get it for my daughter. She was too high functioning. My understanding of guardianship versus the power of attorney is. Is more in the sense of guardianship, all decision making is my responsibility. Whereas I, I give her a good amount of, I think a good amount of independence.”

Melanie shared her experience having guardianship for such a length of time and how the guardianship laws have changed since she became the guardian “I had no idea that the guardianship requirements, um, the paperwork would have to be done to make end of life decisions... Basically my understanding has always been that when you have legal guardianship of an individual who is not capable of making decisions, you can make all the decisions, social, money decisions It was news to me to learn that I couldn't make end of life decisions, but short of that with the way the paper is written, it's my understanding that it's like him speaking for himself, I speak for him.”

Caryn shared her knowledge of what guardianship means “they don't have any rights anymore. You're taking them away. The person who has guardianship makes all financial, legal, personal decisions, medical; I can override any decision that she makes.”

Knowledge of Alternatives. Through the interview questions, it appeared as though the advocates were not keenly aware of alternatives to guardianship. Several advocates were able to share limited knowledge of alternatives, most notably the two advocates who opted for an alternative to guardianship. Peggy, who is in the process of gaining limited power of attorney for her daughter, shared the following knowledge of alternatives, “really the only thing I don't have is guardianship. And I, I feel like what we have or what we have planned to be in place gives her some sense of autonomy. That guardianship would, would take away from her... it's like the rep payee or the trustee or, or whatnot. That's all I know about.”

Caryn, who has spent time working in special education, shared her knowledge, “power of attorney, healthcare, proxy, you have supported decision making...” Donna, who is the healthcare proxy for her son expressed her knowledge and feelings on supported decision-making “the decision-making the facilitated decision-making of decision. I think, you know, that really, they should really, uh, legislate that and make that a, uh, an option. I think, you know, it's a, it's a good compromise.”

Mary shared that when she was going through the guardianship process about ten years ago, there were not many options for alternatives aside from Article 81 guardianship and a new vague knowledge of supported decision-making, “well, when we were doing it, there wasn't so much of the other options. I mean, I knew there was, um, the guardianship that you could just have for sort of that's 81, I guess, for sort of limited parts of things I knew about this, like some years ago, but again, it, it, my understanding was that it could be

undone at any point. And I, I didn't want that to be, I wanted to be able to, um, you know, to take care of her if, if I needed to take care of her... I guess as the article 81 and finding out that people could say, no, I don't want to do that anymore. And they said, that's not going to be good. And I've actually heard a bunch of people speak on, is that what it's called supported decision making." Despite other advocates having no known knowledge of alternatives, they felt strongly that guardianship was the right decision for their loved one.

Finds Guardianship the Right Choice. Of those who had guardianship, they felt that guardianship was the appropriate choice regardless of their knowledge of alternatives. In fact, as shown above, many were not keenly aware of alternatives to guardianship. Jenny shared "so, for the guardianship, I'm actually really happy with it. So I actually don't know of any other alternatives. So, um, because I'm so happy I haven't gone seeking elsewhere. It's just been something that really works for us." Caryn bluntly stated "there is nothing else available that's appropriate for her."

Mary shared strong feelings on why guardianship is right for her daughter stating "I wouldn't do anything besides guardianship, because I really feel like there's not really a reasonable option for her and that if she was in some less, you know, structured, if she was in, I suppose it's called supported decision-making, that I really fear, and this is a general systemic issue, I'm just really concerned about who's exactly going to be supporting people and whose best interests they're going to have at heart. I think people should have as much autonomy as they can. I'm just the question is who's going to be influencing all of these really easily influenced people." Mary's main issue appeared to be a lack of knowledge and understanding on how supported decision-making works and who will be influencing decisions in that method. Caryn shared a similar desire to learn about supported decision-

making but would not opt for it herself. Instead, she shared how she would like to see it incorporated into Article 17A guardianship, “nothing? I would like to see supported decision-making the part of the 17A mindset.”

Would Opt for an Alternative. Kevin, who is working to remove his guardianship over his son over time shared that he would prefer an alternative to guardianship should his son’s skills continue to progress and implying that the judge also requested he follow up. Kevin shared “maybe after five years he can be more independent. Then he, he don't need the guardianship anymore. And we, we, we did not argue it was judged because that's what that I will hope too. So, judge has said, you know, five years, come back again. Let's see what's happened.” In regard to what he would like to choose Kevin stated, “probably will choosing lots of things because the supported decision-making, which is, I'm not quite familiar, but sounds like it's a very good better way to compare with the guardianship, because I really do not want the cut through my, my son's decision... He have a little ability to think a little bit to learn., so I want to support to him. I don't want guardianship. You know, so if I have, if I know that time, I definitely was starting with the supported decision making to see whether compare with this one there. That's the, the choice compares with the guardianship.” Kevin also shared that he is in the process of obtaining an alternative to guardianship at this time sharing, “...power of attorney which is we try to do it from our lawyer right now. And I believe that in our situation, the power of attorney can help us something with the financial requirement.”

Donna shared a similar desire to utilize supported decision-making, but doubted whether her son would allow this to be used stating “depending how it's formulated? I might, uh, discuss with him the supportive decision-making, but I doubt whether he would allow it.”

Mental Health

These themes address the observed mental health effect that guardianship has had on the individual. Several of the participants' loved ones did not currently see a mental health professional for this effect to be addressed or for the advocates to have been able to discuss the potential effect prior to taking on their roles.

Did the Advocate Seek Guidance?

Specifically, information was sought to determine if the advocates consulted with a mental health professional in regard to their loved one and the effect that guardianship could have on their mental health.

Not on This Issue Specifically. Lisa interpreted this question to mean speaking to her own psychologist and how the guardianship affected her own mental health. She reflects on that saying "I talked to my personal psychologist about it and he said, yeah, you definitely shouldn't not do nothing." Jenny shared the following "I don't remember doing that at all."

Peggy shared about her daughter, who has several mental health diagnoses, about if she would qualify for guardianship, not how guardianship would affect her "so, it's never been like, oh, she just had mental health issues because of the guardianship or anything like that. It's been a part of disability her whole life. I asked her providers when, when she was 18 and, and whatnot, if, if they thought she would qualify for, for someone for guardianship and they did not think that she would, she was too high functioning."

Kevin shared that, while his son sees a psychiatrist he did not seek advice on guardianship past evaluations "I do not, do not worry about that right now." Mary shared a similar relationship with mental health professionals "No. I didn't really get any help from a mental health professional on the guardianship. I mean, she's had psychiatrists..." The other

participants reported that their loved one did not see a therapist or did not address this subject with them.

Has Guardianship Had an Effect on Mental Health?

These responses are based on observed reports of the mental health of the individual from the advocate's perspective rather than those of a mental health professional.

Has Observed a Positive Influence. Jenny had a very specific reason for why guardianship has had a positive mental health effect on her son. She was in an abusive relationship and spent some time in the hospital due to this. Jenny shared that her son expressed that not knowing who would care for him if his mother died gave him some level of anxiety. Therefore, knowing that there were back-up guardians in place as part of the process, and being people that he knew and had spent time with, eased his anxieties. Jenny went on to say that “should something happen to me? She will make your surgery decisions or your medical decisions. You know, those sorts of things. So I told him that and that made him really happy. So, I made sure he met them both. And um, he, I think the one thing about the guardianship, knowing that I had backups, that part made him feel secure. Cause he knows now that I could die. And that was something he had never considered before. And since then, knowing that we went for guardianship and that he has my cousin and my friend, his backups, it seems that the guardianship has been a positive thing for him.”

Peggy shared that, although she does not have guardianship for her daughter, that due to her daughter's mental health needs, having someone to assist in making decisions has had a positive effect “her mental health is bad; she's almost relieved by someone taking control and making the decisions.” Angelica shared a similar sentiment about her son preferring that someone take over decision-making, “he has no problem with it [guardianship]. He's all

good. His mental health is fine about it. He, he prefers that I would take control of it. It, you know, it helps him in his life and he knows that whatever it is I'm doing, I'm doing for the best, for his best. And he trusts me.”

Has Observed No Influence. Lisa shared that on the day guardianship was awarded, the only thing that was different was a court hearing “well, nothing's changed for her. It was just the same old day...I continue to make decisions, necessary decisions for her, for her mental health, whether it's going to tweak the medications or, you know...” Jenny shared that, although having a backup to care for him made her son happy, he has not had any observed mental health reactions to someone making decisions on his behalf, “I don't think he really has grasped a whole lot of that. I told him that we were doing that, and he just wanted to focus on the checklist that we had to do. So, I don't think it's affected him at all.” Caryn simply shared that her daughter has been “the same.” Mary shared that there has been no influence from the guardianship on her daughter’s mental health as her daughter does not have an understanding of what she has or does not have, “I really don't think it's had anything to do with anything because it's nothing that she's really conscious of. She really kind of doesn't, which I think actually makes it a little easier for her, she doesn't, she's not as conscious of what she's not having or what she's losing, so I don't think it's had any effect on her mental health at all.”

Does Not Have Guardianship Due to Potential for Negative Mental Health Outcomes. Peggy discussed her daughter’s mental health concerns and how her decision about guardianship was made with them in mind. Peggy shared that “we make the decisions jointly. She, no, I don't make decisions for her without her input. And I think, I think it actually, if I had pursued guardianship and that, that license had been taken from her, that it

would have negatively impacted her mental health and she's already kind of struggling with it.” In regard to her reasons for only opting for alternatives to guardianship for her son’s autonomy and mental health, Donna shared her son’s past reactions to the idea of guardianship, especially through her divorce proceeding stating, “there was nasty custody battle, and actually his, his father tried to take a guardianship of him. It was such a traumatic process...once I jokingly said, if you really do that, you know, I'm gonna, you know, whatever I'm gonna take guardianship or something. I was just joking and he got so upset and he was crying.”

Decision-Making

The themes discussed here address the individual’s desire to participate and level of participation in decision-making. This connects to the previous themes as a guardianship order affects the decisions the advocate needs to include the individual in and as the literature above showed, a lack of participation in decision-making has proven to have a negative mental health effect.

Level of Participation in Decisions

These themes look to how decisions are presented to the individual. Limited option decisions are described here as a set of several controlled options and open-ended decisions are those where a question is posed with no set of limitations for responses. No participants labeled their loved one as making choices completely independently.

Presented with Limited Options. Limited options in decision-making are typically presented as a series of options already pre-determined by the questioner in order to limit the scope of the response to what the questioner prefers. For instance, Jenny shares that she

presents her son with several activity options as choices for the day's activity "and so I give him usually about three choices of things we're going to do, and he chooses."

Peggy uses limited choices depending on the situation, as described "we have a very open line of communication. We're very close. It kind of depends on the situation. So, like when she decided to go back to school, it was a little bit of a limited choice." Melanie shares a similar tactic in presenting her brother with options, "Yes, he does it non-verbally by point, he points. He has to see, you know, this or that." No participants described presenting their loved one with open-ended or independent choices.

Kevin and his wife take a similar approach stating that they give their son options, but explain to him what the options are and their outcomes so he can gain decision-making skills. Kevin shares that they "gave him different options to see, explain what options is. Then, based on our recommendation, he make one. So, I can say that almost all the bigger decision he want to face it, we do those this way. That's the means of, we encourage him to do it. We gave [him] advice that eventually he will pick up the decision. You know, if we, if we pick up as a wrong decisions and we tried to explain why it's not good, then he probably would change your mind."

Open-Ended Questions. These types of questions are defined as those with unlimited options, typically who, what, where, when, and why questions fall under this category.

In discussing how she presents options to her son, Jenny stated that she first gives limited options but, "if he voiced that he didn't really like them, I would absolutely change I give him open-ended. But I think the group home gives him limited." Angelica prefers to give her son as much information as possible to include him in decision-making stating, "I let

him know [about decision that need to be made]. I speak to him about it. If it's something major where I feel that he needs to know about it, I speak with him about it. We have little discussions in the car when we're alone... It's not like I want him not having the information. I want him to have the ability to decide that he, you know, I take him with me to the stores and I say that me, what are we going to get?"

Caryl, who shared that she likes to incorporate aspects of supported decision-making into how she works with her son stated, "I try to incorporate as many supported decision-making techniques in, in everything that we do, we don't tell him what to do. We try to coax out of him, what it is that he wants to happen. And then we ask him if he wants our help, and then we step in. He's taken supported decision-making, I guess, workshops."

Decisions on the Individual's Behalf

Specifically, these themes explore how many decisions in the individual's life is the advocate responsible for making. Themes emerged regarding for the advocate making all decisions on the individual's behalf. No participants described the advocate making some decisions. Only one participant described the individual including the advocate in decisions, which is not a significant theme; this participant does not hold guardianship.

Advocate Makes All Decisions on Their Behalf. This theme explores how the advocates classify all decisions and which decisions the advocate makes on the individual's behalf. Lisa shares that they make all decisions for their daughter; they include her in minor decisions such as what she would like to eat for dinner, "...every decision, you know, medication, um, doctor's appointments, um, we have to make a decision on... So we have to make all the decisions for her. She isn't able to, you know, she can make a decision on what she wants to have dinner."

Jenny, whose son is in a group home, shares her experiences on balancing which decisions the group home makes and which she feels she should be making “so it's very well known within that group home that I am the one that make decisions...But for, um, the, the major life decisions, you know, um, where he's going to school, where he's going to [program], I made all of those. I did the tours. I make those decisions.” Caryn shares a similar experience as her daughter is in a residential school, “All of them. Well, I should say all the big ones, cause she's in a residential school. I have to sign off on medical procedures, her IEP, her services, pay for social security...”

Kevin shared that he works with his son to make more decisions independently, but that he and his wife are still involved in decisions. “He was a very happy [for us] to take it because he do not want to make his own decision. So all this decision, most of them is basically we have to push him a little bit, I don't want to give you the option right now. I want you make decision. I can't help you... That's a mean we have to push him to make a little decision by himself.”

Types of Decisions the Individual Participates In

The advocates described several levels of decisions in which they would include the individual. These range from minor/non-life altering decisions (i.e. choosing which color shirt to wear) to some type of participation in all decisions.

Non-Life Altering (minor) Decisions. Specifically, the advocates describe including the individual in decisions that have no lasting effect. Lisa speaks about the minor decisions she includes her daughter in “...depends what the decision is. I have to make all the decisions unless it's the basic, you know, do you want a red pen? If it's an important decision, no.... she's involved in like day to day stuff, do you want to wear this shirt or that shirt?... Nothing,

nothing life-altering. She can't make decisions that will drastically affect her life... It's just decisions that are not going to drastically, drastically affect her life... It's not leaving it up to her where it's dangerous.” Caryn shared similar sentiments, “I'll try to get her to pick out [items], you know, big decisions, not really... very basic? You know, what snack do you want? That type of stuff. Go outside or not go outside, stuff that's appropriate for a toddler.” Fanny spoke about how they present limited options and decisions to their son, “We ask him questions; yes or no. Like sometimes with what clothes he wants to wear, what he wants to eat...”

Mary describes the decisions she typically involves her daughter in, “I try to let her make as many decisions as she can, you know, what to wear, what activities to do. You know, I really, we try and let her, as long as it's not dangerous, she gets pretty much do what she wants, but, um, but, um, not for health and safety issues... In every way and anything that I can there were things in life that you don't have a choice for her and that, you know, and I really try to limit, limit those.” Angelica shares that she includes her son in decisions he can understand, “I mean, all the things directly affect him, but things that he can, I could say physically understand, not abstract, anything serious or deep he's not getting. Again, the important things in life insurance he is not getting.”

All Decisions. This theme speaks to the full involvement of the individual in decision making. Jenny shares that she includes her son in all decisions about his life, “He participates in, um, everything from daily entertainment to, um, which [day program] that he was going to go to.” Peggy, who is not a guardian, describes how she includes her daughter in all decisions, “I don't think I make any decisions completely without her input, you know, other

than like, I do the grocery shopping, you know, I pay the bills that kind of stuff... I think I fully include her in decision making.”

Donna, who is also not a guardian, shares that her son makes decisions independently, “I just figured that he would, if he needed, you know, assistance with making a decision, he would ask.” She goes further stating that at times, she does need to step in and assist, but it is rare, “and in most all areas, and ultimately, because whatever of like executive function and being a procrastinator, the plans would not be there. So, I said, I would say, okay, you're going here. I'm going to make the plans and you're going here.”

Caryl, who only has guardianship over the person due to her son's level of independence, shares that her son is included in all decisions, “I don't make any decisions for him. Everything is done with him... The other thing is we'd let him know that he has choices. There are choices, you know, every time you do something, you have a choice.” Further, there are areas of his life where he makes decisions completely independently, “He really, you know, he makes a lot of decisions on his own. Like he's decided to go to college. He decides what he's taking. He decides how he's spending his money.”

Most, Within Reason. The delineation in this theme from the previous is that that individual is involved in more than minor decisions (such as the color shirt they are wearing, what to eat, etc.), but maybe excluded from serious, life-altering decisions. Jenny, while previously stating that she includes her son in all decisions, explains further here that his participation more closely resembles all decisions that make sense to her, “I make sure that I include him in those, but because he is, um, deemed someone with an intellectual, significant intellectual disability, I still have the rights to make sure that the right decisions for his safety and financial wellbeing, you know, I really have the say so in that... I make the decisions

together. I would say probably it's 60, 40. Um, I do want his input, but sometimes, you know, he's not able to, or he doesn't care." Melanie puts what decisions her brother participates in simply, "everything that makes sense."

Kevin shares that he tries to include his son in most decisions to continue building his skills, but that his skills in this area are deficient right now, "I don't think this he has much decision-making, basically made to require the guardianship because currently all the decisions, we discuss with him and eventually will, he will make the final decision to see what it is he wants... So, I don't much using this guardianship requirements to over-throw whatever he says. We don't have a situation like that. So, so far we all are discussing ourselves here. We got agreement with each other and he will be able to, to make the final decision... I would say like 80% of his decision, small, big one, basically he was asking advice, and we give to him."

In regard to their relationship in decision-making, Kevin states "We still have like a normal kid relationship with our children. We will talk first, discuss it first, make a decision, both of us comfortable... We try to do our best to discuss with him first. Let him express his, his concern. First, if you do not have any concern, then he will asking us advice that we give our advice both sides. Good or bad one." Kevin added "So far is very low level right now, for example, what are they going to eat, right? [about big decisions] we still have to guide him to the decision-making right now." Lastly, Kevin shared about his son's ability to participate in these decisions, "so I think I can see that I try to every decision, small or big, try to include him. I ask him his opinion, do this well, but the reality is lots of the big decision, he's still looking for our advice because he has no idea what he going to do in the future there. He don't have experience, he don't have any social resources who care like a friend or something

talking about him... his first reaction is to deny, to refuse or reject it. So, all this situation that we have to encourage him and say, Oh, you have to do big decision. You cannot just refuse this one here. So, I think that's a while he going to, to learn a little bit, a little bit by himself and also with our help here. But mostly he's still looking for our advice.”

Mary described a stubbornness to her daughter and how that has affected their relationship in decision-making, “but if you say to her, well, it needs to be vacuumed. It's up to you. Five minutes later, she'll start doing it on her own. It's like, this is this independent. I really see it's because you keep calling it decision making, which it is. And I think of more is independence, but it really is the same thing. I mean, she wants to control, you know, what she's going to do. And that is just like over almost everything. Especially when I tell her to do something, she doesn't want to do it of course, because I'm her mother.” Mary has learned to use this to her daughter's benefit and still finds it important to include her in decision-making. Mary further added about the decisions her daughter is involved in, “she certainly, she puts her clothes out for herself. She decides which sheets, which blankets she wants at night. She has a lot of things scheduled, but if she doesn't want to do it and it's nothing that she has to do, she just says, I don't want to, you know.”

Angelica simply stated about her son's participation in decisions is that he is involved in “every decision there is that's major. [Otherwise] he doesn't want to be bothered.”

Why this Level of Involvement?

These themes discuss the reasoning behind including the individual in the decisions they are involved in. The participants shared both an understanding of the autonomous feelings behind being involved in decisions or if they felt their loved one's disability was too severe to be included in meaningful decisions.

Does Not Want to Take Away Sense of Agency. Although she makes most of the decisions for her son, Jenny shared that she includes him in the process so he can maintain some sense of autonomy, “I don't want to, um, take away his agency. I think there's so much of [son]'s life that he's lost his agency...It's a heartbreaking thing and I don't want to dehumanize him. You know, one of the things that separates us from other species is our ability to actually articulate what it is that we want through verbal means. And he has the ability to do that. Thank goodness. And so, I don't want it to take away one of the fundamental rights of being a human from him.” Peggy shared a similar sentiment about a sense of autonomy for her daughter. However, she does not have legal guardianship and does ensure to include her daughter in all decisions about her life “cause I do believe she has, you know, a human right to her own agency and I think that taking it away or putting my, what I want above what she might want is wrong. It's just, it's ethically wrong.”

Kevin added about his son's frame of reference in decision-making and his ability to learn to be more independent. Kevin stated, “because he's still have this normal IQ. So basically, he still have some way to learn. Okay. But he do not have a lots of experience. You don't have any social experience, social reference to other people, then he's still depending, mostly depending on us to provide to him this you know, the facts. I was options good or bad stuff there. So, I think that's one way because his level is this, he's not like a high functioning as Asperger's or something.”

Donna shared about her son's decision-making strength, “he is capable of making good decisions as long as, um, they are, are not impulsive and they are discussed so that they are, you know, thought, you know, thought out decisions.” Mary discussed the importance of providing autonomy, “everyone has to have some level of autonomy and I really, you know,

that's really important. So, uh, you know, I mean, does she, she usually decides what to wear and sometimes I grimace I really try to, to pretty much limit it to health and safety stuff to make making her decisions [for her]. I think, I hope I do. I try.” Mary added more in the same frame of thought on her daughter’s autonomy, “because she's a person, because I feel like every person gets, should get as much autonomy as they can. And it looked, you know, because it also makes them feel better. I mean, that's everyone needs that.” Angelica discussed the importance of personal responsibility, “...and it doesn't have to be a major issue. It could be something minor, but I usually confer with him because I would like him to get a little bit of a sense of responsibility.”

Not Able to Participate in Decision-Making. Lisa stated simply about her daughter’s ability to participate in decisions, “she's severely delayed. She doesn't have the level to make the decisions.” Caryn shared a similar thinking about her own daughter, “she doesn't really understand. She can't make her needs and or wants known, well, I mean beyond simple things like opening the cabinet and pulling out the snack that she wants, stuff like that.”

Does the Individual Want to Participate?

Lastly, these themes ask if the individual has expressed a desire to participate in decision-making and, through that shed light on additional information on their ability to make decisions.

Wants to Be a Part of All Decisions. Jenny’s son has shared a desire to be involved in all decisions about his life, “Oh, he definitely wants to participate in everything. He definitely has strong opinions about things and he will verbalize them over and over and perseverate on them.” Peggy, the only participant without legal guardianship, shared about

her daughter, “She's expressed that. Yes. She wants to participate. She also kind of defaults to me a lot.”

Can Only Be a Part of Simple Decisions. Lisa’s daughter is not able to express her desire to participate in decision-making, but is included in minor decisions as described above, “Not really. She doesn't really. So, you know, not major decisions.” Caryn shared that her daughter will let her wants be known, and that this is how she participates in decision-making, “Sometimes she'll let her wants known. Sometimes she'll grab your hand and take you to another room to try to get you to get something that she wants.” Fanny’s son participates in a similar fashion, “He can't really, you know, verbalize what he wants to do, but we would just ask him yes or no questions.”

Chapter Eight: Discussion

This last chapter provides insight into the findings as well as their connection to the objectives of the study. The aim of this study was to identify what the motivations were for selecting legally defined guardianship or its alternatives, and what were the observed mental health characteristics of the individual thereafter. Additional information was sought on why advocates chose a specific avenue of support and what mental health outcomes were seen as a result of that choice. Information was also sought to determine what supports and alternatives, if any, are being offered to those that clearly do not have full cognitive ability to make decisions independently but also do not meet the criteria for requiring a full guardian, and therefore may have their rights restricted. This study also looked to discover the information available on these alternatives; this was obtained through measuring access to information. The study further explored the psychosocial health of the individual following a guardianship appointment.

Through a qualitative phenomenological approach, this study explored the shared experiences of a special population. Each of the advocates that was interviewed discussed their experiences in selecting their support choice, their observations on the mental health of their loved one, and their loved one's role in decision-making. In doing so, the advocates shared information that yielded results, which were then separated into three main themes: guardianship, mental health, and decision-making. These themes encompassed several more specific secondary and tertiary themes that addressed the experiences and decisions of the advocates.

This study provided information and insight on the degree to which there is severe lack of knowledge on alternatives to guardianship. All but four of the participants could not name alternatives to guardianship, two of those four were the only participants that were not legal guardians. Despite having no knowledge of alternatives, the participants who had legal guardianship stated that they felt guardianship was the right level of care for their loved one. One guardian noted that she did not know of any alternatives but liked guardianship because it covered all of the bases to make decisions for her child.

Additionally, several participants did not know what type of guardianship they had. The researcher had to describe the differences to make it clearer to them to discern which they held, or they offered to find the paperwork for clarification. This shows that they have not had to check in with the court as this would typically refresh one's memory and were likely not aware of Article 81 as an option for guardianship (they all held Article 17A guardianship). Article 81 is a legal guardianship option for people with mental illness and the aged; it is also available to individuals with I/DD. The process for this type of guardianship is typically more time-intensive but is also more customizable to the needs of the individual; Article 17A is considered the easier route between the two (Guardianship of an Incapacitated," n.d.). This shows an additional lack of knowledge on their behalf in terms of their own rights as guardians, as they have not had to use this document, as well as lack of information on options as the researcher had to name the options for what they held to become clear.

The participants each made a point to include their loved one in decision-making to the best extent possible as per the individual's level of understanding. The two participants who did not have guardianship did note that their loved ones involved them in decisions

rather than the advocate making decisions for them. This was a notable revelation from the data, and a positive one, as studies show that a lack of participation in decision-making can lead to a negative mental health effect (Moller, Ryan, & Deci, 2006). Nevertheless, it is worthwhile to note that the decisions many of the individuals are described to be included in are minor ones at best, i.e. picking which color shirt to wear, what toy to play with, etc. As discussed in the literature, decision-making skills can be developed and ensuring the individual participates in decisions to the best of their abilities is important. McManus (2006) discussed the theory of therapeutic-jurisprudence and how participation in decision-making leads individuals to an improved sense of control and satisfaction with their decisions. In regard to the advocates' understanding of what guardianship means for the individual, some knew that it takes away the rights and spoke about it in a negative way i.e. it removed the autonomy of their loved one (even though they need to make the decisions) and others liked that it takes away the rights because they need to be the ones making the decisions.

Millar (2014) notes that there are many systems involved in the guardianship process and that a lack of a consistent language can make this system difficult for families to navigate. Several participants noted learning about guardianship from more than one source such as their child's school, their case workers, a lawyer, and/or their peers. The participants also noted some difficulty in navigating the court system during the actual proceedings, which provided them a certain level of frustration with the process. One participant noted a lack of clarity regarding the different options for guardianship therefore making it difficult for him to find the right supports for his son. Those who stated they had the most information also utilized self-direction, an OPWDD program in which the individual and their advocates can have more control and customization over their services. This shows a somewhat wider

base of knowledge about available services. They further stated they had done the research on their own with no assistance from others when looking into support options.

In discussing the mental health aspect of guardianship, some advocates did not understand the questions being posed. One advocate thought the question was about her mental health, one discussed the paperwork she needed to secure for the guardianship hearing. One participant replied that she did not think about it too much because she did not want to think about how it would affect her daughter, rather she knew it was the right choice for her needs. This shows a lack of regard for the effect guardianship can have on the mental health of the person subject to it. Those who did not hold guardianship had a much keener understanding on their loved one's mental health needs. Rather than being able to determine if guardianship had an effect on mental health, the research instead showed that the guardianship did not consider mental health as part of their decision-making process.

This was a meaningful study as the needs of this population too often are not at the forefront of research, especially regarding their rights. This is shown through the lack of available research in this specific area. The current guardianship statutes in New York State have been largely unchanged for several decades. Even with the passage of United Nations Convention on the Rights of Persons with Disabilities (CRPD) treaty of 2006, the United States has, at this time, has chosen not to ratify it (Lee, 2011). These recommendations have not been ratified to date as the civil rights given the individuals through CRPD go beyond current U.S. laws. Further, due to guardianship laws being variable from state to state, a widespread change would be difficult (Houseworth et al., 2019 and Brady et al., 2019). Future research should continue to explore these issues due to its importance to the field of

social work, but also due to its importance to policy and the rights and well-being of individuals subject to guardianship.

While these results are limited due to the nature of the sample size, the results obtained here have the potential to be influential in order to promote a better quality of life for individuals subject to guardianship. This can be focused towards their mental health, the services and information they and their advocates have access to, and/or a clearer system of services to navigate. This information is particularly crucial because it has the ability to inform policymakers, families, and other advocates as they set out to assist the vulnerable population. Moreover, it has the ability to create shifts in practice as it clearly shows that schools, case workers, and other practitioners are limited in their own scope of knowledge regarding alternatives to guardianship.

Limitations of the Study

Due to the qualitative nature of the study, the results are not considered generalizable. Additionally, this study is limited to New York State, as guardianship law differs from state to state, making this study even less generalizable for the I/DD population at large. I chose to sample advocates rather than the individuals themselves. While the best information comes from those affected by the current state of the law, this study could have posed potential harm to them, such as the interview being upsetting or stressful. There is also a potential variability in the cognitive abilities of the individuals and therefore it could have been difficult for them to understand the questions and communicate their answers. Therefore, to address this limitation, I chose to survey their advocates as they were a best option for sources of information regarding guardianship decisions and their outcomes. As this is a non-probability volunteer sample, there is an increased likelihood of a volunteer sampling bias. I

worked to address this potential bias by sampling participants through the aforementioned social service agencies, social networking sites, and private contractors, which yielded an appropriate sample size and therefore a more representative sample. Social desirability, or a desire to be viewed well by the researcher and therefore untruthful, was a concern when interviewing parents and other loved ones of individuals (Charles & Dattalo, 2018). Throughout the interviews I had no reason to believe I was not told the full truth by participants.

Lastly, four of the six participants described their loved one as severely or profoundly disabled, and two described their sons as moderately disabled as per the diagnostic criteria. Five participants described their loved one as having a mild disability (if they could not classify, their FSIQ was used). Of those classified as mildly disabled, only two of the participants did not have guardianship; one was in the process of obtaining it and one only had guardianship over the person. However, this connotes that individuals classified as mildly disabled continue to be subject to guardianship statutes when alternatives are available. This study would have been better served with a larger sample with more variability amongst the functioning levels of the individuals being discussed as well as a greater representation of alternatives to guardianship. The purpose of this study was to identify what the motivations for selecting legally defined guardianship or its alternatives and what the observed mental health characteristics of the individual were thereafter. Additionally, information was sought to determine what supports and alternatives, if any, are being offered to those that clearly do not have full cognitive ability to make decisions independently but also do not meet the criteria for requiring a full guardian and therefore have their rights restricted. It was also sought to determine if any psychosocial harm was

derived as a result of inappropriate guardianship appointment. Through the information gathered from the advocates, the individuals described to me as moderately to profoundly disabled were best supported by a guardian and did not fall within the criteria of not requiring one. Therefore, I was not able to explore the full spectrum of disability in relation to guardianship. A future, larger, study would be the best next step to address these issues.

Contributions of the Study

This study sought to examine the mental health outcomes of guardianship and its alternatives for those with an intellectual and/or developmental disability. It further looked to highlight the knowledge and availability of alternatives to guardianship. Due to guardianship law being variable from state to state, this study focused on New York State statutes. However, these results have the potential to impact guardianship laws across the globe as many countries have not ratified the proposed United Nations treaty. This is because the CRPD made recommendations for changes to guardianship procedures to improve quality of life for individuals and protection of their rights. These findings support that agenda. Further, as shown by the National Council on Disability (2019), there are several states that have outdated guardianship statutes and hold separate statutes for this population. While I sampled parents and other advocates, as opposed to the individuals directly affected by guardianship, the contributions of this study can influence advocates (parents, social workers, lawyers, etc.) for those who are subject to the statute, as well as affect practice with this population. The results of this study show a severe lack of information on alternatives to guardianship. Despite having no awareness of alternatives, the majority of the advocates interviewed continued to feel that guardianship was the right choice for their loved ones. Despite a lack of results on the mental health effect of guardianship due to the limitations previously

discussed, a contribution of this study is the advancement in understanding of the lack of information being shared to caregivers and other advocates. With that in mind, this study has the potential to inform policymakers on how to improve policy to best support the needs of this population.

As part of the NASW Code of Ethics (2017), social workers “strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people” (para. 16). The results from this study show that the advocates interviewed were guided towards guardianship by their case workers, teachers, and other professionals. Moreover, the advocates had limited to no knowledge of alternatives to guardianship. As we are meant to share all information to our clients so they can make an informed decision *and* ensure meaningful participation in decision-making, social workers should knowledgeable of all alternatives to guardianship and be ready and able to explain them to their clients. Social workers must be better educated on this population and their services. This information should be shared through social work education programs, continuing education, and places of employment if the employer caters to this population.

This may not seem like a strictly social work area as far as policy is discussed. However, social workers should be involved in the court proceedings. A social worker or other mental health professional should be assigned to the individual at the outset of the guardianship hearing. Their position must be to ensure the individual’s wants, needs, and desires are advocated for regardless if they have an understanding of guardianship. In basic ways, all individuals are able to communicate and the court should be ensuring that their voice is heard.

This study also has the potential to impact policy. Based on the literature and the research, changes need to be made to Article 17A guardianship in order to protect the rights of individuals with intellectual and developmental disabilities. Similar to Article 81, individuals should be assigned their own lawyer during the hearing. This will ensure that their rights are protected and being spoken for, especially when these rights are being prepared to be removed. Additionally, people with I/DD have slower development, not arrested development. Due to this, a guardian that was placed at age 18 may not be appropriate at age 30, 40, etc. As the individual could have acquired better decision-making skills over time, especially if taught, periodic reevaluation of the guardianship order needs to be done, such as in California and Michigan (Andreasian, et al., 2015). Periodic check-ins with the court to assess the appropriateness of the guardian and the guardianship will protect the individual from an undue removal of rights as they continue to grow and develop. This current lack of reevaluation has the potential to put these individuals at risk of harm, both emotionally and physically. Lastly, the need for functional assessments rather than focusing on IQ testing is highly warranted. Individual's skill levels in different areas of life cannot be measured by an IQ test. However, they are one of the main assessment tools the court uses in determining the functioning level of the individual and therefore their level of need for a guardian. Using functional assessments during the court proceedings would give much better insight into the individual's functioning and activities of daily living skills. Further, a specific functional assessment could be tailored to assess decision-making skills.

As for implications for future research, results of this study showed a lack of information on guardianship and its alternatives. As this was not the focus of the study, the questionnaire did not seek information on income levels; therefore, the researcher is not able

to make a determination on differences on access to information amongst various socioeconomic backgrounds. Future studies should endeavor to gain this information and compare and contrast if access to information differs between areas. Finally, this study has the potential to inform future directions to test or assess novel interventions and prevention methods for the mental health of individuals, as well as further research on the effect of guardianship and its alternatives. Specifically, a larger scale study on the same subject, using a quantitative method, may yield additional data to better inform the subject matter.

It takes an open minded individual to look beyond a disability, and see, that ability has so much more to offer, than the limitations society tries to place upon them.

- *Robert M. Hensel*

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.)
- APA Dictionary of Psychology*. (n.d.) dictionary.apa.org/cognitive-ability.
- Andreasian, K., Chin, N., et al. (2015). Revisiting S.C.P.A 17-A: Guardianship for People with Intellectual and Developmental Disabilities: *Report of the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association* (Rep.). New York, NY: City University of New York Law Review, 287-335.
- Bailly, R., & Nick-Torok, C. B. (2011). Should we be talking - Beginning a dialogue on guardianship for the developmentally disabled in New York. *Albany Law Review*, 75(2), 807-840.
- Barker, R. (1999). *The social work dictionary* (4th ed.). Washington, DC: NASW Press
- Berg, B. L. (2009). *Qualitative research methods for the social sciences* (7th ed.). Boston: Pearson.
- Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives. *Journal of Applied Research in Intellectual Disabilities*, 1078–1087.
- Brault, M. W. (2012). *Americans With Disabilities: 2010* (pp. 1–24). U.S. Census Bureau.
- Campigotto, M., & Hilburn, B. E. (2016). Petitioning for protection: Without repeal or reform of article 17a, can practitioners maintain ethical guardianship practices while

simultaneously protecting the rights of persons with intellectual disabilities. *Fordham Urban Law Journal*, 43, 869-913.

Charles, J. L., & V. Dattalo, P. (2018). Minimizing social desirability bias in measuring sensitive topics: The use of forgiving language in item development. *Journal of Social Service Research*, 44(4), 587-599.

Cohen, A. M. (2017, November). Personal communication with Andrew Cohen [Telephone interview]. Principle, Andrew M. Cohen P.C

Creswell, J. W. (2013). *Qualitative inquiry et research design: choosing among five approaches* (3rd ed.). Los Angeles: SAGE.

Curryer, B., Stancliffe, R. J., Wiese, M. Y., & Dew, A. (2019). The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*.

Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., Clift-Matthews, V., & Martin, A. (2015). Supported decision making: A review of the international literature. *International Journal of Law and Psychiatry*, 38, 61–67.

Deci, E. L., & Ryan, R. M. (2008). Self-determination theory: A macrotheory of human motivation, development, and health. *Canadian Psychology*, 49(3), 182–185.

Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106–402, 42 USC 15001, (2000).

Dinerstein, R.D. (2012). Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, *Human Rights Brief*. 19. 8-12.

Glen, K. (2018). Introducing new human right: Learning from others, bringing legal

- capacity home. *Columbia Human Rights Law Review*, 49(3), 1-98.
- Guardianship and Protective Proceedings Act. (n.d.). Retrieved July 19, 2020, from <https://www.uniformlaws.org/committees/community-home?CommunityKey=d716e47d-f50b-4b68-9e25-dd0af47a13b7>
- Guardianship, Conservatorship, and Other Protective Arrangements Act. (n.d.). Retrieved July 19, 2020, from <https://my.uniformlaws.org/committees/community-home?CommunityKey=2eba8654-8871-4905-ad38-aabbd573911c>
- Guardian for Michelle M., 41 N.Y.S.3.d 719 (Sur Ct, 2016), 1-7.
- Houseworth, J., Stancliffe, R. J., & Tichá, R. (2019). Examining the National Core Indicators Potential to Monitor Rights of People with Intellectual and Developmental Disabilities According to the CRPD. *Journal of Policy and Practice in Intellectual Disabilities*, 16(4), 1-10.
- In the Matter of the SCPA Article 17-A Guardianship Proceeding for Mark C.H., Ward., 906 N.Y.S.2d 419 (Sur Ct, 2010), 1-16.
- Johnston, A. (2014). Rigour in research: theory in the research approach. *European Business Review*, 26(3), 206–217.
- Kohn, N. A., & Blumenthal, J. A. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disability and Health Journal*, 7(1). S40-S43.
- Kohn, N. A.; Blumenthal, J. A.; Campbell, A. T. (2013). Supported decision-making: viable alternative to guardianship. *Penn State Law Review*, 117(4), 1111-1158.
- Lee, B. Y. (2011). The u.n. convention on the rights of persons with disabilities and its impact upon involuntary civil commitment of individuals with developmental

- disabilities. *Columbia Journal of Law and Social Problems*, 44(3), 393-446.
- Massad, P. M., & Sales, B. D. (1981). Guardianship An Acceptable Alternative to Institutionalization? *American Behavioral Scientist*, 24(6), 755-770.
- McManus, P. C. (2006). A therapeutic jurisprudential approach to guardianship of persons with mild cognitive impairment. *Seton Hall Law Review*, 36(591), 591-625.
- Menikoff, J. (2001). *Law and bioethics: An introduction*. Washington D.C.: Georgetown University Press.
- Millar, D. S. (2013). Guardianship Alternatives: Their Use Affirms Self- Determination of Individuals with Intellectual Disabilities. *Education and Training in Autism and Developmental Disabilities*, 48(3), 291–305.
- Millar, D. S. (2014). Addition to Transition Assessment Resources: A Template for Determining the Use of Guardianship Alternatives for Students who have Intellectual Disability. *Education and Training in Autism and Developmental Disabilities*, 49(2), 171–188.
- Millar, D. S. (2014b). Extending Transition to Address Guardianship Alternatives: An Issue Concerning Students who have Intellectual Disability. *Education and Training in Autism and Developmental Disabilities*, 49(3), 449–463.
- Moller, A. C., Ryan, R. M., & Deci, E. L. (2006). Self-Determination Theory and Public Policy: Improving the Quality of Consumer Decisions without using Coercion. *Journal of Public Policy & Marketing*, 25(1), 104–116.
- Monthie, J. J. (2016). The myth of liberty and justice for all: Guardianship in New York State. *Albany Law Review*, 80, 947-993.

NAMI. (n.d.). Future Care Planning. Retrieved July 15, 2020, from

<https://www.naminys.org/mental-health-support/navigating-details/future-care-planning/>

NASW, Code of ethics (2017). Washington, DC: National Association of Social Workers.

National Council on Disability. (2019). Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities, 1–108.

New York State Unified Court System. (n.d.). Guardianship of an Incapacitated Adult.

Retrieved from <https://nycourts.gov/courthelp/Guardianship/AIP.shtml>

National Conference of Commissioners on Uniform State Laws, (2018). Uniform

Guardianship, Conservatorship, and Other Protective Arrangements Act. 1-250.

New York State. (n.d.). Guardianship Case. Retrieved from

<https://www.nycourts.gov/CourtHelp/Guardianship/case.shtml>

New York State. (n.d.). Guardianship of a Person Who is Intellectually Disabled or

Developmentally Disabled. Retrieved from

<https://www.nycourts.gov/CourtHelp/Guardianship/17A.shtml>

New York State Report: 2015-16. (n.d.). Retrieved from

<https://www.nationalcoreindicators.org/states/NY/report/2016-17/>

New York State Report: 2016-17. (n.d.). Retrieved from

<https://www.nationalcoreindicators.org/states/NY/report/2016-17/>

New York State Unified Court System. (n.d.). Guardianship of an Incapacitated Adult.

Retrieved from <https://nycourts.gov/courthelp/Guardianship/AIP.shtml>

Olmstead Development and Implementation Cabinet, (2019). Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting. 8-30.

Olmstead v. L.C., 527 U.S. 581 (1999)

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78.

Shea, S. E., & Pressman, C. (2018). Guardianship: A Civil Rights Perspective. *NYSBA Journal*, 19-25.

Surrogate's Court Procedure, SCPA, Sections (§§) 1750-1761, (1969).

The NADSP Code of Ethics. (2016, April 12). Retrieved from <https://nadsp.org/code-of-ethics-text/>

United Nations, (2008). Convention on the Rights of Persons with Disabilities and Optional Protocol. 1-31

Zhang, D., Walker, J. M., Leal, D. R., Landmark, L. J., & Katsiyannis, A. (2019). A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning. *Journal of Child and Family Studies*, 28(7), 1803–1814.

**Appendix A:
An Exploration of Guardianship: A Qualitative Study**

Dear Intellectual/Developmental Disability: colleague, neighbor, clinician, administrator, etc.:

My name is Rachel Minkoff, LMSW and I am a doctoral candidate at Yeshiva University, Wurzweiler School of Social Work. I am requesting your participation in a study about the motivations for selecting legally defined guardianship or its alternatives and the observed mental health characteristics of the individual thereafter.

The purpose of the Study:

This study explores the motivations for selecting legally defined guardianship or its alternatives and the observed mental health characteristics of the individual thereafter. There is a need to investigate this because participation in decision-making is shown to have an effect on the mental health of individuals with disabilities. This study hopes to generate more knowledge around why advocates for individuals choose the guardianship route that they do and what effect it has on the mental health of the individual they support. Findings may also be able to inform to what extent individuals with different types of support participate in the decision-making process.

This interview should take approximately 60 minutes or less to complete. We'd like to schedule a Zoom (computer or smartphone) based interview by July 31st, 2020 by calling 347-633-1904 or emailing Rachel.minkoff@mail.yu.edu.

Consent Information:

The interview questions were developed to better understand the motivations for selecting legally defined guardianship or its alternatives and the observed mental health characteristics of the individual thereafter. The interview will include questions about what type of support you provide to the individual, their mental health, and their role in decision-making. Your interview will be recorded and transcribed for research purposes. To protect confidentiality, the recorded interview will be deleted from all files once your recorded answers have been transcribed into text. Your name and contact information will be deleted from the file and you will be assigned a participant ID number or code name. Your informed consent form will be kept in a password protected computer in an encrypted folder for three years as is outlined for ethical research procedures. At the end of the three years, it will be deleted. Thank you so much for your shared insight and time! By signing the attached consent form, you agree that you are over the age of 18 and you are consenting to this interview and the publication of the information therein.

The Institutional Review Board of Yeshiva University has approved this study.

- **The survey is online and by hitting the Agree button, you are consenting to participating in this study.**
- **Your participation is entirely voluntary and will be de-identified.**
- **You can discontinue participating in the study at any time without any penalty.**

- **All written and published information will be reported as group data with no references to agency or names.**

Thank you so much for participating!

Should you have any questions, please feel free to contact the researcher student name at:

Rachel.minkoff@mail.yu.edu

Sincerely,

Rachel Minkoff, LMSW

Appendix B:

Interview Questions

A. DEMOGRAPHICS

1. Age:
2. Sex:
3. Race:
4. Religion:
5. Employment: Full time, part time, self-employed, unemployed, other
6. Location: Lower New York (Long Island Area), New York City, Upper New York (Westchester and Above)
7. Please list the disability(s) that the individual has:
8. Functioning level of the individual as defined by their most recent psychological evaluation
 - a. Mild disability
 - b. Moderate disability
 - c. Severe disability
 - d. Profound disability
9. Full Scale IQ Score
10. Age of the individual:
11. Sex of the Individual
12. Living Arrangements of the Individual
13. What is your relationship to the individual?
 - a. Parent
 - b. Sibling
 - c. Other family member (please specify)
 - d. Other (please specify)
14. Please describe the individual to me
15. Do you provide legal guardianship?
16. What type of support do you provide?
 - a. Article 17A guardianship
 - b. Article 81 guardianship
 - c. Other support method (please specify, can be more than one possibility)) (i.e. supported decision-making team member, representative payee, durable power of attorney, health care proxy, other)

B. QUALITATIVE

a. Support Method

1. How long have you maintained this support role?
2. What led you to taking on this support role?
3. Please describe what factors contributed to you taking over this role if applicable.
4. How old was the individual when you decided to formalize this support method?

5. Please describe any age-related factors that contributed to you formalizing this support role.
 - a. Please describe anything related to the age of the individual that led to your decision to formalize your support role
6. Please describe any factors that are not related to age that led you to seeking formal support methods.
 - a. Please describe anything besides the age of the individual that led to your decision to formalize your support role
7. Please describe what motivated you to choose the form of support that you are currently using?
8. Who, if anyone, guided you towards a specific support method?
9. What support method(s), different from your current, would you choose at this time if it was available, and why?
10. Please describe any additional information you would have liked while formalizing your support role.
11. Can you please describe your understanding of what Article 17A guardianship means in terms of supports and rights for the individual (ward)?
12. Please name and describe other support options that you are familiar with.
 - b. Mental Health**
 13. Describe how you know if the individual's mood has changed
 14. Please share your observation about the mental health of the individual since taking your supportive role.
 15. What do you think has contributed to the mental health of the individual since taking your supportive role?
 - a. In what ways has your role as the guardian affected the mental health of the individual?
 16. To what extent did you seek guidance from a mental health profession prior to taking your supportive role?
 - c. Decision-Making**
 17. What decisions do you make for or on behalf of the individual?
 18. A) To what extent do you include the individual in decision-making?
 - a. (range from I make all of the decisions to they make all the decisions themselves/I include them in all decision making)
 19. B) Why this level of involvement in decision-making?
 20. Describe how the individual is involved in decision-making.
 21. Please describe the individual's expressed desire to participate, or not, in decision making.
 - a. Does the individual express a desire to participate in decision making? Please elaborate
 22. What types of decisions does the individual participate in?