

Connecting postsecondary quality of life to promises of IDEA: An issue of educational equity

by

Margaret (Nikki) Heiman

B.S., Peru State College, 2002
M.S., Emporia State University, 2009

AN ABSTRACT OF A DISSERTATION

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Abstract

This mixed methods study on postsecondary outcomes for individuals with disabilities focused on the experiences of young adults with intellectual and developmental disabilities (IDD) and significant disabilities from their perspective. The research questions include understanding their overall quality of life (QOL), the supports, services, and experiences they received during Individuals with Disabilities Education Act (IDEA) Part B, and how these experiences contributed to their current QOL as young adults. The study used a constructivist and pragmatic worldview, focusing on the importance of understanding IDEA supports and services from the perspective of individuals who received them.

The research design involved collecting both qualitative and quantitative data, with the qualitative phase informed by the quantitative phase. The research was completed in two phases, with the first phase focusing on the participants' overall QOL rating using the Wisconsin Quality of Life Survey and the second phase on the qualitative aspects of their QOL. The research provides a more comprehensive understanding of the experiences and perspectives of young adults with disabilities in postsecondary education.

Ultimately, the study participants emphasized the challenges they face as young adults transitioning from IDEA Part B to adulthood. They stressed the importance of social networks and the need for individualized education plan (IEP) teams to support social nuance and meaningful connections throughout all their IDEA journey. The findings also bring to light the need for specialized ages 18-21 special education services, which are crucial for cultivating employability skills and life competencies. The findings in this study highlight the need for bridging the gap between policy and practice, which would empower young adults with disabilities to chart their own destinies with autonomy and agency. By bridging this gap, we can

better create a future where individuals with disabilities are not just survivors but architects of their destinies, with dignity, in a place where opportunities abound.

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Approved by:

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Your stories are powerful reminders of resilience, determination, and the unwavering spirit that propels individuals forward despite societal barriers. By sharing your narratives, you have not only shed light on the challenges faced by those with disabilities but have also paved the way for greater empathy, understanding, and inclusion. Your voices are instrumental in driving meaningful change and dismantling the barriers that hinder progress toward a more equitable society.

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Dedication

My son, Trenton, was born perfectly with an extra 21st chromosome. I have spent the last 20 years of my life trying to unpack the personal and professional puzzles of creating a beautiful life for this young man who brings others so much joy with his infectious laughter. Trenton's sisters, Madelynn and Kaydence, are just as dedicated as I am in figuring out how to do life as a family impacted by disability. Madelynn is a fierce advocate for Trenton's social life, always trying to help him find a date to prom or social event. Kaydence has admired him since she was born. She is innately sensitive to society's discriminatory attitudes and practices toward people with disabilities. Having an older brother with a disability has given them a perspective on life that has given them incredible compassion and empathy. I am so proud of all three of my kids and appreciate them being patient with me as I worked to achieve this dream of my own. This work is dedicated to all three of them.

Thanks to my mom, Lorinda, who encouraged me to become a teacher; the 6th generation teacher in our family. I'll always cherish the hours and hours my sisters and I spent in her classroom in the evenings, weekends, and on summer breaks as children.

In loving memory of my dad, Don. Thanks for always telling me I could be anything I wanted. When things get tough, I hear your voice telling me I'm tougher.

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Chapter 1 - Introduction

One in five citizens in the United States live with a disability (Hughes & Avoke, 2010). This is the fastest growing minority group in the country. Disability will impact everyone at some point, no matter race, ethnicity, or socioeconomic status. In the last four decades, aggressive legislation has been passed assuring students with disabilities have access to a “Free and Appropriate Education,” (*Fulfilling the Promise of IDEA*, 2018) presumably ensuring equity amongst their peers. However, the post-secondary outcomes of students with disabilities remain alarmingly low. People with disabilities experience significantly higher rates of food insecurity, inadequate housing and medical care, difficulty paying bills, and a lower quality of life (QOL) (Hughes & Avoke, 2010). Adults with disabilities in the United States account for more than 42 million people (Bureau, 2022). Thirty-five million are disabled significantly enough to interfere with daily living, the majority of whom are graduates, completers, or former students of programs promising an equitable education (*Disability Rights Movement | Backgrounders*, 2017).

Public policy, specifically the Individuals with Disabilities Act of 1975 (IDEA), clearly articulates the rights of students with disabilities to an education equitable to that of their nondisabled peers. However, achievement outcomes continue to be abysmal; according to the National Assessment of Educational Progress (NAEP), academic achievement for students with disabilities in reading and math has shown little improvement over time (*Fulfilling the Promise of IDEA*, 2018). Ninety-eight percent of districts throughout the United States report not having adequate special education personnel to provide the services and supports required to meet the needs of students (*Personnel Shortages in Special Education and Related Services*, 2021). With as many as 82% of professionals in the United States reporting there are not enough special

education and related service providers to fill vacancies, many districts are hiring staff on nontraditional licensure pathways to fill the void (*Personnel Shortages in Special Education and Related Services*, 2021). When teachers lack the appropriate credentials and/or are expected to manage impossibly high caseloads, the turnover rate is significantly higher and student outcomes are lower while teachers are completing their training (Curry et al., 2018). Students with more significant disabilities often require supports from adult services, through vocational rehabilitation (VR), but due to staff shortages and high turnover in that field, they are also dealing with exceptionally high caseloads, rapid turnover, and new staff that require intensive training to adequately support people with disabilities (Jones et al., 2020).

It is clear this problem is systemic, multi-faceted, and complex. While students and their families are promised a free and appropriate public education (FAPE), districts are often faced with many challenges when tasked with providing FAPE. There is a chronic lack of highly qualified personnel trained to deliver specialized services (*Personnel Shortages in Special Education and Related Services*, 2021). Students with disabilities graduate high school and are unemployed or underemployed, and they spend their lifetimes requiring public financial assistance such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and Medicaid to access necessities for life including food, housing, and healthcare. The cost of this cycle of inadequacy is shocking (Hughes & Avoke, 2010). The financial cost for taxpayers is in the billions of dollars annually for both teacher recruitment and retention and ongoing public assistance for the millions of Americans who want to work but were not appropriately prepared or supported to be successful in the workplace (Hanushek, 2010). Most costly, however, is the expense individuals with disabilities pay themselves, which is their overall QOL. Many of these individuals want to work but lack skills and support. Many others

falsely believe they cannot work because they believe they will lose access to Medicaid and other government programs if they work (Employment Systems Change Coalition, 2017); (Janus, 2009).

Perhaps one of the largest hurdles to overcoming the barriers to equity in education is clarity in understanding exactly what FAPE (as promised in IDEA) really means. Several court cases have come before the supreme court since the enactment of IDEA. In 1982, the case of Amy Rowley was heard in the supreme court. Amy Rowley was a deaf student who, according to her individual education plan (IEP) which is the centerpiece of IDEA, was to have access to a frequency modulation (FM) hearing system. Amy's parents requested a sign language interpreter but were denied because the school claimed she was making the appropriate academic gains (Jansen, 2017, p. 4). The court eventually concluded that there was a disparity between her achievement and her potential due to lack of access to the curriculum. In 1982, the supreme court ruled that IDEA did not require "[s]trict equality of opportunity or services," or rather the requirement was only "de minimus" (Jansen, 2017, p. 4).

In 1997, amendments were made to IDEA to require not only measurable annual goals, but also a statement of a description of how the goals were going to be evaluated. Public Law 105-17 added that at age 16, there must also be a section dedicated to how the student is working toward postsecondary success with measurable postsecondary goals (A History of the Individuals with Disabilities Education Act, 2023). In 2004, another amendment was added to require states to align their goals for students with disabilities to students without disabilities (Individuals with Disabilities Education Act, 2019). This revision was meant to improve accountability, and therefore, improve outcomes for individuals with disabilities. This was part

of the No Child Left Behind reauthorization (A History of the Individuals With Disabilities Education Act, 2023).

In 2017, the case of *Endrew v. Douglas County School District* provided more recent clarifying statements (Jansen, 2017). Endrew had a dual diagnosis of Autism and ADHD and was not making progress on his IEP goals, so his family enrolled him in a private school and sued the public school to pay for his education. The petitioner pointed out that as far back as *Brown v. Board of Education*, the supreme court itself claimed the purpose of state and local government is to “awaken the child’s cultural values, prepare them for later professional training, and help them to adjust normally to their environment” state (*Brown v. Board of Education of Topeka*, 347 U.S. 483, 1954 p. 494) The 1954 *Brown v. Board* ruling goes on to state:

In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right which must be made available to all on equal terms.
(*Brown v. Board of Education of Topeka*, 347 U.S. 483, 1954 p. 494)

The question for the courts then became, if that is the standard for everyone else, then why is the standard for students with disabilities “de minimus,” as that seemed to be a contradictory ruling (Jansen, 2017).

The *Endrew* case spurred the Tenth Circuit to analyze the original statute of IDEA and the agreement was that congress never guaranteed “any specific outcome for children with disabilities...”, rather, it promised “to provide full opportunities and benefits for students with disabilities and not merely borderline ‘de minimus’ ones” (Jansen, 2017, p. 9). The final ruling in *Endrew* stated it was the court’s belief IDEA “requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances,”

which, unfortunately, leaves a considerable amount of ambiguity due to the “in light of the child’s circumstances” (Cowin, 2018, p. 604).

To gain clarity, Cowin (2018) wrote in *Northwestern University Law Review*, an article that broke that standard down into a two-part test. The first part evaluated whether the IEP includes adequate resources to develop IEP goals, monitor student progress, and implement instruction. Adequate resources can include instructional materials, technology, and professional development for staff and is also inclusive of academic, social-emotional, and behavioral goals. The second part evaluated the substantiveness of the IEP goals. Each year, the IEP must consider the prior year’s performance, have ambitious goals, and consider state and local educational standards. For students who are 16 and older, postsecondary transition goals must be created, and vocational assessments must be completed as part of the annual IEP. The Endrew case was seen by many in the disability advocacy community as a win to raise expectations and take another step toward equity, but as with the Rowley case in 1982, there continues to be a broad range of interpretations of the ruling, which causes frustration for parents (Cowin, 2018).

Children with disabilities in the United States are promised a FAPE (*Fulfilling the Promise of IDEA*, 2018). Parents, when they learn that their child has a disability, should be relieved to know that their child will be appropriately educated among their nondisabled peers. Read collectively, the body of literature presented in chapter 2 can be interpreted to suggest the intent of the law is for parents to be presented with services and supports so they will have peace of mind that their child will be successfully integrated into their local communities. Instead, the reality is that people with disabilities (PWD) is the largest minority group in the United States yet to acquire basic civil rights (Marini, 2017). When students with disabilities complete IDEA Part B services, they enter adult services where they learn it remains legal to pay PWD far below

the federal minimum wage (WorkforceHub, 2016). Corporations holding 14C tax exemptions, allow them to not have a minimum wage floor when hiring PWD, meaning, they are allowed to pay PWD as low as \$0.01 per hour legally in the United States (WorkforceHub, 2016). If you happen to be one of the one in five Americans with a disability, you are statistically most likely to experience food and housing insecurity, unemployment, and be dependent on government programs like Medicaid, SSI, or SSDI (Hughes & Avoke, 2010). PWD are also more likely to struggle to have basic needs met and experience a lower QOL (Hughes & Avoke, 2010). PWD who are also of an ethnic or racial minority descent, those statistics increase significantly (Hughes & Avoke, 2010).

Statement of the Problem

Laws and policies have been in place for decades promising equity for all. Nondiscriminatory educational policies have been ensuring equitable access to education for students with all levels of physical and cognitive needs and abilities. Despite all those promises, very little research has been done to identify how individuals with intellectual and developmental disabilities (IDD) and significant disabilities perceive the quality of their own lives, or how they define success or QOL after receiving those services.

The existing literature does not provide guidance to help us understand if the level of education currently being provided is contributing to a better life for people with IDD and significant disabilities from their perspective. There is literature regarding the weight of disability on families, especially mothers, and the cycle of poverty that individuals with disabilities experience (Lee, 2015; Parish et al., 2008).

There is a significant amount of literature on legislation regarding the Americans with Disabilities Act (ADA) and how businesses have been marginalizing the intent of the ADA at the

expense of PWD. For example, as recently as 2011, there was a class action trial against the city of New York for their lack of emergency preparedness during hurricane Irene. Judge Furman, in the *Brooklyn Center for Independent Living of the Disabled v. Bloomberg* class-action trial, found the city of New York negligent in fulfilling their legal obligations under the ADA (Marini, 2017). Among other infractions, they gave 911 and 311 operators no information on how to evacuate people in wheelchairs and did not have a coordinated plan to evacuate those with disabilities. Judge Furman called it “benign neglect” of citizens with disabilities, adding that even the shelters were inadequate and inaccessible to the needs of those with disabilities (Marini, 2017, p. 22). Judge Furman further stated that in the future, emergency preparedness groups should bear the responsibility of creating accessible shelters under the ADA, noting:

When it comes to disasters, people with disabilities are often viewed by many as the least worthy of saving. This sentiment echoes across industries where airline policies are that in the event of an emergency, those with disabilities will be assisted only after all able-bodied people are evacuated (Marini, 2017, p. 22).

This accountment and powerful quote from Judge Furman regarding the ADA and emergency management demonstrates the sentiment that people with disabilities come last in planning. This is a recurrent theme. Emergency and disaster preparedness is a literal life or death example of the stress that falls on family members and self-advocates. Loved ones and caregivers understand from very early on the sociological hierarchy of their child, and have a belief set of “if not me, then who?”. This onus of responsibility to meet every need in every potential situation places extreme stress on the caregiver, often the mother (Lee, 2015). This level of extreme stress over time leads to chronic health issues in caregivers and warrants the investigation of QOL for PWD. In addition, the role and responsibility of public education to

give students with disabilities the skills they need to obtain the best QOL they can achieve, given their strengths and talents despite their disability must also be addressed.

A significant gap in literature exists in how individuals with disabilities and their families/caregivers are being served by policies and programs and if they feel their needs are being met for equitable post-secondary success. The literature review in chapter 2 outlines aggressive legislation that has created tremendous change in the last 100 years. That legislation is largely thanks to families and caregivers that refused to accept that their child be treated any less than any other child. Legislation lays the groundwork for equal rights. However, when the literature is synthesized, it appears there is a significant gap between policy and practice, and an even larger gap when analyzing intended outcomes. One potential cause preventing these policies becoming fully realized is decades of systematic underfunding. Throughout the literature, there are stories of powerful legislation and insufficient funding to support these intended outcomes (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018).

Purpose of Study

IDEA promises a FAPE with specially designed instruction (SDI) developed to equitably meet the unique needs of each student identified as having a disability (Individuals with Disabilities Education Act, 2019). This led the researcher to perform a simple Google search to identify what the purpose of public education is for all students. If the promise is an “equitable education,” what would be the measuring stick that could be used to identify it as “equitable”? The first challenge with this inquiry is that the National Education Association (NEA) has determined there is a lack of clear consensus on the purpose of education (Walker, 2016). If there is no clear consensus on what the purpose of education is for all students in general, how could anyone define what it means to provide an equitable education? Yet, there are federal

compulsory education laws, and a high school diploma is often required for employment in adulthood.

In 1954, *Brown v. Board of Education* provided clarity on the purpose of education, stating that education lays the foundation for good citizenship (*Brown v. Board of Education of Topeka*, 347 U.S. 483 1954). It expanded to state a quality education is “the principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment” (*Brown v. Board of Education of Topeka*, 347 U.S. 483 1954, p. 494.). In the body of research reviewed, this statement provides the most clarity at the federal level. While this statement would be difficult to use as a measuring tool to decide equity, it provides supporting evidence of the incredible value of giving students the tools they need to be successful when they graduate or complete their experiences under IDEA Part B.

Since the participants in this study are Kansas residents, this research uses the Kansas State Board of Education (KSBOE) outcomes which defines a successful high school graduate as an individual that is academically and cognitively prepared, has technical and employability skills, and demonstrates the appropriate civic engagement skills necessary to be successful in the postsecondary option of their choice, whether that is higher education or entering the workforce (*Board Outcomes*, 2023). Kansas utilizes the Rose Capacities as the basis for determining the standards of success (Kan Legis. Assemb, 2014 H.B. 2506). The Rose Capacities are used in several states and are based on the opinions and outcomes of the *Rose v. Council for Better Education* lawsuit in Kentucky. In that lawsuit, it was decided the Kentucky General Assembly had not been providing an effective statewide school system that had previously been constitutionally mandated (*Rose v. Council for Better Education*, 1989).

Kansas adopted the Rose Capacities in March 2014 after the *Gannon v. State of Kansas* school finance decision was made because the courts in Kansas said these were the standards for determining suitable funding levels for public schools in Kansas (*The Rose Capacities Primer for Kansas Boards of Education*, 2014). The Rose Capacities include communication/basic skills, civic and social engagement, physical and mental health, arts and cultural appreciation as well as postsecondary and career preparation (*The Rose Capacities Primer for Kansas Boards of Education*, 2014). It is beyond the scope of this study to cover all the Rose Capacities. This study focused primarily on the areas of postsecondary and career preparation, although participants shared information about communication and basic skills and physical and mental health as well.

Although there are both long-held federal and state legislative and policy mandates (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018) promising equity in education, they have all fallen short of their funding promises. Important questions to this study include: Are there educators who have discovered simple, pragmatic strategies to prepare individuals with disabilities for post-secondary success despite the lack of funding? What are the most meaningful or impactful school experiences through the lens of someone with a disability? Can we use that knowledge to inform future practice? The purpose of this study is to better understand how young adults with IDD and significant disabilities perceive their QOL, with a particular emphasis on how they define “success” and to disclose and describe the practices and activities they perceive that contributed to their successes and postsecondary QOL. This study intentionally focused on individuals with more complex needs and those who required more support in adult services.

To achieve the study’s purpose, the research plan involved communicating directly with individuals with IDD and significant disabilities who have a variety of needs, including those

with more significant needs who relied on personal care attendants and family members or caregivers to make decisions or assist with daily living and communication. Because there are varying methods of measuring the significance of disability, data collection included questions about how much support a person needed to perform activities of daily living (ADL).

Significance of Study

On a national level, IDEA promises a FAPE, yet the definition of what is appropriate for individuals with more significant disabilities remains unclear, particularly by their definition. This study provides an opportunity and foundation to better understand what it means to provide equitable education access directly from the voices of self-advocates who have recently graduated from an educational system. If self-advocates can define what a good life means to them, and a way to measure it can be developed, it will serve to provide valuable information for accountability and systems built for each student. Currently, the United States has a federal system that is underfunded and understaffed. Promises of equity abound in the literature, yet statistically, if you have a disability, you are most likely to experience poverty (Hughes and Avoke, 2010). If you are a minority with a disability in the U.S., that statistic increases significantly. This study offers unique insight into the lived experiences of individuals with IDD and significant disabilities. To treat other humans with dignity is to respect and honor their lived experiences. Once we all understand the experiences of people with disabilities (PWD) and involve them in decisions and planning, we may be able to provide the equitable education that has been promised for decades.

Research Questions

The study will be guided by the following research questions:

1. How do young adults with IDD and significant disabilities feel about their overall QOL?

2. What supports, services, and experiences did young adults with IDD and significant disabilities have during IDEA Part B?
3. How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences that contributed to their current QOL?

Theoretical Framework

On a small scale, this work gives voice to individuals with disabilities regarding the level of accessibility they experience in a FAPE, promised to them decades ago. On a more local level, their voices can help Kansans develop a system that includes their voice and vision to lead the world in the success of *each* student. The constructivist worldview with a pragmatic or salutogenic theoretical framework offers an appropriate and viable framework for this study. In simple terms, what are practical ways we can look at practices that are working to create change? Constructivist research has historically given voice to marginalized people and advocated for reform (Creswell & Creswell, 2018). This is often seen in anti-discrimination and social justice work. According to Creswell, “For the mixed methods researcher, pragmatism opens the door to multiple methods, different worldviews, and different assumptions, as well as different forms of data collection and analysis” (Creswell & Creswell, 2018, p. 11) This is a mixed methods constructivist research study, open to different perspectives from the participants.

While the timeline of events and the progress that is documented in chapter 2 may lead readers to believe there continues to be a path of inadequacy and inequity for individuals with disabilities, the researcher is committed to leaving open the possibility that successes are occurring so that they can be documented, and the education community can learn from them. The research outcomes will follow the data, giving voice to marginalized and underrepresented individuals with disabilities while informing improved practice in the education community.

Study Design and Methods

This mixed methods research study aims to provide a comprehensive understanding of the QOL of individuals with IDD and significant disabilities by combining quantitative and qualitative research approaches. The study begins with a quantitative survey of their current QOL and progresses to a qualitative exploration of their experiences during IDEA Part B.

The first phase of the study employs quantitative research methods to assess the current QOL for individuals with IDD and significant disabilities. The Wisconsin Quality of Life Survey was used which measured a variety of QOL dimensions to give an overall life satisfaction score (Diamond et al., 1999). This provided a broad scope of the perceptions of QOL of individuals with IDD and significant disabilities.

The second phase of the study delved into the lived experiences of individuals with IDD and significant disabilities during their educational journey under the IDEA Part B. There was an in-depth exploration of their challenges, experiences, and support systems during their formative years. Participants shared narratives that offered insights into the impact of how their education impacted their current post-secondary QOL.

By analyzing the data at each phase and then synthesizing the data when both phases were complete, the study offers a holistic perspective. The triangulation of data provides a comprehensive view of the factors that contributed to the participants' current well-being. Understanding the link between their past experiences and their current QOL can inform both policy and practice to improve outcomes for individuals with IDD and significant disabilities.

Delimitations

Delimitations of this study include the population and scope of the work. The population of this study focused on students with IDD and significant disabilities. This study was not

intended to be a comprehensive study of all the individuals included in IDEA. Participants shared in both phases the level of support they required in daily living activities to articulate the categories most representative of their experiences.

A second delimitation exists in the timeframe of the study. The Covid-19 global pandemic erupted in March 2020. In Kansas, schools shut down from March through May 2020, with some schools remaining closed throughout some or all the following academic year (Dwyer, 2020). This study was conducted in 2023-2024, when the world was still learning the long-term impact of a global pandemic, not only in school systems but on the individual mental health and QOL of all, not just people with disabilities. It is anticipated some of the participants will have participated in IDEA Part B during Covid-19 when schools were shut down (Muir Knox, 2024). There is no way to differentiate pandemic related experiences from strictly disability related experiences as the pandemic impacted all facets of life.

Throughout this paper, IDEA as federal legislation is mentioned. However, this study is limited to individuals who recently graduated or completed a course of study in a public school system in Kansas. The Kansas Constitution, article 6, section 5 explains that Kansas is a local control state, meaning each local school board has significant control over the operations of a school (Kan. Const. Art. 6. §5). Students may have entirely different experiences due to the beliefs and practices of each local school board. This research generalized the responses in identifying patterns, but some practices may be community-based and not state-based.

An additional delimitation exists in that the population of participants in this study is limited to individuals with who are more significantly impacted by their disabilities, or IDD, which leaves out students with mild to moderate learning disabilities. Students in this disability category may also include students with multiple diagnoses such as blind or low vision or deaf or

hard of hearing in addition to IDD. Some participants may not be able to respond to the questions without the assistance of a caregiver who has the potential to alter the data.

Limitations

A limitation of this study is there is no standardized way to define mild/moderate or significant disability. While there are various measures such as intelligence tests, there are other factors involved such as an individual's ability to adapt that could impact how much they are impacted by their disability (Bertelli et al., 2018). For example, there could be two people, both with similar intelligence quotient (IQ) scores in clinical ranges indicating an IDD criterion in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (Bertelli et al., 2018). However, if one of those individuals can perform activities of independent daily living, it may indicate they are less impacted by their disability, even though clinically, they appear to be similar based on that measure. The scope of this research did not involve triangulation of data to measure an individual's cognitive or adaptive performance or level of independence. The focus remained on their lived experiences. To keep that focus, the participants self-reported how much their daily lives were impacted by their disabilities, and participants were not required to self-report any official diagnosis due to this nuance.

Phase two of the study included only five participants and while there was intention to select a variety of participant level of independence with ADLs, all participants had stable family lives and secure housing. In addition to these data, demonstrating that subminimum wage continues to be practiced across the United States, Hughes and Avoke (2010) write extensively about the intersectionality of disability and poverty. A larger pool of participants may find more food, healthcare, and housing insecurity closer in alignment to the literature (Hughes & Avoke, 2010; WorkforceHub, 2016).

Additional limitations include the scope of this study, characterized by a small sample size and the characteristics of participants that may have shaped the findings and some of the conclusions drawn from the research. The extensive nature of the quantitative component of this study may have prevented some people who are very reliant on others for assistance in communication from being able to complete the survey. It's plausible the participants who completed the entire study were more likely to possess a certain level of independence, thus potentially excluding individuals with more profound disabilities. This inherent bias in participant selection underscores the importance of acknowledging the limitations imposed by the study's design and sample characteristics.

In particular, the qualitative segment of the study, comprising of only five participants, further highlighted the inherent constraints of the research approach. Notably, all participants hailed from stable, supportive family environments, a factor that emerged as a consistent theme throughout the study. This reliance on familial support manifested in various facets of participants' lives, influencing their experiences and perceptions in profound ways. However, it's crucial to recognize that this thematic consistency may not necessarily reflect the broader spectrum of experiences within the disability community.

A salient limitation is the recognition that the familial context plays a pivotal role in shaping the experiences of individuals with IDD and significant disabilities. However, the homogeneity of the sample limits the generalizability of these insights. A more comprehensive study that encompasses participants from a more diverse array of familial backgrounds could yield markedly different findings.

By expanding the participant pool to include individuals from varied familial contexts, ranging from those with robust support systems to those facing more complex challenges, a

richer and more nuanced understanding of the dynamics at play could be attained. Capturing a broader spectrum of experiences could shed light on the resilience strategies employed by individuals with IDD and significant disabilities across diverse familial settings. By embracing diversity and acknowledging the multifaceted nature of lived experiences within the disability community, an opportunity to generate more comprehensive and contextually grounded understandings of QOL and well-being could be achieved.

Connecting Literature, History, Public Policy and QOL

The following chapter will include a literature review. The literature review details the history of civil rights of individuals with disabilities and the progression of significant events over time. Chapter 2 will cover the progress in legislation and public policy; however, this historical account does not paint a complete picture of what life has been like for those with disabilities when considering important news and headlines during similar time frames.

Importantly, the literature review also uncovers and demonstrates there has been a population of individuals with disabilities whose standard of living and QOL has been chosen, largely without their voice.

Chapter 2 - Literature Review

The literature review will present a historical framework, followed by a juxtaposition of promising progress in public policy regarding civil rights for individuals with disabilities highlighting news and headlines from individuals with disabilities that tell a different story. The standard of living for individuals with disabilities has long been determined by individuals without disabilities with very little voice from the individual or disability community. At the end of this chapter, promising literature about the study of QOL will be shared, and its relevance in improving outcomes for people with disabilities, using their voices and giving them choice. There are promising practices happening in isolation across the country, but unfortunately, none of them are being implemented in a systematic way. Viewed collectively, throughout our history, disability services and support do not align with policies and practices promising equity over time.

Historical Perspective

Throughout history, disability has been something that many cultures have struggled to understand (Marini, 2017). This section will consider practices from early civilization until the twentieth century, drawing primarily on the work of Marini (2017).

In early civilization, many cultures such as the Greeks, Romans, and Hebrews practiced infanticide (the killing of an infant) or eugenics (selective reproduction to “breed out” a certain disease, ailment, or undesirable characteristic within a population) due to cultural or religious reasons. Some Romans allowed individuals with intellectual disabilities to live only because they owned them, and they allowed them to perform as court jesters (Marini, 2017).

By the Middle Ages, 600-1500 AD, the principles of Christianity were beginning to spread. The Old Testament linked disability to sin many times, claiming that if a person had a

strong enough faith in God, their disability would be cured. This also implied conversely, if their disability was not ever cured, their own sin and lack of faith was the cause of their disability or blindness. While Christians were beginning to put forth efforts to “save” individuals with disabilities, the practices of killing and torturing people with individuals continued throughout Europe. Disability was viewed as something that wasn’t understood; therefore, it was to be feared (Marini, 2017). This fear-based mindset continued for centuries.

During the Renaissance period, 1500-1700, small medical advancements led to longer life expectancies and more understanding of physical ailments. Unfortunately, that progress was slow. Between the years of 1480-1680, the “The Great Witch Hunts” occurred, where up to 20 million people, mostly women, accused of witchcraft were murdered (Marini, 2017). We now know many of the markers of what they believed to be witchcraft were more accurately symptoms of mental illness or disability. Occasionally, a woman was accused of witchcraft and murdered just for giving birth to a child with an impairment or disability (Marini, 2017).

In colonial America (1620-1800s), like the Christians of the Middle Ages centuries before them, the Quakers viewed disability as a punishment from God and a child with a disability was something of which to be ashamed. These children were either quietly kept at home or sent to asylums that were run as prisons. Medical advancements were made when Benjamin Franklin supported the Quakers in building the first hospital in America. Prior to the first hospitals, medical healers were either self-trained or poorly trained. When a government supported hospital was built, this was followed by the establishment of formal medical schools and better training for “healers,” or doctors, which would prove to be essential for individuals with complex needs. While hospitals were supposed to be open to everyone, many with disabilities or mental illness were turned away or treated poorly (Marini, 2017).

The Industrial Revolution between 1790 and 1870 brought many changes in the United States. With the sudden influx of urbanization and factories and no government oversight or regulations in those factory settings, workers were becoming injured on the job, which created a new type of disability. This eventually led to worker's compensation legislation. When companies could no longer immediately fire employees for becoming injured on the job, they had to learn how to modify or create work accommodations for employees to continue to work on the factory lines (Marini, 2017). Eventually this led to legislation that would serve as the foundation for the Fair Labor Standards Act (WorkforceHub, 2016).

Hope arose by the mid-1880s, for students who were deaf/hard of hearing or blind/low vision when special schools began opening all over the world as people learned more about people's abilities rather than their disabilities. People with mental illness and physical disabilities did not fare as well. Their disabilities continued to be feared and viewed as incurable. They were sent to institutions and treated inhumanely with very little stimulation from outside the walls of the institution (Marini, 2017).

Societies and cultures around the world have feared and even refused to accept disabilities; in some cases, to the extent that we cannot discuss disability in history without also discussing the history of eugenics. Eugenics is "the study of hereditary improvements of the human race by controlled selective breeding" (Marini, 2017, p. 8). The term, *Survival of the Fittest*, was originally coined from Social Darwinism philosophy (Marini 2017). It was the belief or fear that if those who were deemed inferior produced more than those who were superior in society, it would eventually drain all government supported public programs. This belief supported systemic forced sterilization for thousands of individuals. Those who weren't sterilized were forced into inhumane institutions. At the same time in Germany, Adolf Hitler was

studying the principles of Social Darwinism (Marini, 2017). Those principles laid the foundation for the dark ideologies of the Nazi regime that aimed to cleanse Germany of their disabled and Jewish populations (Marini, 2017).

Even in more modern times in America, fear of disability and people who were different seeped into society. One striking example is the “Ugly Law” that was in effect until 1974. This law proclaimed that people who were deemed unfit for public viewing would be fined up to \$50 for showing their ugliness in public places. This law specifically listed physical disabilities and medical diseases that caused visible physical ailments. The law deemed their ugliness considered a substantial burden on the nondisabled population. Despite opposition from advocacy groups the enduring stigma surrounding differences endures today (Marini, 2017).

20th-21st Century Legislation in America

Throughout recent decades, programs have been built, however, it is especially important to note that many programs have consistently been only partially funded. This section will explore how legislation came to pass and why many parts of modern legislation remain largely less effective than originally intended. Legislation has been written and rewritten in attempts to right the wrongs of the past. However, this literature review will continue to present a connection between a lack of appropriate funding and a continuation of the cycle of poverty, inequitable access to resources, and current lack of oversight for legislation. This historical framework will establish that individuals with disabilities have been the last minority group of Americans to access equal rights as citizens (*Disability Rights Movement | Backgrounders*, 2017). It also establishes the pattern that due to the lack of accessible materials, transportation, and support, progress in policy and practice have been largely due to family members or loved ones of a disabled individual advocating either on their behalf or fighting alongside them. Finally, it will

be illustrated that while there has been progress, the last group of Americans to experience fully realized access to basic human civil rights with respect to an equitable QOL, remains Americans with disabilities (Davis, 2015). One of those basic rights is the right to a FAPE. While that has long since been passed in legislation, the question remains whether individuals with disabilities feel service is equitable to their nondisabled peers.

An example of this contradiction is the story of Willowbrook (Reimann, 2017). Not long after the world learned of the atrocities of genocide in World War II in 1947, an institution called Willowbrook opened in Staten Island. This institution was built for individuals considered defective, which was ironic considering World War II had just ended and the world was reeling at the treatment of Jews and Hitler's ideas of a supreme race. Residents of this facility were victims of physical and sexual violence from the staff. Daily, they sat in their own feces and urine, rocking back and forth, naked. They were used as human lab rats for dangerous medical experiments without their consent. Unfortunately, Willowbrook was not an isolated institution. This was just one of many institutions across America, stating they were "caring" for the "mentally ill and feeble," but behind closed doors existed a place of heinous and unspeakable abuse and neglect for a vulnerable population of American citizens (Reimann, 2017).

Most Americans were completely unaware of the deplorable living conditions until, in 1969, Senator Robert Kennedy compared the living conditions of Willowbrook to a snake pit. (Reimann, 2017). Eventually that institution became the source of many bioethics' lawsuits. A physician at Willowbrook, Dr. Saul Krugman, deliberately infected non-consenting patients who also had intellectual disabilities with hepatitis in 1955 and defended this practice as ethical until his death in 1995. When he passed away, the New York Times celebrated his "medical contributions" even after his grossly unethical practices were the source of decades long

litigation and controversy (Saxon, 1995). In 1972, Geraldo Rivera aired a documentary which featured the horrors of the country's mental institutions, but even after mass media shared this information, it took decades for these institutions to close and most were never held accountable for the traumas they caused (Reimann, 2017).

Americans with Disabilities Act and the Civil Rights Movement

The Civil Rights Movement laid the foundation for the ADA. The ADA prohibits discrimination against people with disabilities and was written in 1989, decades following the Civil Rights Movement of the 1960's (Davis, 2015). During the Civil Rights Movement, people filled the streets with both peaceful protests and sometimes riots. People with disabilities were not originally included in the Civil Rights Movement for reasons which will be uncovered in this section. Passing legislation with protests in the streets of Washington D.C. was not possible before the ADA was passed. Much of this descriptive narrative is adapted from a book titled "Enabling Acts, The Hidden Story of How the Americans with Disabilities Act Gave the Largest US Minority its Rights," by Davis (2015).

Long before the ADA, Hubert Humphrey, a senator and grandfather of a child with Down Syndrome, played a significant part in passing the 1964 Civil Rights Act. On January 20, 1972, he presented an amendment to the Civil Rights Act to include the words "physical or mental handicap" by sharing an emotional speech to his colleagues and the President, including some of the following:

No longer dare we live with the hypocrisy that the promise of America should have one major exception: Millions of children, youth, and adults with mental or physical handicaps. We must now firmly establish their right to share that promise, so well described by Thomas Wolfe [the novelist, in his *You Can't Go Home Again*]: 'To every

man his chance; to every man, regardless of his birth, his shining golden opportunity...[T]his... is the promise of America...Justice delayed is justice denied. (118 Cong. Rec 542, 1972, p. 542)

Following that speech, the amendment was approved in a unanimous bipartisan vote (118 Cong. Rec 542, 1972).

Researching legislation regarding disability and the civil rights of people with disabilities in America led to questions regarding our country's timeline (*Timeline of Disability Rights | Resources | Accessibility.Com*, 2023). In 1964, our country legally banned segregation in public places and employment discrimination based on race, color, religion, sex, or national origin. In 1972, an amendment was made to include disability in the language of the Civil Rights Act of 1964. However, the civil rights of people with disabilities were still being debated 17 years later in 1989 (Davis, 2015).

To pass the civil rights act, citizens who had been marginalized gathered in large groups to protest, to speak up, and to have their voices heard. Before the ADA was passed, there was no accessible transportation. Sidewalk curbs made it impossible for wheelchair users to navigate independently. Media was not presented in a way that was readily accessible for people with low vision or who were deaf or hard of hearing. Unlike the Civil Rights Movement where people could flood the streets in protests, for the voices of people with disabilities to be heard, it took an incredibly sophisticated group of people to assist with transportation and other personal care needs to organize protests and sit ins. It also took a politically powerful group of people working together, who were all personally impacted by disability in some manner to pass bipartisan legislation regarding the civil rights of individuals for whom lawmakers loved (Davis, 2015).

Two years after Willowbrook closed (July 28, 1989), a group of politicians, including Senator Orrin Hatch, Senator Tom Harkin, Senator David Durenberger, and Senator Bob Dole, Attorney General Dick Thornburgh, Secretary of Transportation Samuel Skinner, and other White House staffers met to negotiate a piece of legislation known today as the ADA. The people in the room that evening all had a shared interest, which was disability. Senator Bob Dole was the only one with a visible disability, as he was shot by a sniper in World War II and narrowly survived. It took him years to learn to walk again and he never regained the use of one arm. Senator Ted Kennedy had an older sister named Rosemary who was diagnosed with an intellectual disability. Unfortunately, because of a lack of medical advancements at the time, when she was 22, his father, Joseph Kennedy, made the decision to lobotomize her, which caused her condition to significantly worsen. She was later institutionalized. Ted Kennedy and his brother John both had some physical ailments. Ted Kennedy's son, Teddy, had bone cancer as a child which led to many hospitalizations and ongoing illness due to chemotherapy. Senator Tom Harkin had a brother who was deaf and a nephew who was a paraplegic because of an accident in the military. Dick Thornburgh's wife was killed in a car accident that also caused one of his sons to suffer traumatic brain injury. Senator Hoyer's wife was an epileptic. Senator Hatch's brother-in-law contracted both types of polio in college. Hatch was also a devout Mormon, and his faith taught that disability wasn't punishment for sin, but an opportunity or a learning experience.

At this time in history, this thinking was a unique paradigm in the realm of disability advocacy as disability was still thought of as a punishment for past sins (Marini, 2017). President Bush also served as a disability advocate, and even though he was not at the meeting that drafted the original language in the ADA in 1989, he also had an uncle who had contracted polio. His

son, Neil, had severe learning disabilities and another son, Marvin, had a colostomy. President Bush also lost a daughter, Robin, to leukemia when she was only four years old (Davis, 2015). As with many other civil rights acts, the politicians who wrote the original language in the ADA, all had a personal connection like the many Americans who live with a disability.

The ADA was passed in 1990 and signed by President George H. W. Bush (Davis, 2015). The ADA offers protection from discrimination based on a person's disability, ostensibly providing an equal opportunity. However, 30 years after the ADA was enacted, individuals with disabilities continue to have ominously higher unemployment and poverty rates (*2020 Progress Report on National Disability Policy: Increasing Disability Employment*, 2020). The 2020 Progress Report on National Disability Concerns states that in July 2017, people with disabilities were almost three times as likely to live in poverty as people without disabilities (*2020 Progress Report on National Disability Policy: Increasing Disability Employment*, 2020).

Individuals with Disabilities Education Act

The original legislation of the IDEA, which guarantees FAPE, was passed by President Ford in 1975. In the most current form of this law, congress states:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. (The Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, 118 Stat. pp. 2049-2050)

When this law was enacted, congress promised to pay up to 40% of the cost to educate a child with a disability, recognizing that the costs associated with educating students with

disabilities is more than educating students without disabilities (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). In researching the congressional research service website, the most current document available is from 2019. In fiscal year 2019, the United States Federal Government appropriated \$12.4 billion, approximately 14.3% of the cost to educate a child with a disability (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). Current funding of IDEA is \$12.4 billion (Van Hollen, 2021). According to those projections, this is an annual shortfall of approximately \$43.1 billion (Van Hollen, 2021). The budget proposed for fiscal year 2024 by The White House for IDEA Part B only includes a \$2.1 billion increase (Biden, 2023). Senator Van Hollen proposed a bill that would fully fund IDEA by the year 2033, which is estimated to be \$55.5 billion annually (Van Hollen, 2021).

These budgetary restrictions have a widespread impact on quality programming and school systems. Schools are forced to make personnel decisions that often result in not hiring staff such as transition specialists, who can help facilitate the complicated process of post-secondary transition. In a system that requires specialization in supporting and including students with disabilities and knowledge in workforce and economic development, not having staff that can fully help the process is a systemic barrier to fully realizing the promises of the law (2020 *Progress Report on National Disability Policy: Increasing Disability Employment*, 2020).

IDEA is the legislation that allocates the amount of money authorized to be appropriated. However, even if the authorization reaches a certain level, it is up to the annual appropriations committees to make funds available to state education agencies. Appropriations bills are passed annually by congress to identify how much money will be appropriated every year. If for some reason congress fails to pass an appropriations bill, then the funding remains the same as it was

in the previous year (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018). In 45 years, the appropriations have never matched the funding that was authorized in 1975. This has resulted in significant federal underfunding for schools in providing a FAPE since the original passage of this bill. The remainder of the excess costs to educate students with disabilities continues to fall on each state (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018).

A report written by the National Council on Disabilities to the President of the United States, found several violations of IDEA caused by budgetary restrictions, including one state even placing an illegal cap on identifying students with disabilities (*National Council on Disability*, 2020). Some states and districts place limits on the number of personnel and providers available to hire or service hours allowed to provide service to students. Other states reduce or eliminate programs that serve students with disabilities (*National Council on Disability*, 2020).

The provisions of IDEA are built from the constitution. While it is illegal for states and districts to claim lack of funding as an excuse to limit supports and services to students with disabilities, qualitative research surveying parents and school personnel confirms that is commonly the excuse (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018). In 2016, the *Houston Chronicle* uncovered an identification and eligibility cap imposed by the Texas Education Agency which unlawfully limited the number of eligible students, or the level of services provided, or both. Parents reported to researchers that school personnel personally apologized to them privately following IEP meetings, explaining that the school limited services based on personnel they could hire. One parent shared concern that the district had an agenda, or preconceived ideas of plans to offer students based on the district's budget (Rosenthal, 2016). Another parent of a student already identified as having a disability reported the school told them

they couldn't afford to pay for an evaluation because the school couldn't afford another teacher to provide the student individualized support. Additionally, a parent of a student with multiple disabilities, including autism, pragmatic disorder, articulation disorder, Tourette syndrome, and attention deficit hyperactivity disorder stated their child was only receiving parent training and transportation (Rosenthal, 2016).

Most often, the reasons districts report an inability to deliver services promised in IDEA to all students, is due to personnel shortages and budget constraints (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018). Many districts rely on Medicaid to pay for specialized services where federal funding falls short. While Medicaid revenue assists with closing the fiscal gap, therapists report spending 25-35% of their time on Medicaid paperwork, rather than serving students. The report also indicated the undue burden imposed on therapists related to Medicaid paperwork as a significant factor in staff turnover (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018).

To provide an "appropriate education" as part of FAPE as defined in IDEA, teachers must have the qualifications, experience, and knowledge to be able to provide adequate support and services. Due to inadequate funding, schools are faced with tough decisions, sometimes illegally capping services and support due to personnel shortages. Schools that do not illegally cap services and support are faced with having to hire special education teachers and related service providers with high caseload numbers. Much of their time is spent on required paperwork, as part of managing IEP's and Medicaid reimbursement, to fund their services. This leads to a high turnover rate costing schools, and ultimately, taxpayers, billions of dollars (*IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018).

Workforce Innovation and Opportunity Act

On July 22, 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law with the goals of helping job seekers have more equitable access to employment, education, training, and other support services crucial to enter the competitive labor market. This federal policy was designed to align workforce programs, including Temporary Assistance for Needy Families (TANF) and Carl Perkins career and technical education programs. In addition to aligning programs, it was also created to improve employers' services, promote more work-based training, and allow individuals seeking employment to access high quality training to enhance their skills. Language in WIOA specifically articulates that it increases access for individuals with disabilities to workforce services available to other job seekers. It also asserts state vocational rehabilitation agencies will reserve a minimum of 15% of their federal monies to provide pre-employment transition services (Pre-ETS), a program to prepare students for vocational rehabilitation services, to students with disabilities who are still in high school (2020 *Progress Report on National Disability Policy: Increasing Disability Employment*, 2020).

This aggressive legislation has been a part of our country's narrative for over 40 years, so it led the researcher to question why, when 42 million Americans are reported to have a disability, so many continue to struggle with food and housing insecurity, unemployment, and lack of access to healthcare. Hughes and Avoke (2010) stated:

The first step to address the challenges derived from the intersection of poverty, disability, and employment is to acknowledge that there is a problem. When the third largest minority group in the United States-people with disabilities and, in particular, those with intellectual and developmental disabilities-is experiencing mass unemployment and underemployment; lack of affordable housing, food scarcity and

material hardship; limited health care and transportation; few education or job training opportunities; and limited socializing, community participation, and satisfaction with life, we cannot keep our heads in the sand. Educators, policy makers, adult service providers, parents, and advocates need to ensure that providing quality employment with health care and other benefits, sufficient community and residential supports, and appropriate education and employment training opportunities for people with severe disabilities-and disabilities in general-is on the national agenda as legislative and funding priorities. (p. 10)

The table below is data from the 2020 American Community Survey. It breaks down populations by age and disability status. Individuals responding to the survey have chosen to self-disclose their disability status. The right-hand column indicates the percentage of the population within that age group that falls either within the category of having a disability and living in poverty or not having a disability and living in poverty. In every age group, it is statistically significant that people with disabilities are far more likely to live below the poverty line than those living without disabilities (Bureau, 2022).

Table 1*American Community Survey Data Depicting Americans Living with Disabilities in Poverty*

Label (Grouping)	United States Estimate	% poverty
Total:	323,173,982	
Total with a disability:	42,230,089	
Total with a disability in poverty:	8,475,388	20%
Total without a disability:	280,943,893	
Total without a disability in poverty:	32,886,638	11.7%
Under 5 years:	18,313,189	
With a disability:	124,080	0.7%
Income in the past 12-months below poverty level	37,901	31%
No disability:	18,189,109	99%
Income in the past 12-months below poverty level	3,311,248	18%
5 to 17 years:	53,983,908	
With a disability:	3,202,122	6%
Income in the past 12-months below poverty level	788,590	25%
No disability:	50,781,786	94%
Income in the past 12-months below poverty level	8,105,480	16%
18 to 34 years:	70,737,485	
With a disability:	5,404,652	7.6%
Income in the past 12-months below poverty level	1,299,381	24%
No disability:	65,332,833	92%
Income in the past 12-months below poverty level	9,203,278	14%
35 to 64 years:	125,397,606	

With a disability:	15,660,163	12.5%
Income in the past 12-months below poverty level	3,839,452	25%
No disability:	109,737,443	88%
Income in the past 12-months below poverty level	9,153,080	8.3%
65 to 74 years:	33,423,201	
With a disability:	8,013,445	24%
Income in the past 12-months below poverty level	1,182,351	14.5%
No disability:	25,409,756	76%
Income in the past 12-months below poverty level	1,984,617	7.8%
75 years and over:	21,318,593	
With a disability:	9,825,627	46%
Income in the past 12-months below poverty level	1,327,713	13.5%
No disability:	11,492,966	56%
Income in the past 12-months below poverty level	1,128,935	9.8%

Graduation from an accredited public educational institution is a commonly accepted achievement; whereby, a diploma leads to employment. IDEA recognizes the process of transitioning from public education into adult life is incredibly important, as evidenced by the requirements of schools to provide for post-secondary transition planning beginning at the age of 14 (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). However, as the 2020 National Disability Policy report states, schools recognize being funded at 18% of estimated costs rather than at 40% as promised by congress as far back as 1975. This continues to be a barrier. Barriers include hiring enough specialists and support staff to seamlessly connect secondary and post-secondary transitions,

especially regarding post-secondary employment and independent living outcomes. As a result, special education teachers are expected to provide support to general education teachers, know all the legal requirements of the IEP, and the legal rights and responsibilities of both the student and the school. High school special education teachers must assist in the transition to adult services, which are often disjointed and complicated (*National Council on Disability, 2020*).

Employment First Initiative Act

Competitive, Integrated Employment (CIE) is employment which offers competitive pay and is part of the Employment First Initiative Act in 2011 (K.S.A. 44-1136 et seq., as amended). The Employment First law's purpose is to establish that Kansas policy should offer CIE as a first option for all people with disabilities when transition planning. The purpose is to fight the cycle of poverty and the continuing dependence on government assistance for individuals who want to work and to be independent (*Kansas Employment First Oversight Commission 2020 Recommendations to the Governor and Members of the Kansas Legislature, 2021*).

The intent of the Employment First Initiative Act is that the first option when discussing post-secondary transition should be evaluating a job or career that offers competitive pay (equivalent to those without disabilities who perform the same work) in integrated settings (community-based settings with more than 50% non-disabled employees), or CIE (*Kansas Employment First Oversight Commission 2020 Recommendations to the Governor and Members of the Kansas Legislature, 2021*). Kansas was one of the first states to implement such a law, but due to a lack of oversight, there continues to be a lack of effective implementation. There is an oversight commission, which is made up of individuals appointed by the governor. The role of the appointed commissioners is to primarily make recommendations to the Governor's office

about needed change (*Kansas Employment First Oversight Commission 2020 Recommendations to the Governor and Members of the Kansas Legislature*, 2021).

As a result of inconsistent oversight and implementation, many Americans and specifically, Kansans with disabilities, continue the cycle of poverty (Employment Systems Change Coalition, 2017). The United States census in 2022 reported that 42 million Americans have some type of disability (Bureau, 2022). This is one of the largest and fastest growing minority groups in the nation (Hughes and Avoke, 2010). Disability also occurs across all racial and ethnic groups. Thirty-five million Americans report having disabilities significant enough to interfere with ADLs. Individuals with disabilities in employment are often not employed full time, report working less than half time, earn only a couple hundred dollars a week, which is not nearly enough to live on (Hughes & Avoke, 2010). These positions also tend to be entry level jobs and are the first to be eliminated in times of economic hardship (Hughes & Avoke, 2010).

The cycle of poverty for individuals with disabilities is a perfect storm of the continuation of low expectations, laws without oversight or fiscal appropriations, and the perpetuation of myths surrounding disability services. A study completed by the Employment Systems Change Coalition of Kansas (2017) found that 76.4% of individuals with a disability report they believe they will lose their social security income by working, and therefore, working is not a financial benefit. Individuals in this study reported a strong desire to work within the community at 81%. However, even those who are employed understand that organizations continue to utilize the 14C tax exemption, which allows businesses to pay people with disabilities less than minimum wage (Employment Systems Change Coalition, 2017). Hughes and Avoke (2010) wrote:

Why are we putting a person with a disability on a path to poverty instead of a path to prosperity? There is an urgency with which we must address the situation... it seems

obvious to try to reduce exposure to poverty for individuals with disabilities and their families in order to address the social and economic inequalities they face; however, public policy fails to do so....workers with disabilities cannot achieve parity with their nondisabled counterparts in terms of earnings, benefits, and job security until they have equal access to and equal representation in better paid and more highly skilled occupations... Service providers and special education personnel must challenge themselves to look beyond entry-level, low-paying jobs for employment options for people with severe disabilities. Research shows that individuals with severe disabilities can be successfully employed in well-paying jobs requiring complex skills. However, these jobs need to be the norm- not the exception.... There is no reason why individuals with significant disabilities should not contribute to the nation's productivity and gross national product. There is no reason to exclude these persons from the opportunity to participate in the American dream of greater wealth and economic independence because of a label of severe disability. (p. 10)

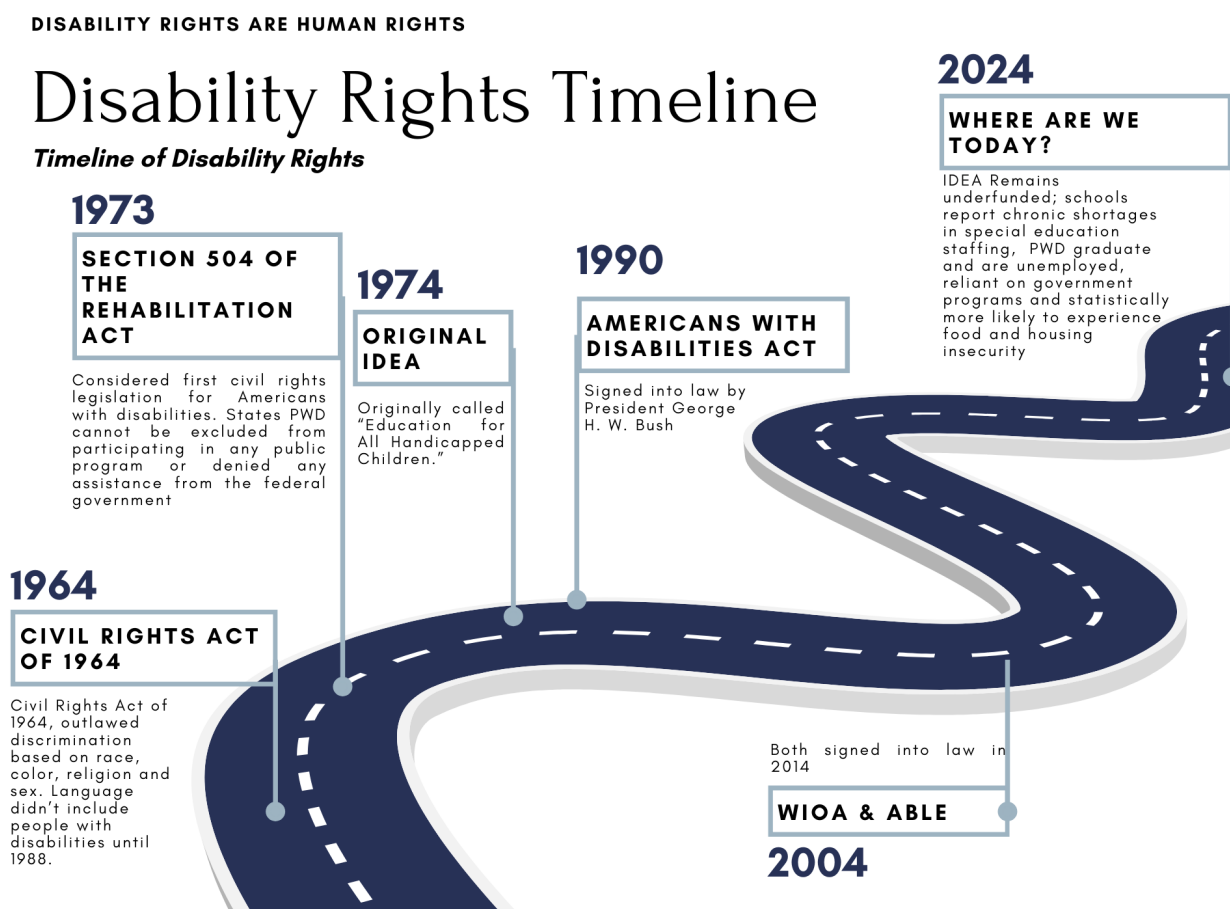
For an individual with IDD or a significant disability, CIE is often viewed as complicated. When an individual has a disability, by definition, there are tasks they are unable to complete. It takes a skilled educator or job coach to be able to work with a place of business to find tasks within the business that need to be completed that match a student's gifts and talents. Fortunately, models already exist that can be replicated such as the Individualized Career Planning Model (Condon & Callahan, 2008). These models take staff training, community involvement, and financial incentives for businesses, but show strong potential for filling a need for the business and a need for the individual with a disability (Condon & Callahan, 2008).

In 2014, a law was passed called “Achieving a Better Life Experience,” or the ABLE Act (Internal Revenue Service, 2023). Prior to this law, PWD were limited to the financial assets they were allowed to have in their name and still receive disability services. The ABLE Act allows individuals with disabilities to contribute to a 529 savings account for themselves or to a designated beneficiary. There is a limit of \$115,000, but that is significantly higher than the previous amount of \$2,000. This law does allow PWD more freedom to keep the money they earn from working competitive wages (Internal Revenue Service, 2023).

Figure 1 below demonstrates a timeline of disability rights, beginning with the Civil Rights Act of 1962, which outlawed discrimination based on race, color, religion, and sex. While it was debated when the bill was being written, language regarding people with disabilities was not included in the original bill. The timeline ends with 2023, when this paper was written, with the most current data indicating that people with disabilities remain in a cycle of poverty. Data to create the figure below is from Accessibility.com (*Timeline of disability rights: Resources*, 2023).

Figure 1

Timeline of Disability Rights



Policy Implications for Postsecondary Outcomes

Throughout history, there have been aggressive acts of legislation recognizing disability rights as civil rights. There are many ways to improve practices to match the intended outcomes of those policies. This section will highlight the impact that IDEA-Part B can have on educational outcomes for individuals with IDD. A discussion will lead to the importance of placing value on the voice of individuals with IDD on their own.

Education Relevance

This section will connect the historical framework and political issues to modern educational equity. Considerations to how these events in our past have shaped our education system today and the impact on the cycle of poverty for individuals with disabilities are presented.

Unfortunately, a staggering 98% of districts in the United States report shortages in special education professionals (*Personnel Shortages in Special Education and Related Services*, 2021). There have been efforts to mitigate this shortage, including incentive programs and alternative routes to certification but those have also been underfunded. This results in limited access to needed services, inability to provide early intervention and preventative services, and an overemphasis on compliance to avoid litigation with less emphasis on creatively attaining quality outcomes for students. The lack of special education professionals is compounded in otherwise hard to staff schools such as rural, high poverty, and high crime communities (*Personnel Shortages in Special Education and Related Services*, 2021). Attrition in special education is statistically higher than in general education, which in turn, forces districts to hire unqualified personnel to fill these positions. Special education is the second highest educator specialty in terms of attrition (McLeskey & Billingsley, 2008). Continued high turnover and hiring unqualified staff continues to impact outcomes for vulnerable students (Billingsley & Bettini, 2019).

Across the United States, the cycle of poverty continues to plague the disability community which remains the third largest minority group in America (Hughes & Avoke, 2010). Section 504 of the Rehabilitation act of 1973 is commonly recognized as the first civil rights legislation for the population of Americans with disabilities (Hughes & Avoke, 2010). This law

clearly states that PWD cannot be excluded from participating in any public program or denied financial assistance from the federal government (U.S. Department of Labor, 1973) .

With all the progress in policy and government mandates that have occurred with intent to enhance the QOL and success outcomes for individuals with disabilities, there continue to be missing links with concerning outcomes in the system. There has been movement away from institutions and legal requirements to enhance educational access for individuals with disabilities, but systemically, teachers who are hired to carry out the requirements of IDEA are unprepared to support the needs of students with disabilities to participate fully in community living (McLeskey & Billingsley, 2008). Ninety-eight percent of schools in the United States report special education shortages that impact the services and supports that students with disabilities are legally entitled to in order to receive an equitable education (*Personnel Shortages in Special Education and Related Services*, 2021).

Furthermore, the continuum of government supports in adult living following secondary education is also chronically underfunded, which perpetuates the cycle of poverty, further contributing to systemic food and housing insecurity and profound unemployment rates for individuals with disabilities (*National Council on Disability*, 2020). Upon recognizing the positive impact of closing heinously unethical institutions and recognizing individuals with disabilities as a minority group who deserve equal human civil rights entitled to every American citizen, the question then arises “To what extent have these changes made a difference in the QOL for individuals with disabilities since the enactment of IDEA, and what do they have to say about it?” It has been recognized repeatedly in legislation that disability rights are civil rights, yet this minority group continues to have lower postsecondary outcomes than their nondisabled

peers and fewer resources allocated to improve those outcomes (Hughes & Avoke, 2010; *IDEA Series: Broken Promises: The Underfunding of IDEA*, 2018).

The Study of Quality of Life

The policies that were discussed in the previous section were developed to provide equity in access to basic services and supports that have been available to all American citizens.

Ostensibly, they were developed to improve not only basic civil rights, but also the general QOL for individuals with disabilities. This section will uncover the connection between the study of QOL and the language within those policies.

QOL was originally studied to determine health outcomes, including longer life expectancies, access to health care, low infant mortality rates, and access to education experience for citizens in various geographic regions (Nikolaev, 2014). The domains that were originally studied are at the lower level of Maslow's hierarchy of needs (McLeod, 2022). The principles of Maslow's hierarchy of needs state that when basic needs are met, more complex needs can be met as one moves from physiological needs to self-actualization. Basic needs include food, water, and shelter. Once those needs are met, safety and security are the second tier, and that includes financial and social stability. The third tier includes love and belonging. The fourth tier is self-esteem which includes respect for self and others. The highest level on Maslow's hierarchy is self-actualization which ultimately means finding your true inner potential (McLeod, 2022). There is no differentiation for people with and without disabilities as these needs are defined as basic human needs (McLeod, 2022). Many studies found that although financial security proved to be a positive correlation with QOL, nonmaterial domains of QOL were reported as important to all people in determining their overall QOL (Nikolaev, 2014).

When people with disabilities feel a sense of belonging, see opportunities for full participation in their communities, know how to access independent living, understand strategies for and access economic self-sufficiency, they have fully realized what has been promised in IDEA established by congress:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. (The Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, 118 Stat. pp. 2049-2050).

QOL is defined as “a multidimensional construct that has both subjective and objective components and is influenced by personal and environmental factors” (Faragher & Ommen, 2017, p. 40). The indicators described by Faragher and Ommen (2017) closely align with policy describing ideal postsecondary outcomes in education for individuals with disabilities. They discuss measures of QOL as feelings of empowerment, self-worth, self-image, and generalized well-being across the life span. Unfortunately, the pattern continues with a gap remaining between policy documenting ideals for educational outcomes and what is actually occurring in schools and communities, not only in the United States, but across the United Nations (Faragher & Ommen, 2017).

The first formal study of QOL was a calculation that included measurements of literacy, infant mortality rates, and life expectancy. In the mid-1970s, this was to evaluate overall physical QOL as it related to the wellness of an entire country. The study of QOL at that time was purely from an economic standpoint (Nikolaev, 2014). Since then, researchers have created more

complex models to measure QOL (Diamond & Becker, 1999). The modern models more closely align to Kansas' definition of post-secondary success for all. The KSBOE defines a successful high school graduate as an individual that is academically and cognitively prepared and has technical and employability skills and demonstrates the appropriate civic engagement skills necessary to be successful in the postsecondary option of their choice, whether that is higher education or entering the workforce (*Board Outcomes*, 2023). It is also important to note that the KSBOE specifically states that a successful high school graduate can demonstrate all the above skills without remediation. (*Board Outcomes*, 2023).

In life, it's understood that there will be stressors that occur, but how those stressors impact the overall QOL are influenced by the adaptive skills that a person has acquired, and the resources that a person has to deal with life's inevitably stressor-rich environment (Mittelmark & Bauer, 2017). This description seemed to parallel how *Brown v. Board* defined the function of education, when it stated education's purpose is to prepare a child for future training and help them to adjust normally to their environment (*Brown v. Board of Education of Topeka*, 347 U.S. 483, 1954).

Researcher Aaron Antonovsky defined a term that described psychological resilience that focuses on having the tools and resources to be able to deal with life's inevitable stressors. He began his career as a medical researcher and mid-career pivoted when he realized he wasn't interested in researching diseases. What he was interested in was the protective factors around a person that made them react differently when given a diagnosis. Some people had a strong network and maintained a more positive outlook and therefore had a better prognosis. Others did not fare as well. He called this salutagenesis, or the opposite of pathogenesis (Mittelmark &

Bauer, 2017). This chapter will continue to explore how this term connects to the concept of QOL.

Salutagenesis focuses on wellness, and in the medical field, in very basic terms, means the antonym of focusing on the disease, which is pathogenesis. The National Library of Medicine defines salutagenesis as:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected. (Mittelmark et al., 2017 p. 11)

When considering QOL, many researchers focus on health outcomes. Steger and Dik (2009) determined that when an individual feels a calling to pursue a certain vocation and then they have the resources to eventually obtain employment in that calling, their global QOL increased significantly. Rojas (2006) proposed that overall satisfaction may be as simple as just one healthy interpersonal relationship. Rojas' (2006) study investigated seven potential domains of life satisfaction and studied the relationship between them. Those domains included health, economic security, job, family, friendship, personal, and community environment. These domains surprisingly overlap with the promises of IDEA. The study analyzed if a person's general life satisfaction was 60 on a 100-point scale, would it impact satisfaction in other domains and eventually, overall life satisfaction. For example, if the family domain was a 50 and increased to 70, would satisfaction in the economic domain increase? Conversely, if the community environment domain decreased significantly, would that have an impact on other domains? Although causality is difficult to determine, the final consensus indicated that when people have a high quality, consistent, relationship with just one reliable caring person, overall

satisfaction in life increases. When looking at overall satisfaction, the domains that had the most impact on overall life satisfaction involved healthy interpersonal relationships (Rojas, 2006).

There is a significant gap in literature when it comes to QOL studies that focus on individuals with intellectual disabilities. Crocker et al. (2021) compared the relative importance of QOL dimensions for people with and without a disability. The purpose of this study was for participants to rank the relative importance of the dimensions included in the study. The domains included sleep, independence, physical mobility, mental well-being, control, self-care, pain, vision, hearing, safety, social-relationships, and dignity. The study found that individuals without disabilities ranked independence and control as their first and second most important life domains. People with disabilities ranked safety, self-care, and dignity as their most important life domains. It is important to note that the individuals with disabilities in this study included all disabilities, not just individuals with cognitive or intellectual disabilities (Crocker et al., 2021).

Connecting the Intersectionality of Disability and Quality of Life

As uncovered in this literature review, people with disabilities have experienced heinous inequities throughout history. While public policy has made progress toward civil rights equity, when poverty data is considered, there are profound differences for this minority group. In a speech of gratitude when a federal building was named after him, Hubert Humphrey expressed his values again:

It was once said the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life; the sick, the needy and the handicapped.
(Humphrey, 1977, p. 37287)

This literature review has recounted the repeated horrors faced by people with disabilities, not only throughout time, but in the last 100 years. Legislation has passed efforts to improve outcomes for individuals with disabilities and their families. However, it is evident that legislation hasn't been supported with the fiscal appropriations necessary to carry out the intent of the law to impact daily practice.

Educators have a limited locus of control when it comes to systems change and systems change takes decades. The students in our classrooms today are looking at their own future and wondering what's next. It is essential that we look pragmatically at what can be done, given the lack of funding and resources, to ensure equity and increase the QOL for individuals with intellectual disabilities.

IDEA promises FAPE (The Individuals with Disabilities Education Act, Part B: Key Statutory and Regulatory Provisions, 2019). National Education Association (NEA) says the public cannot come to a clear consensus on the purpose of public education but has narrowed it down to preparing individuals for work, academics, and to be good citizens (Walker, 2016). *Brown v. Board of Education* stated the purpose is to establish a child's values and to prepare them to adjust naturally to their environment. They added it is doubtful that any child could succeed if they are denied the opportunity of an education and separate is not equal (*Brown v. Board of Education of Topeka*, 347 U.S. 483, 1954). Section 504 of the Rehabilitation Act of 1973 establishes disability rights as civil rights (US Department of Labor, 1973). Yet, if you are a young adult with a disability, you have a 24% likelihood of living below the poverty line (Bureau, 2022). Graduating students into poverty does not seem like they are prepared for postsecondary success.

This literature review has highlighted the profound inequities despite legal precedent. Even with such clear violations of the fiscal appropriations of IDEA, educators need practical things to do right now to improve outcomes for students with disabilities. Faragher and Ommen (2017) discuss the QOL as a social construct to highlight the reality for students. QOL is much deeper than having access to tangible things. Having a positive view of your QOL often indicates that one is not only able to set goals and obtain those goals, but there is also a sense of purpose (Brown et al., 2014). Having a severe shortage in personnel that ends up in frequent turnover and hiring individuals that lack full licensure or appropriate training to provide adequate services and supports negatively impacts the minimum expectations of outcomes for students with disabilities (*Personnel Shortages in Special Education and Related Services*, 2021). Having a deep understanding of how to teach students with IDD and significant disabilities the skills of how to set and obtain various goals while simultaneously providing an environment where they feel a sense of belonging requires not only a technical skill set but also a sensitivity to social nuance. With the current turnover and shortages, there is a skills gap between what educators demonstrate as a level of understanding and what individuals with disabilities need to obtain a minimum QOL. For PWD to obtain a high QOL, there is a need for highly skilled personnel that have a deep understanding of the unique challenges of the disability community (Brown et al., 2014).

Promising Practices

While there are many things yet to be done to improve post-secondary transition and QOL for young adults with IDD, there are promising practices emerging in the field. The Self Determined Learning Model of Instruction (SDLMI) is one of those promising practices (Raley

et al., 2020). This model can be utilized not only in the classroom and in the community but across the lifespan (Hagiwara et al., 2022).

SDLMI is a seemingly simple strategy focused on setting goals, acting toward the goal, and then adjusting the goal or plan based on what you learned from the previous step. In addition, the authors of the model created an evidence-based instructional curricula for educators to teach this strategy to students, even with extensive support needs. While this has proven to have a positive impact on students and teachers, there continues to be systemic barriers to full implementation such as comprehensive teacher training, frequent turnover, and teacher acceptance that students with significant intellectual disabilities can fully master the necessary skills outlined in the model (Raley et al., 2020).

Customized employment is another promising practice that can and should lead to CEI, which is a legal requirement in Kansas. Customized employment could have a positive effect on curbing the cycle of poverty for individuals with disabilities. One of the benefits of customized employment is the flexibility in implementation and practice. It can be utilized in rural or urban settings and educators, or VR counselors can implement the strategies. It has successfully been used in IEP transition plans and after school grant programs (Molina & Demchak, 2016). To fully implement the addition of an after-school grant program or a comprehensive transition specialist in a school setting, additional funding is required in most schools. It also requires additional personnel, which is challenging in the current state of teacher shortages, to fully implement successful transition practices. Customized employment utilizes a discovery process that allows a VR counselor or educator to learn about the strengths and interests of the student to find jobs that then align with these strengths and interests. Unfortunately, even though this has been an effective practice, systemic implementation has been difficult due to a variety of factors

including a lack of knowledge about the discovery process itself and a better understanding of connections to community employment (Jones et al., 2020).

While these are promising practices, they are not systemic. Due to the issues outlined above, including personnel shortages and inadequate fiscal appropriations, these strategies are difficult to implement.

Gaps in Scholarly Literature

The National Council on Disability (2020) reports data submitted by individual states to federal offices is often unreliable. This unreliability is caused by variation in how each state reports their expenditures. Without a large-scale study on special education expenditures and expenditure ratios, the council concluded there is not sufficient evidence to draw a definitive conclusion regarding how much federal funding is needed to support states and local districts in providing a FAPE for students with disabilities (*National Council on Disability, 2020*). The council also recognizes the challenge of understanding what effect, if any, the lack of federal funding is having on delivery of special education services and assurances of a FAPE. This does not clarify whether school districts are utilizing general education budgets to maintain special education services or whether services are being reduced or compromised to meet the individual needs of students based on available funds (*National Council on Disability, 2020*).

The most significant gap in literature is whether educational success criteria defined for individuals with disabilities leads to a higher QOL. Part of this gap is because federal educational success criteria is unclear for students without disabilities. The Every Student Succeeds Act (ESSA) was signed into law in 2015 by President Obama and while it increased local accountability and required evidence-based instructional materials, it did not specifically outline the expectations of a successful high school graduate (U.S. Dept. of Education, 2017). IDEA is a

federal law which promises equity, but it is up to each state to determine what the success criteria and measurement is within that state (U.S. Dept. of Education, 2017).

For the purposes of this study, the Kansas definition of postsecondary success is what will be utilized. This definition clarifies the rationale and purpose of the how and why studying postsecondary outcomes for students with disabilities and their perceptions of their own QOL is imperative (*Board Outcomes*, 2023).

Summary

This literature review established a historical framework detailing the fear society has had toward people with disabilities. For centuries, having a disability was a burden of shame and guilt. Legislation and advocacy over time has produced positive gains but without notable progress to instituting equal rights for people with disabilities in practice and without improvement in basic rights to be employed with meaningful work that add to QOL.

Practices in schools have not kept up with policy due to insufficient funding, resulting in understaffed, inexperienced, and high turnover in essential personnel responsible for post-secondary transition planning for individuals with disabilities. While there are pockets of innovation, few places have truly taken time to ask how individuals with disabilities define their own QOL and how they would quantify their own success. Nondisabled people have opportunities to define their own QOL. It is time to afford those with disabilities this same opportunity to better inform educational practice and programs.

Chapter 3 - Research Methodology

This chapter introduces the research methodology for this mixed methods study regarding postsecondary outcomes for individuals with disabilities. This approach allowed for a constructivist and pragmatic worldview. The relevance of a worldview will be discussed in-depth throughout this chapter. Details regarding the research plan, methodology, selection of study participants, research procedures, analysis method, and potential conflict of interest or ethical concerns will be discussed throughout this chapter.

Research Questions

The following research questions guide the inquiry:

1. How do young adults with IDD and significant disabilities feel about their overall QOL?
2. What supports, services, and experiences did young adults with IDD and significant disabilities have during IDEA Part B?
3. How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences contributed to their current QOL?

In education, success is often defined for students for the purposes of accountability in public systems like ESSA (U.S. Dept. of Education, 2017). For students without exceptionalities, there seems to be generalized agreement about what success looks like for the purposes of measuring educational outcomes. In many school systems, there are various stakeholders who work to measure growth with standardized systems of measurement and ensure accountability in schools. In Kansas, the KSBOE has outlined postsecondary expectations (*Board Outcomes*, 2023). Students are expected to have a basic understanding of academics and social emotional skills. After graduation, they go on with their lives, ostensibly either entering the workforce or

pursuing postsecondary education opportunities of their choice (*Board Outcomes*, 2023). If students have the cognitive ability to participate in standardized systems of measurement, stakeholders can visualize progress. Stakeholders perceive accountability to be best represented by visual charts and graphs that depict academic progress relative to established goals.

For students with IDD and more significant disabilities, standardized measures are often not appropriate measures, due to the nature and complexities of disabilities. While students with IDD and significant disabilities are guaranteed FAPE, a gap in research remains as to whether individuals with IDD and significant disabilities feel they received equitable access, achieved equitable “success,” or even how they would define success. The process of transitioning into adulthood can also look different, with supports ranging from adult day services to supports from VR, to CIE, (*Kansas Employment First Oversight Commission 2020 Recommendations to the Governor and Members of the Kansas Legislature*, 2021) or even the 18-21 supports that are available under IDEA Part B (*The Individuals with Disabilities Education Act, Part B: Key Statutory and Regulatory Provisions*, 2019).

Research Design

Mixed methods research involves the collection of both quantitative and qualitative data. The same level of rigor applied to quantitative and qualitative research apply when using mixed methods research. In this study, quantitative research informed the process of the qualitative method, with the researcher integrating and synthesizing data to draw conclusions.

While this methodology dates to the 1980s, it has been rising in popularity in fields such as human sciences, sociology, and education. Through a mixed methods approach, complex research questions can be answered with more depth (Creswell & Creswell, 2018). Data was collected in two phases. The first phase included quantitative data where research participants

ratee their overall QOL using a survey. The second phase was qualitative which focused on asking participants about specific examples of why they rated their QOL the way they did. In this study, the quantitative phase informed the qualitative phase. In the interpretation process, the qualitative data was analyzed to provide more depth to the quantitative data (Creswell & Creswell, 2018).

Research Phase One

Research phase one answered research question one: How do young adults with IDD and significant disabilities feel about their overall QOL? This phase of the research helped to inform phase two, which was qualitative, and helped guide interview questions that were created from the information collected in phase one.

Survey Overview

The participants were recruited from listservs and email lists from various advocacy groups such as Self Advocate Coalition of Kansas, Kansas University Center on Developmental Disabilities, Families Together, The Disability Rights Center of Kansas, and the Kansas Council on Developmental Disabilities. The recruitment letter for phase one is included in Appendix A. In phase one, the participants were volunteers who were recruited and responded to a survey sent out via email, social media, and announcements on advocacy listservs. The survey was adapted from the Wisconsin Quality of Life Survey and provided the researcher an overall understanding of how individuals with IDD and significant disabilities felt about their QOL (Diamond & Becker, 1999). This helped inform the interview questions for phase two of this study. It is important to note that data may have been skewed since the individuals who responded were likely to already have been involved in advocacy work, therefore, having more access to resources than other individuals with disabilities.

Data Collection: Phase One Survey

To answer research question one, “How do young adults with IDD and significant disabilities feel about their overall QOL?” participants responded to a survey. The survey selected was the Wisconsin Quality of Life Survey (Diamond & Becker, 1999). This survey has been validated from the work conducted by the original creators/authors of the survey. The psychometric properties of this widely used instrument are well-established, with multiple studies evaluating its validity and reliability (Caron et al., 2003). The purpose of the survey in its original format was to assess the QOL for individuals with mental illness. The original survey was translated and adapted for cultural relevance and sensitivity to cultural nuances by an advisory board appointed by the original creators. The survey aimed to establish that if clinical professionals were intentional about understanding QOL outcomes, they could more readily be connected to treatment goals, and thus, improve overall outcomes for patients (Diamond & Becker, 1999). While the primary population in this study did not have mental illness, there was an overlap with a need for mental health supports in the disability field and the understanding of professionals about intellectual, developmental, and physical disabilities to develop goals for clients to achieve their full potential. Because this survey allowed for valid responses from a diverse participant pool, it was relevant for this population as well. An additional benefit of using this survey was that the original purpose was to develop therapeutic interventions. Data collected from this study may lead to implications for practice due to thoughtful formatting of this survey.

The survey was originally developed from an advisory board with the intent to make mental health medication decisions for Medicaid in the state of Wisconsin. The authors, along with the advisory board, identified nine different domains of QOL. The data in the original survey was organized in various tables with descriptors. In this research study, Chapter 4

presents all data in tables with numerical values, organized by domain, except for one part of the “Goal Attainment” domain, where participants identified specific goals for themselves.

Survey Domains

General Satisfaction Level - The questions in this section cover a variety of life activities including satisfaction with living environment, housing, food, clothing, and mental health services.

Activities and Occupations - This domain relates to day-to-day activities such as work, school, day support, and other ways an individual can spend their day.

Psychological Well-Being - This domain uses a well-validated rating scale, the Bradburn Affect Balance Scale (ABS) that measures psychological well-being.

Symptoms/ Outlook - The primary focus of this domain is to assess how an individual’s mental health impacts their QOL and functional abilities.

Physical Health - This domain assesses how an individual perceives their own physical health.

Social Relations/ Support - Social skills and interpersonal relationships are an essential component to QOL. This domain assesses general satisfaction with their relationships.

Money - This domain assesses the adequacy of financial resources and how that impacts QOL.

Activities of Daily Living (ADL) - This section is a measurement of the client’s ability to accomplish independent living tasks, such as cooking, cleaning, personal hygiene and running errands.

Goal Attainment - In this section, individuals identify one goal they hope to accomplish. Then participants are asked to rank how important the goal was and how close they feel they were to achieving that goal.

In addition to the above domains that were quite specific, researchers also analyzed the role of hope in QOL and participant sense of control in their lives. While hope is an abstract construct, in this framework, it is measured by analyzing one's ability to develop a goal, the belief that they have control over attaining that goal, and the belief they will have a better future. These questions are asked throughout the survey within various domains.

For this study, the section on medication included in the original survey was removed. Because this survey was originally developed for individuals with severe mental illness who relied on mental health medication, there was a section for medication use. The population responding to this survey may or may not be using medication, but for the purposes of this research, medication usage questions were omitted. The need to establish the effectiveness of a specific medication for Medicaid was important to the original research but deemed irrelevant by the researcher for this study and its research questions.

To make it user-friendly for individuals with disabilities, the language for all questions in the survey was simplified. The answer choices were also simplified by limiting the number of response choices per item. The consent form was also included in the beginning of the survey for both phase one and phase two to simplify and streamline the process for the population and their caregivers (see Appendix B). Qualtrics was the software that was used to collect data. As the researcher entered the survey into Qualtrics, it was altered slightly to create a more user-friendly and simpler format for the target population so that respondents could be more independent in answering the questions. For some participants, it is likely assistance in reading the questions and answer choices was provided by a caregiver. Having the text read aloud was not considered a limitation for the purposes of this study.

Individuals responding to this survey identified areas of their life that their disability has impacted that are significant enough to affect daily living. Participants were also at the completion of their public education experience and had an IEP and post-secondary transition plan or were the primary caregiver or communication aide for an individual identifying in this category. Participation was voluntary. At the beginning of the survey, basic demographic questions regarding race, ethnicity, gender identification, and age were included. The survey also asked whether an individual was employed in CIE or if they were employed at subminimum wage at an organization holding a 14c exemption. This information helped to understand and provide context to how the participants responded to questions regarding finance and economic resources. The survey responses were recorded on a simplified Likert type continuum. The conclusion of the survey asked basic questions about their level of awareness of the post-secondary transition plan that was required as part of their IEP. The survey also asked about their willingness to participate in a follow-up interview. There were five participants who agreed to participate in the interview phase of the study.

Data Analysis

Table 2 provides the format for the display of survey results in Chapter 4.

Table 2

Sample Table for QOL Survey Responses

Sample Aggregate Data for QOL Responses					
	Mean	Std. Dev.	Min	Max	N
General Satisfaction					
Occupational Activities					
Activities of Daily Living (ADL)					
Psychological Well-Being					
Symptoms/Outlook					
Physical Health					
Social Relations/Support					
Money					
QOL Score					

Quality Control and Representativeness of the Sample

To ensure quality control, the completed survey results for demographic characteristics of the collected sample were compared with demographic characteristics of the Kansas population regarding race and ethnicity and assessed for potential sampling bias (Bureau, 2022).

Furthermore, the results obtained from the survey were compared with extant larger studies using the same instrument, with results of the comparison examined to assess whether values obtained were reasonably within the scope of past work. This tool has been used to develop interventions and support programs to improve QOL for individuals with severe mental illness for decades (Becker et al., 1993). Although the populations have different symptoms and concerns, the purpose and intent are the same; to give a marginalized population voice and autonomy in determining what is important to them and to develop interventions and support to improve their overall QOL. The full assessment was multidimensional, taking into consideration the impact of family and paid providers, which is beyond the scope of this study. Other studies agree results should be interpreted with the understanding that there may be potential limitations around literacy with self-reporting. In addition, QOL is a complex, abstract theory, and although has been found to be a valid and reliable instrument, no instrument is capable of predicting outcomes in all situations (Becker et al., 1993). Despite these limitations, the researcher believes this to be a quality instrument for giving voice and autonomy to a historically marginalized population of individuals.

Use of Phase One Results

The results of the survey for phase one were used to answer research question one. The results were also used to inform the interview protocol for phase two. In keeping with mixed

methods research design, some of the content was subject to change based on what was learned during phase one.

Research Phase Two

In phase two, individuals who responded to the survey and were willing to participate in a follow-up interview were selected for the interview phase of the study. Five individuals agreed to participate in phase two.

Data Collection: Phase Two Qualitative Interviews

Phase two of this research used qualitative methods to answer the two remaining research questions: “What supports, services, and experiences did young adults with IDD and significant disabilities have during IDEA Part B?” and “How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences contributed to their current QOL?”

Interview Overview

This data collection process was completed through personal interviews with the researcher. In phase two of this study, the researcher selected a group of participants who volunteered to participate in phase two of the research after completing phase one. The recruitment letter for phase two is included in Appendix C. The participants were young adults who recently graduated or completed a course of study in a public school and had a diagnosis of IDD or another significant disability that impacted ADL. The researcher interviewed them about their experiences in public education to understand how they defined QOL and what experiences they had in school. Asking individuals to share specific experiences that led them to their current QOL provided some explanation for their understanding and feelings. Analyzing this data in addition to phase one data allowed for deeper understanding of the experiences of the

participants. The researcher could interpret the experiences leading to a positive and, conversely, negative viewpoint on one's QOL to inform the development of instructional programs and life experiences that benefit individuals with disabilities as part of the IDEA Part B journey. Through this analysis, the researcher sought to inform other researchers and educators as to what events occur in public education that should be considered or discontinued from the perspective of individuals with disabilities. The researcher's perspective was widened during the study because individuals participating in the study encompassed a wide range of disabilities and circumstances on their general life satisfaction rating from the survey and the depth of the interviews.

There were five individuals selected for the interview phase of the research study. Some individuals required varied levels of assistance from an assistive technology device or a personal care assistant to participate and respond to questions. These accommodations did not exclude individuals from participating in the research. When possible, interviews were conducted in person, in their natural setting, but some interviews were conducted via zoom for researcher and volunteer convenience. All interviews were recorded with both video and audio, when possible, for accuracy and detail in coding.

Interview Format

The interviews were semi-structured, asking both “descriptive” and “grand tour” type questions in order to thoroughly cover the scope of the research questions (Bhattacharya, 2017). The intent was to understand the lived experiences of the research participants. Representative interview questions included:

- Walk me through a typical day in your life as you experienced in school.
- You mentioned ____ happened. Tell me how that made you feel.
 - Why do you think it made you feel that way?

- How do you think that has impacted you today, if at all?
- What was it like during high school?

The interviews were recorded and transcribed using Otter Artificial Intelligence (AI) software. Individuals with disabilities often communicate with a combination of verbal and nonverbal communication so video and audio recordings were available for review by the researcher.

Researcher as Key Instrument

In qualitative research, it is important to articulate one's personal ontology. The researcher has spent two decades in advocacy for equity in education for individuals with IDD and significant disabilities. In addition to the researcher's career in education, the researcher has served on multiple councils and commissions appointed by multiple state Governors in Kansas. The researcher has testified at both the state and federal levels for improving state and federal policies. The researcher is also a parent of a child with IDD who has experienced discrimination and low expectations currently impacting him as an adult. These experiences manifest as both assets (in terms of both background knowledge and familiarity with lived experiences that can aid in interpretation of data) and challenges (in terms of how my own experiences shape and color my perceptions). The researcher's goal was to maximize the contribution of the assets while minimizing the intervention of the challenges.

Epistemologically, these data were analyzed using a constructivist approach (Creswell & Creswell, 2018). Constructivism places importance on the active role of the participants in the research process. It acknowledges their perspectives as valid and meaningful. This is especially important when researching ways to improve systems for marginalized populations and to uncover unique diverse perspectives and subjective realities. The researcher sought to understand the world through the eyes of the participants.

As part of moderating any potential biases held by the researcher, there were contrast questions built into the interview process. Contrast questions were designed to disprove or challenge a perspective. For example, if it appeared that discrimination was the only theme that appeared in an interview, a probing question was asked to further understand the participant's lived experience (Bhattacharya, 2017; Crewell & Creswell, 2018). An example of a probing question might be: "Earlier you mentioned feelings of loneliness and isolation, especially during senior year. Later, you mentioned some strategies you learned to manage those feelings that made you feel happy. Can you tell me about some times you felt happy about a negative situation after you were able to overcome the challenge?". As an additional step toward mediating potential bias, negative case analysis (Lincoln & Guba, 1985) was employed as a technique during data analysis to enhance credibility and trustworthiness. Specifically, as tentative themes emerged from the analysis, the themes were tested by re-engaging the data with the specific purpose of finding disconfirming data for the tentative theme. When such data was found, the tentative theme was nuanced, modified, or rejected as appropriate; when no disconfirming data was found, its absence was presented as evidence of due diligence.

Sources of Data

Often, individuals with IDD have comorbid diagnoses of speech and language impairments. This can make it difficult to understand verbal communication, but sometimes individuals with IDD have developed nonverbal communication strategies to compensate. Due to these challenges, it was important for the interviews to be video recorded with audio. The video and audio feeds were analyzed as multiple sources of data as nonverbal communication was communication that could be coded and recorded into themes. If an individual required the use of assistive technology to communicate, this was recorded in the transcription as well. There was a

signed consent form from all participants. All phase two participants were between the ages of 18-25 years old. Sometimes people with significant disabilities have a legal guardian to sign on their behalf. In those instances, the guardian signed the consent form.

Coding Methodology

The qualitative phase of the study was informed by the quantitative phase of the study. Because the intent was to be open to an array of experiences, an inductive coding approach was utilized (Saldaña, 2021). There was not a set of predetermined codes going into this portion of the study. To truly give voice to this marginalized population, the researcher was open to all experiences shared by the participants in the first cycle coding. In the first cycle of coding, open coding was utilized by the researcher (Saldaña, 2021). The transcripts were reviewed with a clear focus on the participants' supports, services, and experiences as outlined in the research questions. In addition, open coding was used to capture any additional words, phrases, or perspectives voiced by the participants. Since the researcher worked with individuals with significant disabilities with the goal of giving them voice, it was important to use their words (Creswell & Creswell, 2018). Since the researcher used member checking as a method to ensure credibility, plain language was utilized to ensure understanding by both the participant and researcher (Saldaña, 2021). This helped to develop and share themes to inform research question two: "What supports, services, and experiences did young adults with IDD and significant disabilities have during IDEA Part B?".

A secondary coding method was utilized to capture how the participants felt during certain experiences and how they feel now as recent completers. The concept of QOL is largely dependent on how a person feels about their situation. This method of coding is referred to as emotion coding (Saldaña, 2021). The transcript was analyzed a second time to look for emotions

the participants shared and depicted during their experiences. This helped inform research question three: “How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences contributed to their current QOL?”.

Techniques to Promote Credibility and Trustworthiness

Thick description, triangulation, negative case analysis, and member checking enhanced the credibility of research (Creswell & Creswell, 2018; Tracy, 2010). Thick description begins with detailed notes taken during an interview, observation process, and continued through the final presentation of themes which allows for rich details to emerge from the context of participant’s words (Creswell & Creswell, 2018). Triangulation is the enhancement of credibility that occurs when two or more points of evidence speak to the same finding (Creswell & Creswell, 2018; Tracy, 2010). Conducting interviews with multiple participants allows for triangulation of data and themes in descriptions of individual experiences. Negative case analysis was utilized to test tentative themes through intentional pursuit of disconfirming evidence (Creswell & Creswell, 2018). Finally, credibility was enhanced with member checks to “allow for sharing and dialoguing with participants about the study’s findings, and providing opportunities for questions, critique, feedback, affirmation, and even collaboration” (Tracy, 2010, p. 844).

Use of Phase Two Results

The results of phase two were used to answer research question two and research question three and to revisit and nuance interpretations for research question one. Some of the themes developed from analysis of phase two gave additional meaning to the results in phase one. To weave together the conclusions of both phases, the researcher first individually answered the research questions. The researcher then synthesized the data from both phases to provide a

meaningful conclusion to the research questions. The final step was to analyze whether any of the research questions confirmed or affirmed the others.

Summary

Chapter 3 unveiled the research methodology for this mixed methods study. The research plan, selection of participants, and the procedures for data collection and data analysis were presented. Methods for establishing quality processes used for quantitative and qualitative measures to answer the research questions posed by the study were provided. Chapter 4 will present the findings.

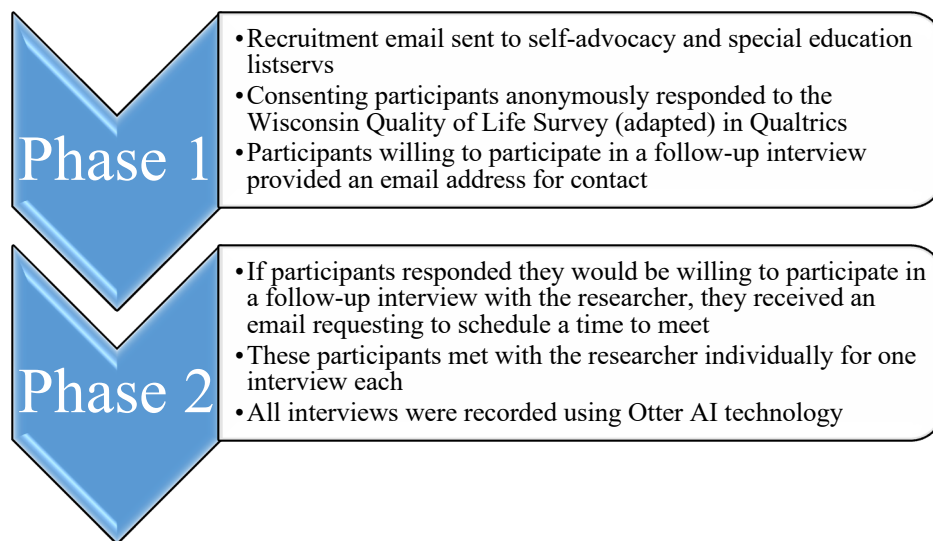
Chapter 4 - Study Findings

Introduction

In Chapter 4, an overview of the data collection, analysis, and study's findings for each phase of the study is presented. The study's results are provided in the order of the research questions to provide a sequential framework aligned with the study's purpose. The final section in Chapter 4 is a synthesis of the results that will lead to connections to the literature and theoretical framework, implications for practice, and recommendations for research revealed in Chapter 5. Figure 2 provides an overview of the data collection process for phase one and phase two of the research study.

Figure 2

Data Collection Process



Overview of Phase One: Survey

To answer the first research question, “How do young adults with IDD and significant disabilities feel about their overall QOL?”, 26 participants responded to a QOL survey that was adapted from the *Wisconsin Quality of Life Survey*. The survey is included in Appendix B as part

of the consent form (Diamond & Becker, 1999). The survey was shortened, and the questions simplified into plain language to make it accessible for this audience. The opportunity to participate in the study was distributed through several listservs, including the Kansas Disability Rights Center, Families Together, Kansas University Center on Developmental Disabilities, Kansas Association of Special Education Administrators, and the Kansas Council on Developmental Disabilities. There was a total of 34 partial responses, but not all participants completed the survey, so the n varied with some responses. The survey took participants an average of 16 minutes to complete. The survey did not collect information as to whether the participant required assistance to complete the survey from a parent or guardian. The survey did include a question regarding level of independence because this was a lengthy survey for individuals with IDD and significant disabilities to complete. It is important to note when interpreting the results, participants may have been more independent than the average population of people with IDD and other significant disabilities. Tables 3-11 provide general demographic information about the participants that joined in phase one.

Table 3

Summary of Frequency Results for Age Group of Participants

Age	N	Percentage
18-25	15	75%
25-30	2	10%
30-35	3	15%
Total	20	100%

Table 3 indicates a wide age range of participants. While the original intent of the study was to limit participation for participants ages 18-25, several participants took the survey over

the age of 25. The researcher deemed it important to include their survey responses in the data for phase one. The researcher selected only young adults ages 18-25 to participate in phase two of the study.

Table 4

Summary of Frequency Results for Gender of Participants

Gender	N	Percentage
Male	15	67%
Female	6	29%
Non-Binary	1	5%
Total	21	100%

Table 5

Summary of Frequency of Educational Attainment for Participants

Educational Attainment	N	Percentage
12 th Grade	7	35%
18-21 Transition services	7	35%
GED	0	0%
Less than High School	1	5%
Some College	5	25%
College Degree	0	0%
Total	20	100%

Tables 3-5 offer important demographic information as it relates to IDEA. All participants who responded to the survey self-reported having a disability that impacted ADL.

Under IDEA, all individuals are entitled to services until they turn 21 to build employment and daily living skills (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). According to the data in Table 5, only 35% of the individuals who responded received services beyond their senior year of high school in the public-school setting, even though 100% may have qualified for those services. IEP teams may choose to receive a high school diploma upon graduation and attend a technical college, an inclusive college experience, a typical college, or enter the workforce if they have desired employment skills. However, as the data shows later, only 16% of the participants in this study had paid employment, while 40% wanted to enter the workforce as their main daily activity, demonstrating a gap in readiness skills to enter the workforce. Further emphasizing the point of a gap in skills, respondents in both phase one and phase two consistently reported a desire to live more independently.

Table 6

Summary of Relationship Status for Participants

Relationship Status	N	Percentage
Single/Never married	19	95%
Married	0	0%
Divorced	1	5%
Committed Relationship	0	0%
Separated	0	0%
Spouse Deceased	0	0%
Total	20	100%

The data in Table 6 substantiates that although relationships remained a theme in the data analysis, romantic relationships were not a high priority. In phase two, only one participant mentioned marriage as a potential future endeavor. Most of the participants focused on friendships and familial relationships as an area they wanted to work on.

Table 7

Summary of Main Source of Income for Participants

Income Source	N	Percentage
Paid Employment	3	16%
Sheltered Workshop	0	0%
Social Security Disability Income (SSDI)	4	22%
Supplemental Security Income (SSI)	6	33%
Money from Family	5	28%
Total	18	100%

Table 7 displays the main source of income for participants. The content of this table is important in understanding context in several future tables and will be referred back to several times. For example, Table 15 will show the main activity for how participants spend their time. In Table 7, only 16% of participants rely on their employment for income. Eighty four percent of participants rely on SSI, SSDI, or family for food, housing, medical care, and other daily expenses. This data is important because it highlights the discrepancy between what participants are doing with their time, what they would like to do with their time, and how they are able to make monetary decisions. For example, while the smallest group in Table 7 is the group that can

financially provide for themselves, the largest group in Table 15 would like to spend most of their time in paid employment. This may be caused by a gap in skills for PWD, a gap in understanding for employers in how to support PWD in the workplace, or a combination of the two issues.

Table 8

Summary of Racial/Ethnic Background of Participants

Racial/Ethnic Background	N	Percentage
American Indian/ Native American	1	5%
Asian	0	0%
African American	1	5%
Hispanic/ Latino	2	11%
White	13	68%
Other	2	11%
Total	19	100%

Table 8 described the racial and ethnic backgrounds of the participants of phase one of the study. Table 9, below, shows the racial and ethnic backgrounds of Kansas residents according to the 2020 Census (Bureau, 2022). When analyzing the general population sample, the researcher was pleased with the diversity that was represented in phase one of the study, as it is a reasonable comparison to the general Kansas population, given the small sample size.

To analyze whether the population within this data set is approximate to state or national populations with disabilities, research was conducted in several places, including the census. It was uncovered that across the United States, there is no standard method of collecting demographic data for individuals with IDD and significant disabilities (*I/DD Counts* | *ACL*

Administration for Community Living, 2023). The Administration for Community Living is currently leading efforts in a cross-agency team to assess the prevalence of IDD in the United States, but due to wide variations in how the data is collected across the states and territories, there is currently no reliable source of data on demographics for individuals with IDD (*I/DD Counts | ACL Administration for Community Living, 2023*). Providing a way to collect this information in the future will be an important effort because the lack of demographic data leads to gaps in supports, services, and health disparities for this population. An additional layer of complexity and barrier in gathering this data is that individuals with disabilities would be required to self-report complex diagnoses.

Table 9

Summary of Racial/Ethnic Background of State of Kansas

Kansas Racial/Ethnic Background	N	Percentage
American Indian/ Native American	30,995	4.8%
Asian	86,273	3%
African American	168,809	12.1%
Hispanic/ Latino	382,603	11%
White	2,222,462	73.5%
Other	145,422	5.6%
Total	2,937,880	100%

Table 10*Summary of Living Arrangements and Preferences of Participants*

In the past 4 weeks, you lived...	N	Percentage	Who would you like to live with?	N	Percentage
Alone	2	10%	Alone	2	10%
With a friend	0	0%	With a friend	6	30%
With children	1	5%	With children	0	0%
With parents	15	75%	With parents	9	45%
With spouse	0	0%	With spouse	1	5%
With other	2	10%	With other	2	10%
Total	20	100%	Total	20	100%

Table 10 highlights current living arrangements as well as preferred living arrangements. While 75% of participants currently live with their parents, only 45% would choose that living arrangement. Currently zero participants live with friends, but 30% would prefer to live with friends. This data indicates a preference for more independent living arrangements.

Table 11*Summary of Living Locations and Preferences of Participants*

In the past 4 weeks, you lived...	N	Percentage	Who would you like to live with?	N	Percentage
In an apartment/home	17	85%	In an apartment/home	15	75%
In a boarding home	0	0%	In a boarding home	0	0%
In a group home	0	0%	In a group home	1	5%
Homeless	1	5%	Homeless	0	0%
At school/college	1	5%	At school/college	3	15%
In an institution	0	0%	In an institution	0	0%
In jail/prison	0	0%	In jail/prison	0	0%
Other	1	5%	Other	1	5%
Total	20	100%	Total	20	100%

Table 11 specifically asked participants what type of living situation they would prefer and assessed their current living situation. One participant reported having a lack of access to stable housing in the past four weeks, which is concerning. For people with disabilities, group homes offer a level of support as an option. This survey question asked participants how they feel about that option. Only 5% would choose to live in a group home, while 75% would prefer to live in an apartment or home and 15% would like to live in a school or college setting. This data speaks to the desire to have more independence in independent living.

Table 12*Aggregate Data for QOL Responses*

Theme (Question Numbers from form responses)	N	Mean	Std. Dev.	Min	Max
General Satisfaction (Q19 subset 1-9)	19	5.08	2.27	1	7
Physical Health (Q33-Q36)	19	3.72	1.71	1	7
Social Relations/Support (Q41 subset 1-5)	17	4.93	2.35	1	7
Money (Amount Q44 subset 1-2)	17	4.45	1.82	1	7

Table 12 presents aggregate data derived from a series of inquiries encompassing distinct themes delineated in the table. Each theme was explored through a set of questions, with corresponding question numbers indicated within parentheses alongside respective themes. Respondents were tasked with rating their level of satisfaction for each question associated with every thematic category, employing a scale where “1” signified dissatisfaction and “7” represented satisfaction.

The themes in Table 12 were initially determined from the original Wisconsin QOL survey. The survey used in this study was adapted to enhance accessibility for the target population. The underlying determination for utilizing this survey was due to the substantial overlap between its identified themes and the desired outcomes outlined by the KSBOE for successful student outcomes (*Board Outcomes, 2023*). Despite not achieving perfect alignment, the rationale was to empower individuals with IDD and significant disabilities to self-report their own progress across the various categories encapsulating what constitutes their own definition of success within the Kansas educational framework.

Table 13*Relative Importance of Each Aspect of Daily Living (Q20 Subsets 1-10)*

Relative Importance of each Theme (Question Numbers from form responses)	N	Mean	Std. Dev.	Min	Max
The way you spend your time (Q20 subset 1)	19	4.16	1.22	1	5
Personal safety (Q20 subset 10)	19	4.37	1.16	1	5
Feeling comfortable alone (Q20 subset 2)	19	4.58	0.84	3	5
Housing (Q20 subset 3)	18	4.22	1.21	3	5
Your neighborhood (Q20 subset 4)	19	3.84	1.54	1	5
The food you eat (Q20 subset 5)	19	4.05	1.39	1	5
The clothing you wear (Q20 subset 6)	19	3.53	1.31	1	5
Your mental health services (Q20 subset 7)	19	3.52	1.74	1	5
Access to transportation (Q20 subset 8)	18	4.44	0.92	3	5
Romantic relationships (Q20 subset 9)	19	2.58	1.71	1	5

Table 13 serves as a barometer of the comparative significance attributed to each thematic element. Notably, the importance of the theme “Feeling comfortable alone” garnered a mean rating of 4.48, accompanied by a standard deviation of 0.84, which, compared to the other themes, was relatively modest. Access to transportation ranked second highest with a mean score of 4.44, with another relatively modest standard deviation indicating agreement among participants.

Romantic relationships ranked lowest in its level of importance, significantly, with the next closest being mental health services at 3.52. This was interesting, as some participants in phase 2 felt strongly about access to mental health services, reporting negative experiences in hospitals while others did not seem to understand what mental health services meant.

Interestingly, both areas had the widest standard deviations, indicating differing opinions among respondents. Areas of relationships, romantic relationships, and transportation access were discussed in further detail in phase two because of this discrepancy.

Table 14

How Satisfied or Dissatisfied Are You With the Main Activity That You Do? (Q23)

Main Activity Satisfaction	N	Mean	Std. Dev.	Min	Max
Scale 0-100	18	65.22	24.61	10	100

This finding is particularly intriguing given its juxtaposition with the results in Table 14. Table 14 indicates a wide standard deviation of 24.61, but a mean score of 65.22 with a max of 100. Participants stated they are more satisfied than not with the main activity that they do during their day. However, when data from Table 15 is analyzed, it appears that many participants would prefer to be doing something else with their time. Only 21% are in paid employment while 40% would like to be in paid employment. Fifty percent are involved in some educational institution and 10% would like to be in school. Fourteen percent have no structured activity provided for them throughout their day but 0% have that as their preference. When synthesizing the data, it does appear that most participants would like to have some structure provided in their day, such as employment, school, support from a rehabilitation program, or access to leisure programs. Zero participants indicated a desire to participate in sheltered workshops or to have no structured activity throughout their day. Given that information, it's interesting that participants would indicate a satisfaction level of closer to "satisfied" than "dissatisfied."

Table 15*Summary of Daily Activities and Preferences*

What is your main activity?	N	Percentage	What would you like your main activity to be?	N	Percentage
Paid employment	3	21%	Paid employment	8	40%
Volunteer or unpaid work	1	7%	Volunteer or unpaid work	0	0%
School	7	50%	School	2	10%
Rehabilitation program	0	0%	Rehabilitation program	1	5%
Craft/Leisure time/Hobbies	0	0%	Craft/Leisure time/Hobbies	4	20%
No structured activity	2	14%	No structured activity	0	0%
Sheltered workshop	1	7%	Sheltered workshop	0	0%
Other	0	0%	Other	5	25%
Total	15	100%	Total	20	100%

In Table 15, additional data reflects two participants who mentioned their preferred activity is “other”. Alternative activities listed included working and playing video games and would like to have access to adult day services. It is worth noting that only 21% of participants reported having paid employment while 40% report that they would like paid employment. Fourteen percent indicated they have no structured activities in their day and zero participants reported wanting that lifestyle. Seven percent indicated they spend time at a sheltered workshop, while zero participants indicated that it was their desired daily activity. Twenty percent would like to have access to more crafts, hobbies, or leisure activities.

Tables 16-18 focus on the importance and quality of friendships and relationships that participants report experiencing. Results reported in Table 16 indicate that nine of the participants reported having zero to two friendships. The following tables will uncover additional data regarding the importance of how PWD feel about the adequate quantity and quality of friendships and relationships for PWD and how those relationships connect to overall QOL.

Table 16

Summary of How Many Friends Participants Report Having (Q42)

Number of friends	N	Percentage
None	2	11%
1-2	7	39%
3-5	4	22%
Over 5	5	28%
Total	18	100%

Table 17*Relative Importance of Relationships (Q43 subset 1-5)*

Relative Importance of Relationships (Q43 subset 1-5)	N	Mean	Std. Dev.	Min.	Max
How important is it to have an adequate number of friends?	17	3.23	1.2	1	5
How important is it to get along with your friends?	17	4.17	1.01	3	5
How important are family relationships?	17	4.41	1.18	1	5
If you live with others, how important are the people with whom you live?	18	4.11	1.41	1	5
How important is it to get along with others?	18	4.11	1.02	3	5

In Table 17, participants were asked to rate the importance of their relationships, with “1” indicating “not important” and “5” indicating “extremely important.” Participants indicated relationships are quite important to them, but rated family relationships higher than social friendships. The question “How important are family relationships?” scored a mean of 4.41 with a smaller standard deviation of 1.18. This indicates that the importance of family relationships is a fairly strong consensus among participants.

Table 17 also reveals survey respondents consistently expressed high levels of importance regarding their interpersonal relationships, as evidenced by their robust ratings pertaining to “getting along well with others” and their desire for meaningful companionship and friendships. This juxtaposition emphasizes a compelling insight into the nuanced intricacies of individuals’ emotional needs and social dynamics. Despite indicating a strong inclination toward

fostering meaningful connections and social bonds, the relatively high mean score for “feeling comfortable alone” suggests either a multifaceted relationship individuals maintain with solitude, or a desire to have the skills and ability to be alone safely. It may also hint at the capacity for individuals with IDD and significant disabilities to derive contentment and fulfillment from solitary pursuits and moments of introspection, highlighting the complexity of human emotional experiences and preferences.

Table 18

Social Relations- How Satisfied are You With the Number of Friends You Have? (Q41 subset 1)

Number of friends	N	Mean	Std. Dev	Min	Max
None	17	3.29	2.49	1	7

Table 18 highlights how satisfied participants are with the number of friends they have. With a mean of 3.29, even though there was a larger standard deviation of 2.49, this score indicates the group is more dissatisfied with their social relationships and the number of friends they have. Table 16 indicated 50% reported having two or fewer people they consider having as friends.

Table 19

Goal Setting-How Important is This Goal to You on a Scale of 0-100? (Q51 subset 1)

Goal setting	N	Mean	Std. Dev	Min	Max
Level of importance	19	72.16	26.73	1	100

Table 20

Goal Setting-To What Extent Have You Achieved This Goal on a Scale of 0-100? (Q51 subset 2)

Goal setting	N	Mean	Std. Dev	Min	Max
Level of achievement	18	32.33	29.59	0	87

Tables 19 and 20 delve into the realm of goal setting, a fundamental aspect of personal growth and development that is often regarded as a beacon of hope for a brighter future, as illuminated by Becker et al. (1993). The underlying premise is that the act of goal setting gives individuals the notion that they can delineate objectives and diligently pursue them, thereby infusing their lives with purpose. Table 19 sheds light on the significance of goal setting by survey participants, reflecting a collective acknowledgement of its importance in shaping their aspirations and trajectories. However, the narrative takes a poignant turn when Table 20 comes into focus, revealing a stark disparity between the perceived importance of goals and the perceived attainment thereof.

The survey question employed the use of a sliding scale ranging from zero to 100, encapsulating the nuanced spectrum of participants' sentiments regarding goal achievement. At one end of the spectrum was the acknowledgement of a goal as inconsequential or unattained, represented by the lower numerical values. Conversely, the higher numbers signified the more profound significance attributed to goals or satisfaction derived from attaining the goal. The dissonance between the perceived importance of goals and the perceived level of achievement underscores a poignant reality wherein individuals harbor aspirations for self-improvement and fulfillment but grapple with obstacles or setbacks hindering their realization. This dichotomy emphasizes the relationship between ambition and achievement. Because there was such a gap

between the level of attainment in goals and perceived importance in achieving the goals, this was an area of focus leading into phase two, to garner a deeper understanding.

Table 21

Quality of Life-Overall Rating a Scale of 0-100? (Q58 subset 1)

Quality of life	N	Mean	Std. Dev	Min	Max
Overall rating	18	73.07	19.03	30	100

In the exploration of individuals' experiences and perceptions, quantitative surveys often encounter a limitation in capturing the nuanced realm of emotions, a vital component in understanding the intricacies of hope and uncovering barriers impeding goal achievement. Those questions will be explored in phase two of this study. While quantitative surveys excel in defining certain aspects, such as overall QOL, they may fall short in capturing emotional nuance, which is why this is a mixed methods study. Table 21, for example, requested participants to identify their current QOL on a scale from zero to 100 with 100 indicating the best, zero indicating the worst. The calculated mean score of 73.07 suggested a generally positive outlook, which positioned the overall QOL closer to the apex of satisfaction rather than discontent. However, the sizable standard deviation of 19.03 indicates variability in each individual experience.

Although this quantitative data provides a valuable snapshot of participants' perceptions, it is important to glean a more comprehensive understanding in phase two. Phase two of the study will introduce supplementary questions aimed at adding nuance to these quantitative assessments. These additional questions are aimed to serve as a bridge to identify underlying factors that connect the numerical data from phase one with the qualitative insights for a more holistic understanding of participants' lived experiences.

Table 22

Quality of Life-If Your Quality of Life is Less Than You Hope For, How Hopeful Are You That You Will Eventually Achieve Your Desired Quality of Life? (Q59)

Quality of life	N	Mean	Std. Dev	Min	Max
Level hope	16	3.06	0.85	2	4

Table 22 attempts to quantify some elements of hope. Survey respondents were asked to rate themselves on a scale reflecting their degree of hopefulness, with a core of four indicating optimism. The mean score was 3.06. This implies an inclination toward optimism in the survey respondents, signifying a collective belief in the potential for positive outcomes in their futures. Although the concept of hope is abstract, this quantitative representation of hopefulness offers insight into an overarching mindset within the population that responded to this survey. Despite the challenges they may have faced, most participants seem to be experiencing emotional resilience and positive psychology.

Because the purpose of this survey was to develop instruction and interventions, this finding emphasizes the importance of fostering and nurturing hope as a catalyst for personal empowerment and resilience-building. By capitalizing on the strength of participants' optimistic outlooks, instructional interventions and support systems can be tailored and customized to enhance their sense of autonomy, thus facilitating pathways toward realizing their own visions for their futures. A question that arose when analyzing the data was regarding the juxtaposition of reliance of others for typical adult stressors and how that may impact hope, overall optimism, and QOL. For example, the participants in this study seemed less concerned about money and personal safety because others typically took care of that stressor for them.

Table 23

Quality of Life-How Much Control Do You Feel You Have Over the Important Areas of Your Life? (Q60)

Quality of life	N	Mean	Std. Dev	Min	Max
Level control	18	2.55	0.85	1	4

Table 23 demonstrates how much control participants feel over various aspects of their lives. With a minimum of one and a maximum response of four, the mean was 2.55, which is approximately slightly higher than the midpoint. In phase two, participants tell stories of feeling reliant on family members for money and transportation, which could be an explanation for participants feeling like they don't have much control over various aspects of their lives.

Table 24

Please share a goal you have made for yourself (Q50)
To get a driver's license
Shower every other day or more
Trying to find things that I enjoy, making friends
Meal prep
I want to have friends
Transition within school without behaviors to allow access to community activities to start
Get my GPA to a 3.0
Go see Garfield the movie
Get IDD services
Create dolls of my favorite movie directors
Buy a car
Get an ABLE account
Read music and play a piano
Be independent with hygiene
Communicate better with others around me
I want to be a veterinary assistant to take care of animals
Get a real girlfriend
Not sure
Live with a friend

Table 24 highlights some of the goals that were shared in phase one. These goals are reflective of individuals' aspirations and offer insights into the diverse array of ambitions driving personal growth and development within the surveyed cohort. They are also reflective of the level of need in activities of daily living.

Table 25

Level of Independence–How Often Do You Require Help with Personal Care (Taking a Shower, Brushing Teeth, etc.) (Q49)

Help with care	N	Mean	Std. Dev	Min	Max
Personal care assistance	19	2.39	1.16	1	4

Table 25 allowed participants to share their level of independence. Participants may have interpreted personal care differently, as some participants have physical disabilities such as blindness/low vision while others have intellectual disabilities or multiple disabilities. As mentioned before, there is no national clearinghouse data, nor is there a clear-cut way to measure “significant disability,” which is why this study is reliant on self-disclosure.

Table 26

Money–How Often Does Lack of Money Keep You from Doing What You Want to Do? (Q47)

Access to money	N	Mean	Std. Dev	Min	Max
Money-activities	18	2.11	1.08	1	4

Table 27

Money–How Do You Feel About the Amount of Money That you Have? (Q44 subset 1)

Amount of money	N	Mean	Std. Dev	Min	Max
Money-satisfaction	16	3.81	2.56	1	7

Table 28

Money—How Satisfied Are You About the Amount of Control You Have Over Your Money? (Q44 subset 2)

Control of money	N	Mean	Std. Dev	Min	Max
Money-control	17	5.06	1.82	1	7

Table 29

Money—Overall Importance (Q46 subset 1)

Importance of money	N	Mean	Std. Dev	Min	Max
Money-overall	18	3.22	1.66	1	5

Tables 26-29 provide insight into the sentiments of survey respondents concerning finances and the degree of perceived control they have over their monetary resources. Notably, these tables reveal a trend where participants communicate that, although their occupation is a significant factor in influencing their QOL, the importance they attribute income in shaping their overall well-being is inconsistent. This observation led to further questioning in phase two to gain a deeper understanding of this relationship between career satisfaction and financial consideration. Phase two participants discussed employment as structured social opportunities they wouldn't otherwise have.

Eighty-four percent of participants rely primarily on SSI, SSDI, and family primarily for income. This reliance showcases the critical role these support systems have in sustaining the livelihood of the surveyed individuals. This statistic should prompt further investigation into broader socio-economic factors impacting the financial dependence and interdependence of this

population, and study the dynamics of personal aspirations, support systems, and societal and economic realities.

Table 30

Importance of Determining Factors in Quality of Life

<i>In rank order Form Questions are in ()</i>	N	Mean	Std. Dev.	Min	Max
Friendships & family (Q56 subset 4)	17	4.65	.79	3	5
Occupational activities (Q56 subset 1)	17	4.52	.87	3	5
Feelings about yourself (Q56 subset 2)	17	4.53	.87	3	5
Self-care (Q56 subset 6)	17	4.17	1.01	3	5
Physical health (Q56 subset 3)	17	4.17	1.01	3	5
Mental health (Q56 subset 7)	15	3.92	1.32	1	5

The purpose of phase one of this study was to answer research question one: “How do young adults with IDD and significant disabilities feel about their overall QOL?” Based on the information collected, there is an intriguing dichotomy revealed in participants’ perceptions in their overall QOL. On the one hand, data shows a sentiment of general satisfaction with overall well-being. However, upon closer examination, there is a nuanced layer of discontent intertwined with acknowledgement of the intrinsic value of certain aspects of the human experience. Table 18 highlights one example of this in the domain of friendships and relationships, where participants expressed a sense of dissatisfaction. Yet, the data in Table 30 also showed a keen awareness of the significance of how these connections shape their overall QOL. Here, participants ranked friendships and family relationships as the most important factor in determining their QOL. This duality highlights the tension between longing for deeper, more

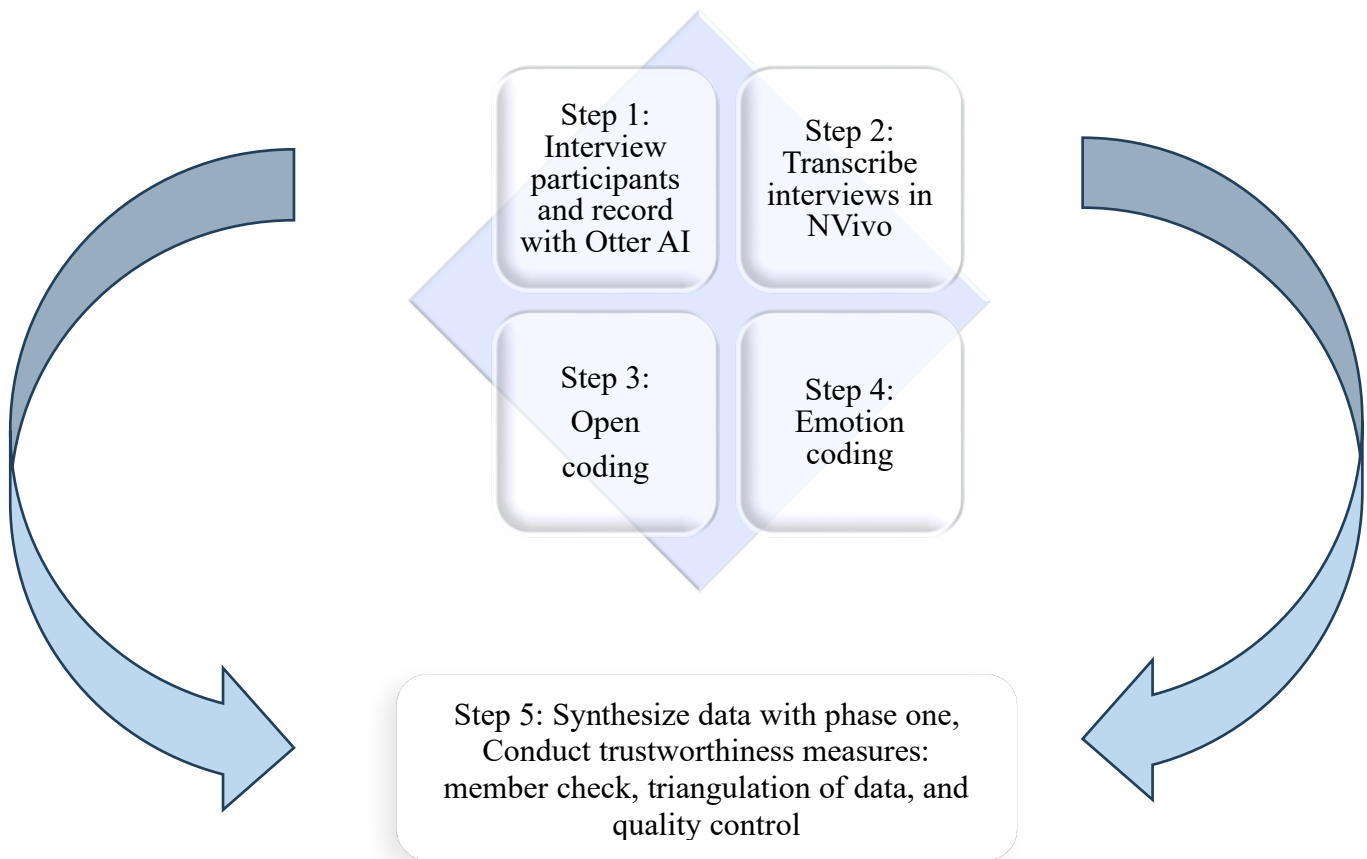
fulfilling relationships, and gratitude for the pivotal role that existing relationships have and how these relationships foster a sense of fulfillment.

Another duality present in the data set in Table 30 was that participants attributed substantial value to their work and how it added purpose to their lives. However, despite this recognition, data in Tables 26-29 demonstrate inconsistent values about the importance of money and having control of their own finances. This divergence suggests a deeper motivation rooted in personal fulfillment related to personal passions or relationships, rather than financial success. The importance of factors determining QOL in Table 30 highlights a complex interplay between satisfaction, discontentment, and personal values. It offered insights into the multifaceted nature of the well-being of individuals with IDD and significant disabilities and stresses the importance of utilizing a holistic approach when assessing QOL.

Overview of Phase Two: Interviews

The purpose of phase two was to answer research question two: “What supports, services, and experiences did young adults with IDD have during IDEA Part B?” and research question three: “How and in what ways do young adults with IDD perceive those supports, services, and experiences contributed to their current QOL?”. Data collected during phase two also added nuance to deepen understanding for research question one. Figure 3 provides an overview of the data collection and analysis process for phase two. This included participant interviews, transcription of the interviews, and two phases of coding. The researcher conducted data analysis following open coding, separately for emotion coding, and finally synthesized data from phase one and phase two to complete the data analysis process. Quality control processes were also addressed.

Figure 3



Phase two consisted of interviewing five participants from those responding to the consent form asking if they were willing to participate in the interview phase of the study. Eight participants were contacted, and each one was asked if they would be willing to participate in the interview phase of the study. Three individuals did not respond to the request to participate. The five participants agreeing to an interview were asked if they would like to schedule an interview over zoom or in person. Three interviews were conducted in person, one on the phone, and one over zoom. All interviews were recorded using Otter AI technology. Immediately following the interview, the transcripts were edited for accuracy and clarity and

then deleted from the online platform for privacy. The transcripts were uploaded to NVivo software for analysis.

All participants in phase two were between the ages of 18-25 and ranged in ability. Some participants were more impacted by physical disabilities, and some were more impacted by intellectual disabilities, but the challenges they faced were similar. None of the participants required the use of assistive technology for communication, but two participants did require family members to assist with clarity of their responses due to challenges with speech articulation and the researcher being an unfamiliar listener.

A semi-structured guide for the interviews was used and the questions to guide the interviews are noted below. If a participant wanted to take the conversation down a different path, the researcher accommodated the participant to capture important nuance, increase understanding, and allow for detailed storytelling. It also helped build a trusting relationship and added to the quality of the data provided.

Phase Two Questions

- Tell me about yourself
- Where do you work?
- Do you like where you work? Is it a goal you set?
- Where do you live?
- Do you like where you live?
- Do you have adequate supports?
- Do you have access to the things you need like food, transportation, and medicine?
- If not, why not?
- When you were in high school, did anyone help you set goals?

- Did anyone help you break those goals down into a plan?
- What supports did you have while you were in school?
- What did they look like?
- What barriers do you have in reaching your goals?
- Do you believe the help you received in school helped you get where you are now?
- How?
- Why?
- Provide some examples of what that looked like.
- What skills do you use today that you learned while in school?
- How would you define success for yourself?
- Personal success?
- At work success?
- Financial success?
- I noticed many activities on the survey were alone. Do you have opportunities to participate in group activities?
- How do you feel about your overall quality of life?
- Has anyone ever talked to you about quality of life before?
- Has anyone ever talked to you about what success means to you before?
- What supports were most useful in school?
- What supports were LEAST useful in school?
- What are some things that you considered a waste of your time?

- Tell me a story about something great that happened to you in school that you still remember today. What is it that made that experience so impactful for you? How did it make you feel?
- If there was one thing that could make your life better right now, what would it be?

First Cycle Coding

Because the theoretical framework was based in constructivism, where the data collection and analysis is viewed as a shared experience between the participant and the researcher (Bhattacharya, 2017), the initial step in analyzing the data in phase two was open coding. Open coding allows for responses of participants to serve as the guiding force of the development of the categories, allowing for truly organic, participant-driven approaches to data analysis (Saldaña, 2021). This methodological approach involved the examination of transcribed interviews within NVivo software, where the primary objective was to identify emergent categories without preconceived notions or predetermined frameworks.

Through a detailed analysis of the transcripts, there were recurring patterns discovered in the participants' narratives. These emergent patterns formed the basis for the development of nine categories, which encapsulated various aspects of the participants' lived experiences. These categories served as the foundation for organizing the data.

The categories that were developed encompassed a diverse array of topics pertinent to the lives of the participants. Notably, the categories and their definitions included:

1. Defining success: Exploring perceptions and criteria for success
2. Familial supports: Examining family relationships and support systems and how they shape participants life experiences and trajectories

3. Friendships and relationships: Social dynamics and interpersonal relationships and their impact on well-being
4. Goal setting: Investigating the understanding of the process of pursuing personal and professional goals and strategies for achievement
5. Mental health: Exploring participant experiences, challenges, coping mechanisms and psychological resilience
6. Overall QOL: Holistic perception of QOL
7. Safety: Exploring perceptions of protection and vulnerability within their environment
8. School-level supports: Examining the roles of educational institutions and support structures and the impact of academic successes and personal development
9. Success stories: Highlights of achievement, resilience, personal growth and inspiration and motivation

Table 31 offers a more detailed explanation of the discoveries pertinent to this study within each category.

Table 31*Summary of Categories Developed from Phase Two*

Category	
Defining Success	Participants had not been asked how they would define success for themselves before. Since this was a new concept, establishing goals during the interview was difficult, but often revolved around living and working independently.
Family Supports	Family support is a primary source of support for all participants during school and into adulthood. All participants expressed gratitude for the family that helped advocate for them and the family that help them as adults.
Friendships and Relationships	Participants consistently reported that having friendships is important to daily living, but they reported difficulty maintaining them in adulthood. In school, there were facilitated activities that helped with friendships but without the support of school it had been challenging to maintain those relationships.
Goal Setting	When asked if anyone helped them set goals in high school, there was a wide range of responses. Some reported there were no instances of goal setting lessons while some stated that their teachers were intentional

	about including them in their IEPs and developing their individual plans of study. As adults, it was consistent that it was more difficult to find someone outside of the family unit to assist with the task of breaking down large goals into smaller, more manageable goals.
Mental Health	Some participants reported having no experience with access to mental health supports so this topic wasn't relevant to everyone. Participants that did utilize mental health services reported different experiences. Some reported adequate access while some reported only having access in times of crisis and even then, the access was not appropriate given the disability.
Safety	Most participants did not report having concerns regarding their safety other than access to mental health supports.
School Level Supports	The topic discussed most often was the level and type of support that participants received while in school. Most study participants had experience with Project SEARCH and reported that was a very good experience. Barriers that were presented were paraprofessionals being removed from IEPs before students were ready and students preferring peer support over paraprofessional support. Extracurricular activities were important to

	engaging in structured social activities and developing relationships.
Success Stories	Participants all reported success stories that involved receiving an award in a public setting of some kind or being recognized for their accomplishments.
Overall QOL	Participants reported some things they would like to have better in their lives, like independence and less teasing, but overall, most participants reported general satisfaction with their quality of life.

From the categories, there were some overarching themes that were developed, including a reliance on family, challenging relationships with peers, and appreciation for highly structured 18-21 supports and services that focus specifically on employment outcomes. Themes were derived from identification of items that showed up across categories as important for many of the participants.

One prominent theme heard by the researcher was the significant reliance on family across all categories. This reliance on family may be why there were so few concerns for safety; there was an assumption that family would be there for support. Participants had an inherent trust that their basic needs would be met by their family members. It's worth noting that this reliance on family could be influenced by the specific demographics of the participant pool, all of whom exhibited stable housing situations and secure familial relationships. A broader range of participant experiences may yield different insights into the role of family support.

Another notable theme revolved around the challenging nature of participants' relationships with peers. During phase one, data indicated there was less access to group activities as adults, so that question was specifically addressed in phase two. Participants continue to rely on others to facilitate activities for them to socialize. This may be because they do not have the skills or access to transportation to initiate social activities on their own or because it takes executive functioning tasks to be able to plan social outings with peers. Some participants had the skills to arrange leisure activities but did not have reciprocating peers to participate in the leisure activities with them. One participant had a creative adaptive skill to maintain friendships virtually. Due to challenges with transportation, this participant was able to access an online community and develop and maintain quality reciprocal relationships through that venue. Not all participants had access to those resources, or the requisite skills required.

Highly structured 18-21 instructional programs such as Project SEARCH were perceived as valuable to the individuals that were able to participate in them. These programs focus on employment outcomes (Schall & Wehman, 2015). However, only 35% of participants in phase one reported receiving any 18-21 IDEA services, even though based on the self-identification response, 100% of respondents may have qualified due to the need for support in ADL. This suggests potential disparities in access to structured support programs, raising questions about equity in access to service provision.

Second Cycle Coding

The concept of QOL is largely dependent on one's perception of their own lived experiences. To capture the essence of QOL from the perspective of individuals with IDD and significant disabilities, it was imperative to conduct a second phase of coding to determine how participants felt about their life experiences. The transcripts were analyzed and annotated in

detail a second time to help inform research question three: “How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences contributed to their current QOL?”

The emotion coding (*Saldaña, 2021*) phase of the study provided insight into their emotional experiences throughout their IDEA Part B experiences and beyond. Through this coding process, seven distinct emotional themes emerged, shedding light on feelings and perceptions of participants during this transitional period. The American Psychological Association (APA) describes an emotion as a pattern of reaction that involves both behavioral, experiential, and physiological elements (UWA, 2023). The process of coding in this part of the analysis involved rich annotation of the individual’s experiences and their self-reported pattern of responses.

Emotions are complex responses to environmental factors. Understanding there could be a variety of interpretations of how each emotion is defined, for this study, the definitions below are provided for the purposes of clarity and consistency. These definitions are based from the American Psychological Association (*APA Dictionary of Psychology 2024*).

1. Belonging: The experience of feeling accepted, included, and connected within a particular group, community of social context
2. Caring: Feelings of compassion, empathy, and concern; desire to alleviate suffering and foster positive relationships
3. Loneliness: Emotional state of disconnection from others or lack of social connections and companionship; may include emotional distress and longing for connection
4. Frustration: Emotional response triggered by unmet expectations or disappointment

5. Optimism: Emotion characterized by positivity and confidence in ability to overcome obstacles in the face of adversity
6. Unheard or misunderstood: Emotional response triggered by feelings of a perception that one's thoughts or feelings are not validated or understood by others
7. Pride: Emotional state characterized by sense of satisfaction or personal achievement or accomplishment; leads to feelings of confidence (*APA Dictionary of Psychology* 2024).

When we understand and address these emotional characteristics, interventionists can support the holistic well-being of this population and promote a greater sense of autonomy and personal fulfillment in adulthood. Table 32 offers a more detailed explanation of the emotions pertinent to this study within each category.

Table 32*Phase 2 Emotions*

Emotion identified	
Belonging	Instances identified included experiences with Special Olympics, feeling independent, or experiences that brought honor. At school, experiences that made them feel a sense of belonging were most often extracurricular activities, or use of peer models over paraprofessionals when appropriate.
Caring/Gratitude	Many identified family members who cared for them, although there were a few school staff members that were identified. The staff members who were identified went above and beyond to spend time with the individuals or to learn about their particular disability.
Loneliness	All participants identified times when they felt excluded from their peers. Most participants indicated sadness regarding a lack of friends or reliance on others to structure leisure activities. Some even identified and articulated that they wished more time had been spent during school years on the skill of finding and keeping friendships.
Frustration	Frustration was shared frequently when discussing whether others understood the impact their disability had

	on their lives. When discussing a desire to be more independent and others not understanding what supports need to be in place, frustration was a common theme.
Optimism	Most participants aspired and hoped for an independent future, although they did not have a solid plan to build that autonomous future. They knew what it would look like as far as financial independence and a healthy relationship but couldn't articulate the steps it would take to attain those goals.
Unheard/Misunderstood	When discussing times when others did not understand the impact their disability had on their lives, many participants shared that it caused hurt and emotional pain.
Pride	All participants were eager to share moments of accomplishment or pride throughout the interview process. These moments included times when they were allowed to be independent and were honored on a stage or with medals, awards, and degrees.

Research Question Two

Based on the five interviews conducted, the participants discussed various supports, services, and experiences they had during IDEA Part B. Many identified activities that were conducted both within the school day and outside the school day. Supports included the use of

paraprofessionals, modified work, assistive technology, vision teachers, orientation and mobility specialists, school social workers, pre-employment transition specialists, speech therapists, special education teachers, transition specialists, Project SEARCH, peer modeling, and participation in extracurricular activities at school and at Special Olympics.

When asked how and in what ways those supports impacted their quality of life now, as a young adult, participant responses did not vary significantly. Most participants reported that they appreciated any adult who allowed them to be as independent as possible, even stating that they preferred peer modeling to paraprofessional support when it was appropriate. However, another participant stated that taking support away too early was detrimental to their progress.

When asked to define success, many struggled to articulate a response, possibly because this was a broad, abstract concept. However, most stated this was a topic that had never been discussed with them before. There was a positive connection between the individuals who were better able to articulate what success means to them and the individuals who had more participation in their individual plan of study and the transition plans on their IEPs. These same participants were more familiar with the process of goal setting as well.

Access to mental health support wasn't a topic that every participant was familiar with, as it wasn't a need for everyone. However, those that did discuss it noted a common theme. Participants felt there is a lack of availability of appropriate support for individuals with disabilities when it comes to mental health support. They did not feel heard or supported by mental health professionals because they didn't understand how their disabilities impacted their mental health. One participant reported "It's messed up because mental illness is also a disability. Especially when it affects you to a certain level... and when you also have autism, it's even harder to find help."

Relationships were a consistent challenge for most participants. One participant stated, “I wish I had more friends or knew more how to meet people. I wish I could be more independent and live on my own and had opportunities to do activities with other people, but I know I’m lucky because my support needs are lower than others. My quality of life is maybe a 3 out of 5.” Another reported, “Talking to people is hard because they don’t understand me, but I want to meet more people. I’m learning how to get people’s attention in speech.” Another participant shared, “Friends just don’t like me and tell me to shut up.” However, even with the barriers they discussed, they still noted their QOL as more satisfying than dissatisfied. The challenges with friendships seem to be buffered by supportive family relationships.

Research Question Three

To answer research question three regarding how participants feel supports impact their current QOL, the researcher found it necessary to provide more structure to the questions to help guide the answers. Many had never heard of the concept of QOL before the research study conversation. Participants consistently stated appreciation for those who took time to understand them, whether it was to understand a challenge with speech articulation, a physical disability, or a need to use assistive technology to communicate. It was incredibly important for others to take the time to honor them personally and acknowledge their contributions to their classes and their work if they were in the workforce. One participant shared how meaningful it was to have a school social worker attend professional development to learn more about the intersectionality of autism and transgender girls just to understand how to provide more support.

When asked what did not work for them in school, one participant shared “the idea that college was the only option for me. I tried. It was a huge failure. Then I went to Project SEARCH and I was successful. Those were the skills I needed to learn.” Another shared “The

IEP team thought I didn't need a para to help me with my assistive technology device, but I wasn't ready to be independent yet." Another shared "I didn't want a para. I liked having peers help me in class." The takeaway from this is the value of having students with disabilities attend their own IEPs and have input in their instructional plans. There is power in giving them ownership and autonomy in planning for their future.

When asked to share stories that still impact them today, all participants shared stories that honored accomplishments in a public way and were inclusive in their environment. For example, Project SEARCH is a support primarily for individuals with significant disabilities, but the feeling of pride participants attained while learning new skills carried through to adulthood.

Very few participants discussed academics when reflecting on IDEA Part B and how it impacted them in adulthood. Most reflected on the social-emotional aspect of the process of transitioning from the level of support that individuals with disabilities experience in Part B to the fewer services they experience in adult services. When asked what they wished they had greater access to, the theme revolved primarily around more support for relationships. Even as adults, they rely on others to structure time with peers. When asked about the most positive and impactful experience during Part B, the most common themes revolved around participation in extracurricular activities. Access to peers and structured social activities continued to be an important theme.

Quality Control

To ensure quality of the data collection and analysis process, participants were asked many clarifying questions throughout the interview. When one participant mentioned something that seemed out of sync or irregular, the researcher asked clarifying questions with the immediate participant to member check. The researcher also provided an opportunity to clarify

understanding during the interview phase with follow-up participants as well as providing a short summary of points to all interview participants to check for accuracy. Triangulation was utilized extensively throughout data analysis (Creswell & Creswell, 2018). Data from phase one was analyzed and data from phase two was analyzed separately. The two data sets were then synthesized by the researcher to add nuance and understanding of the data acquired from the study. Extensive notetaking and annotating were used by the researcher throughout the coding and analysis process.

As an additional quality control measure to protect against potential bias stemming from personal background, the researcher employed rigorous methodological strategies, including negative case analysis. This involved actively seeking out divergent viewpoints and experiences that challenged prevailing narratives, thereby ensuring a comprehensive and balanced understanding of the phenomenon under investigation. The researcher also integrated contrast questions into the interviews to prompt participants to consider alternative perspectives and mitigate the risk of confirmation bias.

By adopting a reflexive stance and leveraging connoisseurship alongside stringent analytical techniques, the researcher sought to enhance the validity and trustworthiness of the research findings. This deliberate approach not only facilitated a deeper exploration of participants' narratives but also served to minimize the impact of subjectivity on the interpretation of the data. Ultimately, the synthesis of insider insights with methodological rigor enriched the research process, yielding nuanced insights into the lived experiences of individuals with IDD and significant disabilities and their families.

Chapter four discussed the data collected throughout the study and answered the proposed research questions. The processes included in both the quantitative and qualitative

processes were shared to promote accuracy, accountability, and trustworthiness. Data was shared in detail throughout this chapter. In chapter five, further synthesis of the combined data will be shared, along with implications for practice and recommendations for further research.

Chapter 5 – Summary and Recommendations

Chapter five will discuss the comprehensive findings of the research study. This chapter will also discuss the connections to the theoretical framework as well as synthesize all the data for both phases, list some implications for practice, and offer recommendations for further research. The overarching goal of this mixed methods study was to gain an understanding of how young adults with IDD and significant disabilities perceive their QOL. In addition, the goal included a particular emphasis on how individuals with disabilities define success and to disclose and describe practices and activities they perceive contributed to their successes and postsecondary QOL. Mixed methods methodology was selected, to explore relationships among the variables and provide deeper insights into underlying educational, societal, and interpersonal dynamics.

The study unfolded in two phases, each serving a specific purpose within the research framework. Phase one involved quantitative data collection analysis, which allowed for the identification of patterns and trends within the data. Phase two subsequently utilized in-depth interviews and thematic analysis to uncover rich and contextually embedded insights into the lived experiences of the participants. Combining both approaches in a sequential manner maximized the strengths of each approach while mitigating their limitations. This integration facilitated a comprehensive understanding of the research questions, offering rich insights into the varied and multifaceted experiences and perspectives of young adults with IDD and significant disabilities. Ultimately, the findings of this study inform policy, practice, and interventions to enhance the QOL and postsecondary outcomes of individuals with disabilities.

Connections to Theoretical Framework

Constructivism places a particular emphasis on the role of the participants in the research process (Creswell & Creswell, 2018). Throughout this study, it was especially important to honor and validate the perspectives and experiences of the participants to best understand through the lens of a person who received intensive services under IDEA Part B. Furthermore, this study embraced a salutogenic model (Mittelmark et al., 2017) to find effective pragmatic solutions or strategies from the perspectives of people with IDD and significant disabilities.

The researcher intentionally set aside their role and experiences as a parent of a child with a disability during the data collection and coding process. For this to be a true constructivist theoretical framework, the data collection and analysis was a shared experience between the participant and the researcher (Bhattacharya, 2017). To achieve this, clarifying questions were asked as often as possible, to allow participants to share their stories and provide opportunity for a shared experience to form meaning and discover themes.

Saldaña's (2021) method of open coding was utilized in phase two of the qualitative methodology, where the transcribed interviews were analyzed and annotated with no preconceived notions or categories. The researcher used the participants' words to develop categories based entirely on information gathered throughout the interview process and constructed in analysis. This allowed the categories to be developed based on the lived experiences of the participants, not projections of the researcher, or perceptions from the nondisabled community. Because this is a traditionally marginalized group of people, the researcher felt it was of particular importance to highlight and respect their voices and their journeys.

When employing a constructivist theoretical framework in interview settings, it is important to utilize open-ended questioning techniques and maintain receptivity toward comprehending the depth of participants' lived experiences. The researcher implemented this approach with integrity by frequently asking clarifying questions to fully understand the participants' experiences. Knowing the possibility PWD may experience the world differently than people without disabilities, the researcher made it a goal to understand some of these nuances. This philosophy led to many open-ended questions and a thoughtful discussion throughout phase two. It also fostered an environment conducive to the rich annotation and meticulous note-taking necessary for the development of categories, from which the overarching themes subsequently emerged. While this process may have taken longer to code and analyze, this conceptual framework more accurately portrays the voices of the participants.

In the exploration of QOL and the endeavor to measure its positive dimensions, a multifaceted understanding extended beyond conventional paradigms. Rather than merely scrutinizing impediments and constraints faced by individuals with disabilities, this methodological framework encouraged a nuanced examination embracing the concept of salutogenesis (Mittelmark & Bauer, 2017). This is especially pragmatic when discussing implications for practice. When practitioners understand positive psychology, interventions can be developed based on what does work, creating momentum based on that positivity.

When analyzing Aaron Antonovsky's salutagenic concept, which was originally developed in 1979 to describe phenomena in the medical field, it was discovered that it applies to other disciplines as well (Mittelmark & Bauer, 2017). In other fields of study, salutogenesis offers a holistic lens through which one can assess an individuals' sense of coherence and their capacity to navigate stressors adeptly. Salutogenesis embodies the proactive integration of

positive psychology principles to not only confront challenges but also foster resilience and well-being (Mittelmark & Bauer, 2017). Throughout this study, participants revealed an innate ability to confront challenges with positivity and resilience. In phase one, they revealed challenges, shared goals they created for themselves, and quantified their QOL in several different domains. In phase two, a small group of participants added nuance and additional information to clarify and add understanding to the information gathered in phase one as well as answer research questions two and three. Throughout the study, participants illustrated salutogenesis in action.

Examples of this innate positive psychology in action include participants frequently expressing recognition of limitations, including a lack of access to transportation, which limited access to leisure activities. This negatively impacted their ability to participate in adult activities with friends. They also recognized the value of adult friendships, and several indicated they would like to have more friendships. The participants noted relationships having a significant impact on their QOL. There was a recognition of the value of occupational activities and knowledge that many were unemployed or underemployed. Despite the striking contrasts of those limitations, where many felt a lack of control, they continued to feel hopeful of a better future. Participants also indicated a QOL more satisfied than dissatisfied.

The incorporation of salutogenesis into research on QOL holds implications for practical interventions and policy development. By shifting the focus toward promoting individuals' capacities for adaptation and growth, practitioners are empowered to cultivate environments that nurture resilience and facilitate positive outcomes. This paradigm shift not only enriches our conceptualization of QOL, but also underscores the importance of embracing diversity and affirming the inherent dignity and agency of all individuals, regardless of their circumstances. When researchers and practitioners alike understand what is working for PWD, not just what

isn't working, effective instructional interventions can be developed that improve outcomes for QOL.

Constructivist theoretical framework enabled participants to have a voice. Open coding naturally allowed the categories to develop from the participants' own words, intimately describing their journey through the educational system, which was the goal. The mixed methods design allowed for a richer understanding of the experiences and the outcomes.

Having been intricately involved in the disability community for over two decades, both as a professional and a parent, the researcher approached the data collection and analysis phases with a distinct understanding of the challenges inherent in navigating the education system and broader societal contexts. This familiarity enabled the researcher to pose probing questions during interviews and delve into participants' experiences within and outside of school settings. By leveraging prior experience, the researcher was able to facilitate richer, more in-depth discussion, extracting nuanced insights that might have otherwise remained obscured.

Connections to the Research Questions

The remainder of this chapter is a summary of the study findings and is organized based on each research question. The first research question was answered through administration of the Wisconsin Quality of Life Survey and further informed the development of interview questions used by the researcher to answer research questions two and three. The responses and analysis of data from research questions two and three also circled back to add nuance and deeper understanding to research question one. Data acquired from the surveys and interviews are integrated in the sections below as the researcher sought to intertwine, inform, and provide a rich understanding to culminate in clear findings for each research question.

Research Question One

Research question one asked “How do young adults with IDD and significant disabilities feel about their overall QOL?”. The results of this phase of the study demonstrate that participants would like to have more independence. They would like to live more independently and would like to work independently. Participants expressed a desire to have more friendships. However, they also shared gratitude for the relationships they have, rating the importance of familial relationships as very high on the rating scale. On a scale of 0-100, the median overall QOL score was 73.07, demonstrating that although there are areas of life the participants would like to see improved, collectively, the group shared their QOL was closer to satisfied than dissatisfied.

These findings highlight the complex nature of QOL among young adults with IDD and significant disabilities. While there are areas for growth and enhancement, such as increased independence and expanded social networks, participants reported deriving satisfaction and fulfillment from existing relationships and life circumstances. By understanding and addressing the nuanced experiences and aspirations of individuals with disabilities, stakeholders can better support their holistic well-being and promote opportunities for enhanced quality of life.

Research Question Two

Research question two asked “What supports, services, and experiences did young adults with IDD and significant disabilities have during IDEA Part B?”. Participants in phase two of the study reported receiving a variety of supports, highlighting both strengths and areas for improvement within the educational system. While some students reported paraprofessionals were crucial in supporting participation and engagement in academic activities, others stated they preferred peer models to help them when needed. Students also reported accommodations and

modifications in academic coursework as essential for success. These adjustments ensured equitable access to educational opportunities.

Some participants reported having access to 18-21 support such as Project SEARCH, which is specifically designed to improve employment outcomes. Participation in targeted skill development programs like this provides valuable opportunities for skill development, vocational training, and transition planning. Ultimately, the students who had this opportunity noted a recognition they had enhanced prospects for paid employment because of this specialized instruction.

Beyond academic and vocational support, respondents reported participation in extracurricular activities, which contributed to both social and personal development. These activities offered opportunities to learn social skills, learn about various hobbies and recreational activities, and cultivate interests and talents outside of school.

There was some mention of assistive technology, both high tech and low tech, and the need to have a support system in place to provide instruction on how to use assistive technology. This highlights the importance of leveraging technological tools of various degrees and complexity to enhance access and promote independence among young adults with disabilities.

While the supports and services shared by participants in phase two reported positive efforts to address the diverse needs of young adults with IDD and significant disabilities, there remain areas for further improvement. There was a gap in what was allowed under IDEA and what students reported receiving. When synthesized with the postsecondary data set, only 16% of survey respondents were relying on paid employment as a source of income. Therefore, it is clear some students under age 21 are exiting IDEA Part B and have missing skills and, as a result, are still eligible for continued services.

Research Question Three

The final research question posed “How and in what ways do young adults with IDD and significant disabilities perceive those supports, services, and experiences contributed to their current QOL?” The insights gained from this inquiry utilizing the constructivist theory framework offer a deeper understanding of the subjective experiences and perspectives of individuals with disabilities regarding their educational and postsecondary transition experiences. Throughout the interview and data analysis experiences, significant value was placed on activities that promoted employment skills and social interactions. Participants with an opportunity to participate in Project SEARCH reported it was a highly valuable program. Structured activities facilitated peer interaction and extracurricular activities were viewed as beneficial for fostering social skills and peer relationships. Only one participant mentioned ADL being offered at school, and it was not an area of focus. However, all participants focused on a longing to have a more independent living situation. This must be a consideration when taking into account whether or not their education adequately prepared them for postsecondary goals. When participants were asked if they were satisfied, none of them complained about their QOL.

Historically, disability discourse has centered on the medical model (*Medical and Social Models of Disability* | *Office of Developmental Primary Care*, 2022). Participants in this study demonstrated an astute awareness and understanding of a more modern understanding of the social model of disability. This perspective views disabilities as a social construct shaped by societal barriers and emphasizes the importance of inclusive design and interdependence. An example of this understanding is the consistent theme of participants highlighting the significance of supportive familial relationships and community networks in promoting their emotional well-being and sense of emotional belonging.

Despite the challenges presented to them and aspirations for greater independence and sense of belonging, participants also consistently expressed feelings of gratitude and optimism. They appreciated the opportunities provided to them, even if they were limited, and maintained a sense of resilience and hope for their future. This reaffirms the application of positive psychology principles outlined in the study's theoretical framework.

Contributions to Literature

Chapter 2 highlighted several gaps in literature. While several gaps pointed out funding issues which are beyond the scope of this study, this study does contribute to existing literature in the realm of QOL and disability. President Obama signed the ESSA into law in 2015 which increased both accountability and required schools to use more evidence-based instructional materials (U.S. Dept. of Education, 2017). However, it did not specifically define the expectations for a successful high school graduate (U.S. Dept. of Education, 2017). Each state is given latitude to determine success criteria, but specific to students with disabilities, IDEA is a federal law which promises equity (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). The Endrew case was considered to be a landmark case as the Supreme Court decided that for students with disabilities to receive FAPE, they must receive relevant educational benefit as part of an IEP (Cowin, 2018). A gap in the literature still exists, however, surrounding the meaning and impact this educational benefit has on life after graduation.

QOL is multidimensional and complex (Diamond & Becker, 1999), but so is the requirement of FAPE that requires schools to “provide a child with a disability opportunities to achieve academic success, attain self-sufficiency, and contribute to society that are substantially equal to the opportunities afforded children without disabilities” (Jansen, 2017, p. 6). The

findings of this study offer insight into the perspectives of young adults with disabilities regarding their own education. Many of the domains of the QOL survey instrument overlap with the postsecondary outcomes determined by Kansas for a successful high school graduate (*Board Outcomes, 2023*), which creates some alignment for educational equity. This study afforded those with disabilities the opportunity to use their voice and experiences to inform educational practice and programs to improve postsecondary outcomes from their perspective.

Recommendations for Future Research

Building upon the insights gleaned from the empirical findings of this study and the comprehensive synthesis of existing literature, the subsequent section will delineate recommendations for prospective research endeavors.

Recommendation One: Social Networks

The most profound theme throughout this study revolved around the importance of friendships and relationships and a struggle to obtain and maintain those relationships. Social-emotional skills are included in the general education curriculum. IDEA already promises measurable annual goals, stating a requirement to include both academic and functional goals. Those goals should ensure progress is made in the general education curriculum and all other educational needs are met as a result of their disability (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions, 2019*). Many times, disabilities impact social skills. It would be interesting to study social-emotional skills related to this requirement, more specifically, and whether a gap between policy and practice exists.

An additional piece around relationships is whether participants had a preference to have friends who did or did not have disabilities. Two students mentioned feeling more comfortable when they began attending a special day school for students with similar disabilities because they

felt less different than their peers. However, all students stated they enjoyed being around other people, regardless of whether they had a disability. These interpersonal skills can be practiced both in an inclusive model and within special settings for students with disabilities. The theme is they just want access to meaningful friendships. It would also be interesting to delve further into understanding what opportunities are being offered to students with disabilities to practice relationship skills throughout their IDEA Part B experience.

Recommendation Two: Evidence-Based 18-21 Services

The second recommendation for research focuses on the provision of highly structured 18-21 services, as outlined in IDEA Part B. These services are crucial for supporting the transition of students with disabilities from high school to adulthood, especially in terms of skill development for employment and ADL. However, despite the potential need for such services among participants in this study, based on the data collected, there is a significant gap between eligibility and receipt of services.

While the self-identification question in phase one indicated that all survey respondents may have qualified for 18-21 services based on reported need for assistance in ADL, only 35% reported receiving 18-21 services. This disparity raises important questions about what factors could be contributing to the gap in service provision and the impact it could have on postsecondary outcomes and the QOL of individuals with disabilities.

Further research is warranted to explore the potential explanation behind the gap in service provision. There are a few avenues for potential inquiry researchers could explore. One angle is to investigate whether funding constraints play a role, even though 18-21 services are not funded differently from other Part B services. Understanding financial dynamics and

resource allocation processes within educational institutions could illuminate potential barriers to the allocation of these critical services.

Recommendation Three: Goal Setting/Self Determination

The third recommendation for further study relates to goal setting and is a component of the prior recommendation written to address the gap between policy and practice in IDEA. Two participants in phase two of this study reported having participated in their transition plans. These two participants also reported having the most understanding of the process of goal setting. Even the participants that had experience with goal setting did not have familiarity with the process of breaking down a goal into actionable, attainable steps. For example, one participant wanted to start a business, but couldn't articulate where to go to get started.

Goal setting falls under the umbrella of the concept of self-determination. Self-determination includes the skills of believing that one can make choices for oneself in their life, self-advocate, set and achieve goals for oneself, and problem-solve through life's challenges (Raley et al., 2018). Although goal setting is only one part of self-determination, it is an important element of a person's belief that they have voice, choice, and power to change the outcome of their own future. There is extensive literature available on the value of self-determination for individuals with disabilities (Raley et al., 2018). However, according to Raley and Shogren, implementation of curricula teaching self-determination skills is inconsistent (Raley et al., 2018). The experiences shared by the participants in this study were in alignment with the study conducted by Raley (2018). Some participants had exposure to a few of these concepts while some participants did not believe they had voice and choice over their own future, nor did they understand the concept of goal setting and working toward that goal. Through additional research and analysis of educational policies and practices, researchers can

gain insight into the root cause analysis of the implementation gap surrounding self-determinism and goal setting.

Recommendation Four: Applications of Positive Psychology

Salutogenesis is a general feeling that things will work out as well as can reasonably be expected (Mittelmark et al., 2017). In this study, participants recognized the frustration of being reliant on family members and caregivers for transportation and ADL, yet they still rated their overall QOL as more satisfied than dissatisfied. While being happy and understanding things will work out aren't necessarily the same, the participants in this study demonstrated a tenacity that seemed to be incongruent to nondisabled adults today. Further research exploring the mental resiliency of individuals with IDD and significant disabilities could provide insight into positive psychological attributes important to the nondisabled population. The participants in this study each faced barriers and challenges, yet they remained grateful rather than resentful of their disabilities.

To delve deeper into this phenomenon, further research is recommended to investigate the mental resilience and coping mechanisms of individuals with IDD. This research should aim to understand how individuals with IDD and significant disabilities maintain a sense of optimism in the face of adversity. Exploring the factors that contribute to this resilience, such as gratitude and acceptance of one's circumstances, could provide valuable insights for enhancing mental well-being in both disabled and nondisabled populations.

Recommendation Five: Supports for Parents

IDEA recognizes parents and caregivers as equal members of the IEP team. As mentioned throughout this study, there were unmet needs for students, whether it was ADLs, social-emotional skills, or employment skills. These are all potential areas protected under IDEA

if defined as an area impacted by a student's disability. An area for further research could be to understand parent and guardian knowledge of the IEP and how to advocate for their student with a disability, or where to go for help when they have questions or disagree with something on the IEP.

Implications for Practice

The responses and voices of the participants included in this study allowed the researcher an opportunity to capture rich data to answer the research questions. In addition, the study's findings led to recommendations for future research and the following implications for practice. The researcher is indebted to the participants for their openness and willingness to share. Utilization of the proposed implications in educational settings detailed in the next section provide an immediate application of the study's findings to improve the QOL for individuals with disabilities. These implications for practice are crucial as they provide a bridge between theory and practice, guiding educators in how to translate research findings into pedagogical insights and effective teaching strategies.

Additionally, each implication for practice was developed with intention. As indicated in Chapter 2, IDEA has never been fully funded, and as articulated throughout the study, there is a sense of urgency students and families are feeling to improve outcomes. To that end, these implications for practice have been developed thoughtfully, as each item is easily integrated into daily practice or built upon an existing framework that wouldn't require a significant infusion of funding. Many of these practices could be found in teachable moments in classrooms throughout the day. However, fully funding IDEA would be immensely helpful in building systemic support systems.

Social-Emotional Instructional Interventions

The recommendation to prioritize the evaluation and inclusion of social-emotional needs in IEPs aligns with the existing framework of IDEA. IDEA mandates that students with disabilities must have an IEP with goals written to provide students access to the general education curriculum alongside nondisabled peers to the maximum extent possible (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). Having the skills to appropriately interact with peers and adults in the classroom falls under that umbrella, as well as accessing all social-emotional and character education curriculum that general education students have access to throughout their day. Participants in phase two of this study were not students who were disruptive in class or would have required behavior plans to participate in class. Because they were quiet and compliant, it may have been assumed by staff they had the social skills to interact with peers, but they were internally experiencing a silent struggle, not understanding how to navigate complex social experiences. Three participants in phase two openly shared how hard it was to interact with peers, and they felt like teachers didn't understand that it was difficult for them because peers appeared to like them. This held true during school hours and during school events. Outside of school, there were very few opportunities for them to interact with people outside of the nuclear family. It's crucial to investigate how opportunities to practice relationship skills evolve as students age. As a student progresses through their educational journey, their social environments and developmental needs change, often becoming more complex. Therefore, it's essential to evaluate the effectiveness and appropriateness of the interventions and supports for social-emotional development.

Implementing effective age-appropriate interventions and aligning services with developmental stages is important. This requires educators to tailor effective strategies and promote social competence and relationship-building skills among students with disabilities. When educators implement social emotional interventions and have a deep understanding of skill development and how it pertains to postsecondary outcomes, educators and policymakers alike can better address the diverse and ever-evolving needs of students with disabilities and their families. This understanding ultimately fosters student social inclusion, well-being, and success in school and beyond.

Training for Building Leadership

An implication for practice is to examine familiarity of building leadership, who often serve as the administrator of record on the IEP, for allowable special education services under IDEA. It is possible that a lack of awareness or understanding of the importance of 18-21 services, or the procedures for accessing and implementing services may contribute to their underutilization (Brownell, 2017). Further inquiry could help shed light on the perspectives and practices of secondary building leaders in relation to the provision of 18-21 services.

By understanding the dynamics influencing the provision gap of 18-21 services, policymakers, educators, and stakeholders can identify strategies to bridge the gap between eligibility and receipt of services. Addressing this gap is essential for ensuring that individuals with disabilities receive FAPE to successfully transition to adulthood and lead fulfilling, independent lives.

Participants in this study indicated a possibility that more of them could have participated in 18-21 services per their IEP, and there was a potential that they lacked the employment skills needed to be successful in competitive employment, which is often a focus of 18-21 services. It

was beyond the scope of this study to determine why they did not participate in the services to which they were entitled. Increasing the understanding of principals through professional learning is a direct and straightforward implication that could have immediate impact.

Self-Determination Instruction

The utilization of strategies and interventions to promote self-determination instruction in special education curricula that would empower students with IDD and significant disabilities to take control of their futures is a key implication for practice. Addressing this need has the potential to enhance the educational experiences and outcomes of students with disabilities and foster greater independence and self-advocacy skills as they transition into adult living. Providing teachers and service providers with professional development and instructional resources to teach students self-determination would be a strategy that could be quickly and easily implemented in classrooms across the state.

Participants in phase two consistently communicated that the ones who had explicit instruction in goal setting and actively participated in their transition plans felt they had more autonomy in their lives. Self-Determination curricula is readily available, as The University of Kansas has conducted significant research on The Self-Determination Model of Instruction (Raley et. al, 2018).

Psychological Resiliency and Mental Health Supports

Participants in this study demonstrated a healthy level of psychological resilience, given unique challenges. Understanding the psychological processes underlying the resilience of individuals with IDD and significant disabilities can inform interventions and other support programs designed to enhance much needed mental health and QOL outcomes for individuals with disabilities. It could also provide lessons in resilience and well-being for all. Ultimately,

increased understanding of resiliency could have the potential to contribute to a more inclusive and supportive community for individuals of all abilities.

Educational Leadership Preparation

Many of the recommendations for both further research and implications for practice are already included in IDEA, which is a decades-old law (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). Students with disabilities should already be receiving specially designed instruction to receive FAPE (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). This provision includes support for social-emotional supports, ADL, and employment skills up to the age of 21 (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). This begs the question why the students participating in this study were not receiving the supports and services they were entitled to under federal law.

An implication for practice is to enhance leadership preparation programs for building and district administrators. Ideally, all administrators should have the instructional leadership capacity to recognize if an IEP is being followed with fidelity and if targeted instruction is being implemented with high quality resources for a student with a disability. At minimum, new administrators should understand what the requirements of an IEP are, where they should go for support, and when to ask for help when they encounter a situation requiring complex case management.

Accountability and Oversight

Data from this study indicated that students were not always fully participating in their IEPs, as indicated in IDEA, particularly in their transition plans. An implication for practice

would be to ensure that students have appropriate skills considering their disabilities and to communicate their wants and needs for their futures. This would involve explicit instruction of self-determination and self-advocacy throughout the year. An essential element of self-advocacy would involve the student understanding their disability and the limitations that are inherently placed on them in our society. Conversely, students would need to be explicitly taught their rights under the law, and what it means to have a disability, so they have the skills to advocate for themselves, not just in the form of asking appropriate questions and getting help but so they understand they have legal protections due to their disabilities.

Accountability within the school system is equally important. Students in this study reported graduating without the requisite skills for competitive integrated employment, independent living skills, or age-appropriate social-emotional skills. As a result, they were not meeting their personal life goals, but they may have graduated from high school. When measuring successful postsecondary outcomes for individuals with more significant disabilities, when standardized measures aren't appropriate, school accountability should be measured in skill sets that are appropriate for each student, individualized based on their disability. Graduation isn't an appropriate measure, as seen in this study. Students graduate with missing skills because the skills weren't listed on the IEP, which may be for a variety of reasons. This warrants further investigation.

Statewide stakeholders must actively hold the entire statewide system accountable for enhancing the outcomes of students with disabilities. Although the measurement of these outcomes is inherently complex, as presented and discussed in this study, its significance cannot be overstated. It is imperative to recognize that the complexity of measuring these outcomes does not diminish their importance; rather, it underscores the critical need for thorough evaluation and

accountability. Prioritizing the improvement of outcomes for students with disabilities within large systems is not only a challenge but also an essential endeavor crucial for fostering equitable and inclusive education.

Parent Information and Support

As mentioned above in suggestions for further research, parents are required members of the IEP (*The Individuals with Disabilities Education Act (IDEA), Part B: Key Statutory and Regulatory Provisions*, 2019). Educators are required to provide certain information handouts at these meetings, which may include the Parental Rights, information about transition, review of the diagnosis, information about occupational therapy, physical therapy, speech therapy, or special education, just to name a few options. It is not unusual for there to be ten people from the school in an IEP meeting. Parents are often inundated with complex information which includes a lengthy IEP, grade cards, behavioral and cognitive reports, and academic testing reports. Students in this study reported being dismissed from receiving services with missing skills, and it is possible their parents signed those IEPs not knowing how to ask questions, interpret information, or understand educational options because the system itself can be overwhelming.

An implication for practice is a simple reminder to keep IEP meetings parent friendly and to ensure parents aren't just given their parental rights but guided through an understanding of the process. Parents and caregivers should be given information regarding appropriate postsecondary outcomes and options in plain language. This information should be inclusive of not only academic skills but also independent living, social emotional skills, communication, self-advocacy, and self-determination. It should also include any other skill included under IDEA that the student is both entitled to receive and requires in order to access their environment safely and successfully when they exit Part B services. An IEP is not a promise of success, but a

promise of access, and parents and caregivers should have the information they need in order to make informed decisions. Parents and caregivers understand their child better than anyone else and have valuable information to contribute to the IEP team. It is important they understand what it means when a school system tells them their child has a disability and how it impacts their education. Parents need a clear understanding of what specially designed instruction means and options to outline the delivery of those strategies as part of the IEP and the guarantee of FAPE. Upholding this practice in all IEP and eligibility meetings will build trusting relationships with families and ensure that open lines of communication are maintained to prevent students from missing important skills when services cease.

Conclusion

The findings from this study show the experiences of transitioning from IDEA Part B to adulthood from the lens of persons with disabilities. There are lessons for practitioners to implement in classrooms that are simple, yet profound. This study identified the critical importance of social networks for young adults with IDD and significant disabilities throughout the educational journey. Even seemingly adept students silently wrestle with the complexities of social interaction, underscoring the imperative for IEP teams to support social interactions and foster meaningful connections.

Support guaranteed for individuals aged 18-21 are integral components of IDEA Part B, not mere extensions of high school. During these important transition years, essential services help cultivate employability skills and instill vital life competencies for young adults. Regrettably, many young adults with disabilities remain tethered to familial financial support because they lack these skills. In the absence of reliable familiar support, many individuals are compelled to depend on government programs for sustenance and assistance, perpetuating the

cycle of poverty for many. Despite being a legislative promise for over four decades, the persistent rift between policy and practice stresses an alarming urgency that demands immediate attention.

Though IDEA mandates assessment and instruction in areas crucial for independence under FAPE, this study exposes multiple glaring gaps between policy and practice. These gaps widen as individuals with disabilities keenly recognize the void in the services available to them, casting shadows over their futures. While this study primarily explores post-secondary transition, it echoes the broader narrative of unmet educational needs.

This mixed methods study serves as a foundational seed from which future research can blossom. While it offers valuable insights into postsecondary outcomes for individuals with IDD and significant disabilities, it merely scratches the surface of a vast landscape ripe for exploration and refinement. By delving deeper into additional facets of educational policy and practice, researchers can unearth a wealth of knowledge that could significantly enhance educational outcomes. Thus, this study beckons for further investigation and collaboration, paving the way for a more comprehensive understanding and improvement of QOL for students with IDD and significant disabilities.

Empowering young adults with disabilities to chart their own destinies, with autonomy and agency, is paramount. Their involvement in shaping their futures is not just recommended but imperative. Yet, these obligations deteriorate amidst the dissonance between policy rhetoric and classroom realities.

Consequently, a bleak panorama emerges, marked by financial dependence, emotional anguish, and social isolation. Despite these adversities, the participants in this study exhibit remarkable resilience and unwavering optimism, testaments to the indomitable human spirit. But

their resilience should not obscure the systemic shortcomings that perpetuate their struggles. In bridging the chasm between policy and practice, we pave the way for a future where individuals with disabilities are not merely survivors but architects of their destinies, where the promise of FAPE is not just a hollow decree but a tangible reality, and where dignity and opportunity flourish.

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Appendix A - Phase 1 Recruitment Letter

To Whom It May Concern:

My name is Nikki Heiman, and I am a Doctoral Candidate at Kansas State University. I'm sending you this email because I'm asking for your help in researching the current quality of life for young adults with IDD in Kansas.

This study is a 2-part study. Phase 1 is the survey attached to this email. If you would like to be anonymous, you can choose to not leave contact information. If you would like the opportunity to be selected for phase 2 and tell stories of your experiences, please leave your email address at the end of the survey. If you leave your email, you will also receive the results of the study when it is complete.

Phase 1 will take around 15 minutes to complete. If you are selected to participate in phase 2, you will participate in an interview with the researcher that may take around an hour. This may take place at a location of your choice, or over zoom, depending on our shared schedules and locations.

You will have the opportunity to help teachers understand important things about your lives, both during school, and how those experiences impacted your life after you graduated.

Thank you for your help!

Sincerely,

Nikki Heiman

Appendix B - QOL Survey and Consent Form

3/13/24, 4:59 PM

Qualtrics Survey Software

Default Question Block

Connecting Postsecondary Quality of Life to Promises of IDEA, An Issue of Educational Equity

LENGTH OF STUDY: 12 months

PRINCIPAL INVESTIGATOR/CO-INVESTIGATOR(S): Dr. Donna Augustine-Shaw, Nikki Heiman

CONTACT DETAILS FOR PROBLEMS/QUESTIONS: donna5@ksu.edu, heiman.nikki@gmail.com

IRB CHAIR CONTACT INFORMATION: For the subject should he/she have questions or wish to discuss on any aspect of the research with an official of the university or the IRB. These are: Lisa Rubin, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224; Brad Woods, Associate Vice President for Research Compliance, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224.

PURPOSE OF THE RESEARCH: The purpose of this study is to better understand how young adults with intellectual and developmental disabilities (IDD) perceive their quality of life, with a particular emphasis on how they define success, and to disclose and describe the most meaningful and impactful school experiences and practices that contributed to their successes and postsecondary quality of life.

PROCEDURES OR METHODS TO BE USED: This is a mixed methods study.

https://kstate.yu11.qualtrics.com/Q/EditSection/Blocks/Ajax/GetSurveyPrintPreview?ContextSurveyID=SV_0BP7mBDeM2Xev7E&ContextLibraryID=UR_6rOE... 1/21

Default Question Block

Connecting Postsecondary Quality of Life to Promises of IDEA, An Issue of Educational Equity

LENGTH OF STUDY: 12 months

PRINCIPAL INVESTIGATOR/CO-INVESTIGATOR(S): Dr. Donna Augustine-Shaw, Nikki Heiman

CONTACT DETAILS FOR PROBLEMS/QUESTIONS: donna5@ksu.edu, heiman.nikki@gmail.com

IRB CHAIR CONTACT INFORMATION: For the subject should he/she have questions or wish to discuss on any aspect of the research with an official of the university or the IRB. These are: Lisa Rubin, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224; Brad Woods, Associate Vice President for Research Compliance, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224.

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PROCEDURES OR METHODS TO BE USED: This is a mixed methods study.

×

clear

Guardian Sign Here (If applicable)

×

SIGN HERE

clear

What age group are you in?

- ☐ 18-25
- ☐ 25-30
- ☐ 30-35

What gender do you identify?

- ☐ Male
- ☐ Female
- ☐ Non-binary / third gender
- ☐ Prefer not to say

Would you like to participate in a follow up interview to tell the researcher about your experiences in school?

- ☐ If yes, enter email address
- ☐ No

Background Information

What is your highest grade completed?

- ☐ 12th grade
- ☐ 18-21 transition
- ☐ GED
- ☐ Less than High School
- ☐ Some College
- ☐ College Degree

What is your current relationship status?

- ☐ Single/ never married
- ☐ married
- ☐ divorced
- ☐ committed relationship
- ☐ separated
- ☐ spouse deceased

What is the source of your income? (check all that apply)

- ☐ paid employment
- ☐ Sheltered workshop
- ☐ social security disability income (SSDI)
- ☐ Supplemental Security Income (SSI)
- ☐ Money from your family

What is your racial/ ethnic background?

- ☐ American Indian/ Native American
- ☐ Asian
- ☐ African American
- ☐ Hispanic/ Latino
- ☐ White
- ☐ Other

During the past 4 weeks, you lived

- ☐ alone
- ☐ with a friend
- ☐ with children
- ☐ with parents
- ☐ with spouse
- ☐ with other

Who would you like to live with?

- ☐ alone
- ☐ friend/ roommate
- ☐ with children
- ☐ with parents
- ☐ with significant other/ spouse
- ☐ with other

During the past 4 weeks, you lived primarily

- ☐ in an apartment/ home

- ☐ in a boarding home
- ☐ in a group home
- ☐ homeless
- ☐ at school/ college
- ☐ in an institution
- ☐ in jail/ prison
- ☐ other, please specify

Where would you like to live?

- ☐ In an apartment/ home
- ☐ in a boarding home
- ☐ in a group home
- ☐ at school/ college
- ☐ in an institution (hospital)
- ☐ in jail/ prison
- ☐ homeless
- ☐ other, please specify

Satisfaction level

	Dissatisfied	Neutral	Satisfied
How satisfied or dissatisfied are you with the way you spend your time?	☐	☐	☐
How satisfied or dissatisfied are you when you are alone?	☐	☐	☐
How satisfied or dissatisfied are you with your housing?	☐	☐	☐

	Dissatisfied	Neutral	Satisfied
How satisfied or dissatisfied are you with your neighborhood as a place to live in?	☐	☐	☐
How satisfied or dissatisfied are you with the food you eat?	☐	☐	☐
How satisfied or dissatisfied are you with the clothing you wear?	☐	☐	☐
How satisfied or dissatisfied are you with the mental health services you use?	☐	☐	☐
How satisfied or dissatisfied are you with your access to transportation?	☐	☐	☐
How satisfied or dissatisfied are you with your personal safety?	☐	☐	☐

Block 2

We have asked how satisfied you are with different parts of your life. Now we would like to know how important each of these aspects of your life are.

	Not at all important	Moderately important	Extremely important
How important to you is the way you spend your time?	☐	☐	☐

	Not at all important	Moderately important	Extremely important
How important is it to feel comfortable when alone?	☐	☐	☐
How important is your housing?	☐	☐	☐
How important is your neighborhood as a place to live in?	☐	☐	☐
How important to you is the food you eat?	☐	☐	☐
How important to you is the clothing you wear?	☐	☐	☐
How important to you are the mental health services you use?	☐	☐	☐
How important to you is your access to transportation?	☐	☐	☐
How important to you is your romantic relationship?	☐	☐	☐
How important to you is your personal safety?	☐	☐	☐

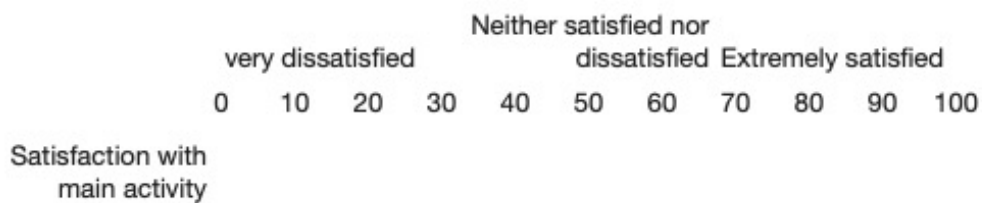
About how many hours a week do you work or go to school?

What is your main activity?

- ☐ paid employment
- ☐ volunteer or unpaid work

- ☐ school
☐ rehabilitation program
☐ craft/ leisure time/ hobbies
☐ no structured activity
☐ sheltered workshop
☐ other, please specify

How satisfied or dissatisfied are you with the main activity that you do?



What would you like to have as your main activity?

- ☐ paid employment
☐ volunteer or unpaid work
☐ school
☐ treatment/ rehabilitation program
☐ craft/ leisure time/ hobbies
☐ no structured activity
☐ other, please specify

Mental Health

Now we would like to know how you feel about things in your life. For each of the following questions, check the boxes that best describe how you have felt in the past four weeks.

	Select 1	
	yes	no
Pleased about having accomplished something?	☐	☐
Do you often feel very lonely or remote from other people?	☐	☐
Do you often feel bored?	☐	☐
Do you often feel things go your way?	☐	☐
Do you often feel so restless that you can't sit long in a chair?	☐	☐
Have you often feel proud because someone complimented you on something you had done?	☐	☐
Have you often been upset because someone criticized you?	☐	☐
Have you often been	☐	☐

There are many aspects of emotional distress that can impact life, including feelings of depression and anxiety. How much distress have these symptoms caused you?

- ☐ not at all
- ☐ a little
- ☐ some
- ☐ a moderate amount

Do you have feelings of depression or anxiety interfered with your daily life?

- ☐ never
- ☐ occasionally
- ☐ frequently
- ☐ most of the time
- ☐ constantly

Physical Health

In the past 4 weeks, you would best describe your physical health as:

- ☐ poor
- ☐ fair
- ☐ good
- ☐ very good
- ☐ excellent

How do you feel about your physical health?

- ☐ very satisfied
- ☐ moderately dissatisfied

- ☐ a little dissatisfied
- ☐ neither satisfied or dissatisfied
- ☐ a little satisfied
- ☐ moderately satisfied
- ☐ very satisfied

How important to you is your physical health? (check one)

- ☐ Not at all important
- ☐ slightly important
- ☐ moderately important
- ☐ very important
- ☐ extremely important

In the past 4 weeks, have you drank any alcohol?

- ☐ yes
- ☐ No

In the past 4 weeks, how many days have you had alcohol to drink?

In the past 4 weeks, have you used any street drugs (cocaine, marijuana, heroin, speed, LSD, etc.)?

- ☐ yes
- ☐ No

In the past 4 weeks, how many days have you used any street drugs

	Select 1	
	yes	no
particularly excited or interested in something?		
Have you frequently been depressed or very unhappy?	☐	☐
Have you often felt on top of the world?	☐	☐

In the past 4 weeks, would you say that your mental health has been

- ☐ poor
- ☐ fair
- ☐ good
- ☐ very good
- ☐ excellent

Mental Health

During the past 4 weeks, have you

- ☐ generally felt calm and positive
- ☐ been having some periods of anxiety or depression
- ☐ generally been confused, frightened, anxious, or depressed

Social Relations/ Support

	Dissatisfied	Neutral	Satisfied
How satisfied or dissatisfied are you with the number of friends you have?	☐	☐	☐
How satisfied or dissatisfied are you with how you get along with your friends?	☐	☐	☐
How satisfied or dissatisfied are you with your relationship with your family?	☐	☐	☐
If you live with others, how satisfied or dissatisfied are you with the people you live?	☐	☐	☐
How satisfied or dissatisfied are you with how you get along with other people?	☐	☐	☐

How many people do you count as friends?

- ☐ none
- ☐ 1-2
- ☐ 3-5
- ☐ over 5

Importance Level

	Not at all important	Moderately important	Extremely important
How important is it to have an adequate number of friends?	☐	☐	☐
How important is it to get along with your friends?	☐	☐	☐
How important are family relationships?	☐	☐	☐
If you live with others? how important are the people with whom you live?	☐	☐	☐
How important is it to get along with others?	☐	☐	☐

Money

Are you paid for working or attending school?

- ☐ yes
☐ no

	Dissatisfied	Neutral	very satisfied
How do you feel about the amount of money you have?	☐	☐	☐
How satisfied are you about the	☐	☐	☐

DissatisfiedNeutralvery satisfied

amount of control
you have over your
money?

Not at all importantModerately importantExtremely important

How important to
you is money

How important is it
to you to have
control over your
money?

How often does lack of money keep you from doing what you want to do?

never

Sometimes

frequently

almost always

Activities of Daily Living

Below are activities you may have participated in recently. Please check YES or NO to indicate whether you have done the activity in the past 4 weeks.

	Select 1	
	YES	NO
Gone to a restaurant or coffee shop		
Gone for a ride in a		

Goal 1

How important is this goal to you? Please use the slider to indicate how important it is (0= not important 100= very important)

Not at all important				Moderately important		Extremely important				
0	10	20	30	40	50	60	70	80	90	100

To what extent have you achieved this goal? (0= not at all achieved 100= achieved)

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

Leisure Activities

Below are activities that you may have participated in recently. Please check YES or NO to indicate the activity in the past 4 weeks.

	Select one	
	YES	NO
Gone for a walk	☐	☐
Gone to a movie or play	☐	☐
Watched TV	☐	☐

	Select 1	
	YES	NO
bus or car		
cleaned the room/ apartment/ home	☐	☐
gone shopping	☐	☐
prepared a meal	☐	☐
done the laundry	☐	☐
Have. you been able to do things on your own such as shopping and getting around?	☐	☐

How often do you require help with personal care? (taking a shower, brushing teeth)

- ☐ never
☐ Sometimes
☐ frequently
☐ almost always

Goal Attainment

Please share a goal you have made for yourself.

	Select one	
	YES	NO
Played cards	☐	☐
Played a sport	☐	☐
Gone to a social group	☐	☐
Read a magazine or newspaper	☐	☐
Gone to church, synagogue, mosque	☐	☐
Listened to a radio	☐	☐
Gone to a library	☐	☐

How important are each of the following factors in determining your quality of life?

	Not at all important	Moderately important	Extremely important
Work, school or other occupational activities	☐	☐	☐
Your feelings about yourself	☐	☐	☐
Your physical health	☐	☐	☐
Friends, Family, people you spend time with	☐	☐	☐
Having enough money	☐	☐	☐

	Not at all important	Moderately important	Extremely important
Ability to take care of yourself	☐	☐	☐
Your mental health	☐	☐	☐
Other	☐	☐	☐

Please move the slider to indicate how you feel about your quality of life.

0 means things are as bad as they could be.

100 means they are as good as they could be.

0 10 20 30 40 50 60 70 80 90 100

Quality of Life

If your quality of life is less than you hope for, how hopeful are you that you will eventually achieve your desired quality of life?

- ☐ not at all
- ☐ somewhat
- ☐ moderately
- ☐ very

How much control do you feel you have over the important areas of your life?
(check one)

- ☐ None at all
- ☐ somewhat
- ☐ moderately
- ☐ very

Block 11

If you would like to participate in phase 2 of this study, or if you would like to receive a copy of the information to debrief, please leave your email address below.

Powered by Qualtrics

Appendix C -Phase 2 Recruitment Letter

Hello,

Thank you for taking the Quality of Life survey!

You are receiving this email because you stated you are interested in being interviewed for phase 2 of this study, which is the interview portion.

At this time, I am scheduling interviews for December 28 and 29 on Zoom. I am available any time after 9:30 am. As explained in the consent, the sessions will be recorded for the accuracy of data collection. I'll be asking about stories from your school experiences and how those experiences impact your adult life. These will be informal conversations as I want to just learn more about you! Your stories will help other teachers know how to better help students who are still in school!

Please reply to this email letting me know if either of those dates works for you. If they don't work, we can look at other dates.

If you have any questions, my cell phone number is **xxx-xxx-xxxx**.

Thank you for your help!

Nikki Heiman, Doctoral Candidate at Kansas State University