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

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EXECUTIVE SUMMARY

This study looked at how young adults with intellectual and developmental disabilities (IDD) and other significant disabilities experience life after high school—focusing on their own experiences and quality of life (QOL). It also examined how supports and services under the Individuals with Disabilities Education Act (IDEA) Part B shape their transition from school to adulthood. Using both surveys (quantitative methodology) and interviews (qualitative methodology), the study first measured each participant's self-reported QOL with the Wisconsin Quality of Life Survey (Diamond & Becker, 1993), then explored their personal perspectives in more depth. The study found that these young adults often face real challenges when IDEA Part B services end, making social networks and relationships especially important. As a result, the study recommends that Individualized Education Program (IEP) teams spend more time and effort intentionally fostering social connections throughout high school. It also highlights the value of continued special education services for students ages 18–21 so they can develop employability skills and life competencies. Overall, the study emphasizes the need to bridge the gap between policy and everyday practice. By doing so, young adults with disabilities gain more autonomy and a stronger sense of control over their futures.

INTRODUCTION

Despite decades of laws and nondiscriminatory educational policies promising equity, research remains scarce on how individuals with IDD and significant disabilities perceive their QOL or success after receiving services. 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 and the cycle of poverty that individuals with disabilities experience (Lee, 2015; Parish et al., 2008).

The Americans with Disabilities Act (ADA) legislation has been repeatedly undermined. Examples abound, including a 2011 NYC case where a judge described "benign neglect" in emergency preparedness for people with disabilities. Emergency shelters were deemed inaccessible for individuals with physical disabilities, emergency responders weren't trained in evacuation protocols for those individuals in case of emergency, and they were told only to evacuate them after all able-bodied individuals had been saved, reflecting a recurring societal disregard (Marini, 2017). Over the past 100 years, there has been aggressive legislation that has laid the groundwork for equal rights. However, when the literature was synthesized, there was a clear gap between policy and practice and an even larger gap when analyzing intended outcomes.

These gaps between policy, funding, and practice leave families to fight for equitable outcomes. Systematic underfunding of critical legislation like IDEA exacerbates this divide, limiting its intended impact on post-secondary success and QOL for individuals with disabilities (IDEA Series: Broken Promises: The Underfunding of IDEA, 2018).

Given these gaps between policy, practice, and intended outcomes, the study aimed to find the most meaningful or impactful school experiences through the lens of disabled individuals. A central focus for the study is how do individuals with disabilities define success for themselves, and how do they describe activities that lead to successful postsecondary outcomes? If we understand the practices that lead to success, from people with IDD, we can implement those practices in classrooms.

METHODS

This study explored the lives of young adults with IDD to better understand how they feel about their QOL and whether their education and support systems helped them succeed. The research questions included: 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?

This study is crucial because traditional measures of success, such as standardized tests, often don't capture the unique challenges faced by students with IDD. There's a lack of research on how these individuals define success or whether they believe they've received fair opportunities in education. This study addresses that gap, providing a deeper understanding of their experiences and perceptions.

The study implemented a mixed methods approach, combining both quantitative and qualitative data. In Phase 1, participants completed a survey that assessed their QOL. This survey, adapted from the Wisconsin Quality of Life Survey, is a well-established tool known for its reliability in assessing QOL. In Phase 2, follow-up interviews allowed participants to share personal stories, giving context to their survey responses and providing a richer understanding of their experiences.

Twenty-six participants were recruited from disability advocacy groups, social media, and email to participate in Phase 1. These results indicated the majority of participants wanted to be employed more than they were, wanted to live more independently, and have more friends than they did, but experienced barriers to those goals. Although the mean score for general life satisfaction was 5.08, on a scale of 1-7, the standard deviation was 2.27, demonstrating a wide variation of responses. When this data was synthesized with Phase 2, participants indicated significant assistance and expressed gratitude for the support received from family members. More research should be conducted with a wider audience and a more diverse family support system, as most Phase 2 participants indicated strong familial supports.

It is important to note that some participants in the study were already engaged in advocacy work, meaning they may have had more resources than others with disabilities. This approach of combining both numerical data and personal narratives enabled the researcher to gain a more comprehensive picture of how education and support services impact individuals with disabilities. Mixed methods allowed an understanding of the scope of QOL and a depth of why IDD felt a certain way.

Therefore, this study took a comprehensive approach to understanding the experiences of young adults with IDD by combining survey data with in-depth personal narratives. While the survey was designed to be accessible and independent, some participants required caregiver assistance. This did not undermine the data's integrity. In the interview phase of the study, five participants from the survey phase participated to delve deeper into their experiences during school and how these experiences shaped their current QOL.

The interviews were conducted in person or via video calls focused on understanding the services participants received during school and how those experiences impacted their lives. The participants, aged 18-25, all had a diagnosis of IDD or another significant disability and were encouraged to share openly through conversational, open-ended questions. The researcher, who has over 20 years of experience advocating for and with individuals with disabilities, approached the interviews with a deep understanding of the challenges but remained mindful of avoiding bias. To ensure the accuracy and fairness of the findings, the researcher used strategies like thick description, triangulation, and participant feedback.

The analysis of the interviews revealed key insights into what worked, what didn't, and how certain experiences shaped the participants' emotional, employment, and independent living outcomes. These findings, combined with survey data, offer valuable guidance for educators and policymakers seeking to improve services for students with disabilities, ensuring that future generations receive the support they need to thrive.

CONCLUSIONS

This study explored the lives of young adults with IDD focusing on their QOL and postsecondary outcomes. It developed a comprehensive understanding of their experiences. The study emphasized the importance of listening to participants and focusing on their strengths, resilience, and well-being. Among the key findings, participants expressed a desire for more independence and social connections but valued their current relationships, especially with family. Overall, they rated their QOL positively. Participants benefited from paraprofessionals, peer models, vocational training programs like Project SEARCH, extracurricular activities, and assistive technology. However, gaps in services left some unprepared for postsecondary life, especially in employment, peer relationships and independent living skills. Finally, programs and activities helped with employment skills and social connections in school settings, but many felt their education didn't fully prepare them for independent living, such as budgeting or cooking.

The study highlighted the need for education systems to focus on overcoming barriers and building on the strengths and aspirations of young adults with disabilities. More targeted support could help them achieve greater independence, stronger social connections, and success in their postsecondary lives.

RESEARCHER RECOMMENDATIONS

The study underscores the importance of several key areas for improving support for students with disabilities. First, it emphasizes the importance of friendships and social skills, noting that while social-emotional learning is part of general education, it often fails to meet the unique needs of these students. More research is needed to bridge the gap between policy and practice in this area.

The study also highlights the need to expand services for students aged 18-21, focusing on life skills, employment, and independence. Despite these services being available, many students did not access them, raising questions about why—such as funding or awareness which contributed to this gap. Another critical finding is the lack of goal setting and self-determination skills among students, which are essential for empowerment nd independence. Schools should ensure that these skills are consistently taught. The study explores the mental resilience of students with disabilities, who, despite facing challenges, show high levels of optimism and gratitude. Lastly, the role of parents is highlighted, as they often face overwhelming challenges in advocating for their child's needs. Schools should simplify the process, clearly explain students' rights, and help parents navigate their advocacy responsibilities.

This study sheds light on the experiences of individuals with disabilities transitioning from high school to adulthood, revealing critical areas for improvement in education and support systems. Key recommendations include incorporating social-emotional interventions into IEPs and ensuring students have consistent opportunities to develop social skills and navigate peer relationships. School leaders must receive better training on IDEA services, especially for students aged 18-21, to ensure this support is consistently offered. The study also stresses the importance of teaching self-determination, with a focus on goal-setting and self-advocacy, to empower students to take charge of their futures. Additionally, IEP meetings should be made more accessible to parents, offering clear, concise information on their students' needs and rights, and providing guidance on navigating the system. Schools must also shift away from using graduation as the sole measure of success. Instead, they should ensure students graduate with the skills necessary for independent living and adult success.

Despite the promises made by law, many young adults with disabilities still face unmet needs, particularly when it comes to employment readiness and life independence. This gap between policy and practice perpetuates cycles of financial struggle and social isolation, leaving many reliant on family support or government assistance. However, the study highlights the incredible resilience and optimism of the individuals involved, showing that while they face significant challenges, they remain hopeful for the future. It's clear that to empower young adults with disabilities to truly thrive, systemic changes are needed to close the gap between policy and classroom reality, ensuring that all individuals can live with dignity and shape their own futures.

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