

Representation of People with Intellectual Disabilities as Students in Higher Education

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Author Note

My inspiration for writing this piece stems from my role as a big sister of a person with Down Syndrome and Autism. My little brother has Down Syndrome and Autism. He is about to graduate from high school following an Individualized Education Plan. As many of his peers will go on to higher education, he will continue his education through various other programs due to the lack of inclusive programming for people with intellectual disabilities in higher education institutions. I see this as an issue, as the current system fails to integrate people with intellectual disabilities with their peers once high school ends.

Abstract

Throughout this chapter I argue that universities in the U.S are not doing their part in creating programs that include people with intellectual disabilities. This chapter aims to uncover why there is such low representation of people with intellectual disabilities attending higher education in the U.S through exploration of the historical exclusion of people with intellectual disabilities. I begin by give context behind why this issue is important and how access to higher education impacts the life outcomes of people with intellectual disabilities. I then share the historical treatment of people with intellectual disabilities in the U.S which has pushed this population to the margins of society. I then share the activism towards inclusion of this population in public primary and secondary education and how it was fueled by activism against segregation by race. I go on to explore the impacts of activism which have resulted in policies which promote inclusion. Next, I assess the current representation of people with intellectual disabilities in U.S higher education. Lastly, I share how we can improve higher education policies in ways that will serve to improve representation of people with intellectual disabilities. As Peterkin (2010) claims, colleges and universities are organisms like humans that are living and breathing, constantly evolving, and changing overtime. We have plenty of room to change our policies.

Representation of People with Intellectual Disabilities in Higher Education

In the U.S there is an evident lack of representation of people with intellectual disabilities in higher education. Intellectual disability is characterized as “significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (Schalock, 2021, p. 2). It specifically refers to “limits of a person’s ability to learn at an expected level and function in daily life” (“Facts About Intellectual Disability”, 2022). This differs from a learning disability given that learning disabilities don’t impact a person’s intellectual capabilities, rather learning disabilities affect ways that a person processes information (“Learning vs. Intellectual Disability”, 2016). The lack of representation of people with intellectual disabilities in higher education is an important issue given the impact that higher education is proven to have on people with intellectual disabilities life outcomes” (Mock & Love, 2012). Having the option to attend higher education is something Americans either take for granted or struggle to achieve. Going to college is a typical step for a high school graduate in the U.S to take. However, people with intellectual disabilities have been historically kept out of these higher education spaces, after being formerly excluded from primary and secondary public education. Although there have been improvements in diversity and inclusivity in higher education, few schools in the U.S offer programs that allow for and support the involvement for people with intellectual disabilities. To promote inclusivity of people with intellectual disabilities in higher education and improve this populations representation, student affairs professionals must advocate for access, collaborate with families of people with intellectual disabilities and allocate funding towards creating inclusive programing.

Attending Higher Education Impacts the Life Outcomes of People with Intellectual Disabilities

There has been an increased number of students with intellectual disabilities into the college world since the implementation of the Higher Education Opportunities Act (HEO) of 2008 (Butler et al., 2016). HEO aimed to include reporting requirements, grant programs, and lower the cost of college education (Butler et al., 2016). However, considering only 6% of U.S. Higher Education Institutions have inclusive programming for individuals with intellectual disabilities, there is a lack of representation and opportunity available for people with intellectual disabilities (“Think Inclusive”, 2022). The lack of representation of people with intellectual disabilities in higher education negatively impacts the lives of people with intellectual disabilities.

Access to higher education is important for people with intellectual disabilities given that it has a significant impact on their life outcomes (Butler et al., 2016). Participation in higher education has been found to significantly improve job prospects, personal and social development opportunities and relationship building opportunities for people with intellectual disabilities (Butler et al., 2016). People with intellectual disabilities attending colleges were getting jobs at three times the rate of the national average after graduating college (“Think Inclusive”, 2022). This demonstrates that higher education programs for people with intellectual disabilities are successful and important. Butler et al. (2016) also found that young adults with intellectual disabilities who had participated in higher education were more likely to exercise, report higher levels of overall health, take less psychotropic medication, be employed or volunteer in their community and have friends and be less lonely than those young adults with intellectual disabilities who had not participated in higher education (Butler et al., 2016).

The experiences reported from people with intellectual disabilities attending colleges speak volumes to the importance and benefit of inclusion in higher education. Corby et al. (2020) conducted a study in Ireland where they interviewed people with intellectual disabilities that attended colleges. This study was able to communicate the lived experiences of college students with intellectual disabilities. The study found that people with intellectual disabilities primarily share positive experiences and feelings when asked about their higher education experiences (Corby et al., 2020). Education has the power to “transform how people with intellectual disabilities view themselves” (Corby et al., 2020, p. 339). It also allows for “supportive learning, independence, confidence, self-esteem, self-belief and meaningful inclusion” (Corby et al., p. 352). As the general population of students towards the end of high school “talk with excitement and anticipation about going to college”, people with intellectual disabilities are too often excluded from this phase of life (Bethune-Dix et al., 2020, p. 310). Going off to college and attending higher education has become a phase of life that is almost central to the American lifestyle. Young people with intellectual disabilities like their “typical” peers “also wonder what lies ahead for them after graduation” (Bethune-Dix et al., 2020, p. 310). Inclusion in higher education serves to not only benefit their life outcomes but serves to keep them connected and included within the greater society. People with intellectual disabilities should be afforded the same opportunities to continue learning, grow personal skills and maintain community with their peers.

Historical Treatment of People with Intellectual Disabilities in the U.S

Throughout U.S history, people with disabilities have been devalued, rejected, ridiculed, and even feared. In the 1907 Immigration Act, people with disabilities were not permitted to enter the U.S even if they came with their families (“Brief Timeline”, 2018). This was because

the U.S did not want to become a country of “defectives” (“Brief Timeline”, 2018). During the turn of the twentieth century “Ugly Laws” were passed in many U.S cities, which made it illegal for people with any sort of viewable disability to be seen in public (“Brief Timeline”, 2018). During this time, many families with a child with a disability kept them hidden or sent them away to an institution to be forgotten (“Brief Timeline”, 2018). People with disabilities were also paraded around circuses during this time (“Brief Timeline”, 2018). It seems that the mistreatment of people with intellectual disabilities has connections to their lack of representation in higher education.

History of Exclusion and Activism for Inclusion of People with Intellectual Disabilities in Public Schools

There is a long history of exclusion of people with intellectual disabilities in the U.S. The reasoning behind the current low representation of people with intellectual disabilities stems from the exclusion of people with intellectual disabilities in public primary and secondary education throughout U.S history. Learning about the process of achieving equal access to higher education in primary and secondary schools will help to reveal the history behind lack of inclusion in higher education to student affairs professionals (“National Council”, 2018). Although representation of students with intellectual disabilities in higher education is distinct from representation of people with intellectual disabilities in primary and secondary education, they are related. It is the same individuals who were disinvited from these learning and community building spaces. Learning about the historical lack of inclusion and steps towards inclusion of elementary, middle school and high school students is essential if we want to understand the lack of inclusion these same students face in higher education. This is an

important aspect that guides our understanding of the lack of representation of this population in higher education.

The activism against segregation by race was the first step towards the movement towards inclusion of people with intellectual disabilities in public primary and secondary schools (“National Council”, 2018). The activism against segregation by race, triggered a movement for inclusion of people with intellectual disabilities. It is important to recognize that much of the activism against segregation by race was fought for by Black college students and particularly those attending Historically Black Colleges and Universities (HCBUs) (Nelson & Williams, 2018). It was the students of HCBUs who participated in protesting and advocating for the broader Black community (Biondi, 2012). For example, during the Vorhees campus boycott, 60-200 Black college students stayed on a closed campus to fight for higher wages and more Black participation in local governance (Biondi, 2012). Howard University was another HBCU that participated in social justice through rejecting Booker T. Washington’s ideas of teaching obedience to Black students to serve White people (Biondi, 2012). These Black college students paved a way for social justice movements, and as a result inspired change for inclusion of people with intellectual disabilities in public schools. It appears that parents of people with intellectual disabilities learned from the practices of the Black students who fought against segregation (“National Council”, 2018).

Activism for desegregation of race connects provoked the quest for quality of access to education for people with intellectual disabilities (“National Council”, 2018). The energy and example of social activism that Black people created was contagious and pushed other movements to take place. Through the 1960s, parents of children with disabilities fought for equal access to primary and secondary education (“National Council”, 2018). Activism for

inclusion of access to education for people with disabilities resulted in laws that served to include people with disabilities in public primary and secondary schools (“National Council”, 2018). In 1970, only one in five children with disabilities were educated in U.S schools (U.S. Department of Education, 2022).

The Education for All Handicapped Children Acts (EHA) was instantiated in 1975 and “allowed the right of disabled children to be integrated into a public-school environment” (“Brief Timeline”, 2018). The law has been since renamed to the Individuals with Disabilities Act (IDA) (“Brief Timeline”, 2018). In 1990, The (ADA) was enacted which “prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life—to enjoy employment opportunities, to purchase goods and services, and to participate in State and local Programs and services.” (“Brief Timeline”, 2018). It is the families of students with intellectual disabilities who have been continuously advocating for inclusive higher education over time (Mock & Love, 2012). Without family activism these policies would have never been put in place, and no changes in inclusion would have been possible.

Improvements in terms of representation of students with intellectual disabilities in general education classrooms in elementary to high schools in the U.S have been made since EHA, IDA and ADA were instantiated. In 2019-20, 64% of children with disabilities were in general education classrooms for more than 80% of their day (U.S. Department of Education, 2022). However, despite there being increased rates of people with intellectual disabilities present in general classrooms in the U.S, ableism has been an issue in primary and secondary public schools (Iwasaki, 2022). Ableism is “discrimination against people with physical and non-physical disabilities” (Iwasaki, 2022). Discrimination is “formed by preconceived ideas and

assumptions that disabled people are weaker or less intelligent” or inferior (Iwasaki, 2022). Ableism results from “negative stereotypes made about people with disabilities” (Iwasaki, 2022). Ableism is not specific to primary and secondary schools and is present in higher education. We see universities to embody ableism given the don’t provide space or programming for people with intellectual disabilities. Ableism surely contributed towards low rates of people with intellectual disabilities in higher education.

In 2004, the Individuals with Disabilities Education Improvement Act (DEIA) was instated, which makes students with intellectual disabilities “eligible to continue to receive public school support and services through the age of 21” (Thoma et al., 2011, p. 185). However, there are shortcomings to this act given that their peers are no longer in high school and there are very few programs offered for people with intellectual disabilities in higher education settings (Thoma et al., 2011, p. 185). Without programs for individuals with intellectual disabilities within higher education, an inclusive higher education setting cannot be achieved (Thoma et al., 2011).

Current Representation of People with Intellectual Disabilities in U.S Higher Education

Increased numbers of students with intellectual disabilities in the college world have resulted from the implementation of the Higher Education Opportunities Act (HEO) of 2008 (Butler et al., 2016). HEOA aimed to include reporting requirements, grant programs, and lower the cost of college education (Butler et al., 2016). Bethune-Dix et al. (2020) found that 300 colleges and universities across the United States now host programs designed to support the involvement of students with intellectual disability in various aspects of the college experience (e.g., academic courses, career development, social relationships, service opportunities, residential life)” (p. 310). Although this sounds significant, as of 2022 only 6% of U.S Higher

Education Institutions have inclusive programming for individuals with intellectual disabilities (“Think Inclusive”, 2022). Some universities that have inclusive programming for people with intellectual disabilities in the U.S are the University of Massachusetts Boston and Syracuse University.

Inclusion involves countering “the discrimination, stigma and prejudices that people with intellectual disability often face” (Corby et al., 2012, p. 70). Although there has been an increase in the number of students with intellectual disabilities in colleges since HEOA was enacted, there remain barriers to inclusion (Butler et al., 2016). A current barrier faced is the complexities involved around creating “ability-leveled courses, providing resources, appropriate teaching styles and disability awareness training” (Corby et al., 2012, p. 75). Another barrier is the gap of literature and knowledge on this group of individuals in higher education contexts given the rarity of programing currently available (Corby et al., 2012). The policies that higher education institutions hold that aim to work towards inclusion, can also lack the ability to fulfill the needs of each individual student given differences of ability among people with intellectual disabilities (Corby et al., 2012).

Implications for Future and Current College Student Services Administrators

A recent study by Mock & Love (2012) assessed one state’s initiative to increase access to higher education for people with intellectual disabilities. Mock & Love (2012) argue that to improve access to higher education for people with intellectual disabilities, educators need to do a better job of “information for families, enhancing collaborations with agencies and schools, and advocating for access to college courses and appropriate academic supports” (Mock & Love, 2012, p. 289). For people with intellectual disabilities to attend higher education, the families and the students must receive information on the programs that they can attend. They must also have

access to information on the current academic supports, individual education plans and hear stories of people with intellectual disabilities who have had positive experiences in higher education. Mock & Love (2012) suggests that to change policies and invoke practices that promote inclusion of people with intellectual disabilities in higher education, student affairs practitioners and university policy makers must involve student and family perspectives. To create programs that best serve students with intellectual disabilities, student affairs practitioners must take the time to learn from these students and their families themselves. The family members know what supports their student will need to succeed. Universities must also allot funding to “create an individualized, sustainable, and inclusive postsecondary option for students” (Mock & Love, 2012, p. 296). Practitioners must examine funding systems, redefine “the concept of diversity in higher education”, redefine best practice standards and advocate for “policy and systems change” (Mock & Love, 2012, p. 296). We must also continue to research and gather data on the impacts and importance of inclusive higher education for people with intellectual disabilities (Mock & Love, 2012). Without knowing the benefits of programs for people with intellectual disabilities in higher education it will be more difficult to recruit these students as well as to obtain funding for inclusive programming.

Conclusion

People with intellectual disabilities were once hidden and exiled from public view. People with intellectual disabilities have historically been pushed to the margins of society and excluded from many institutions in the U.S. They were also excluded from primary and secondary public education institutions. Families of people with intellectual disabilities fought for policy changes that served to increase inclusion of people with intellectual disabilities in education systems. Acts such as EHA, IDA, ADA, DEIA, and HEO have served to increase

inclusion of people with intellectual disabilities in primary and secondary education, but also higher education. However, there are many shortcomings of these acts such as the continuation of ableism in education institutions, as well as the lack of inclusive programming for people with intellectual disabilities in higher education. This has led to there being low representation of people with intellectual disabilities in U.S higher education. Attending higher education has huge impacts on people with intellectual disabilities' life outcomes, health, social lives, employment opportunities. Having access to higher education allows them to learn in community with the general population. To increase representation of people with intellectual disabilities in higher education, college student service administrators must create programs and policies involving students and families of individuals with intellectual disabilities. Administrators must also redefine diversity and allot funding to create inclusive programming for individuals with intellectual disabilities. I ask readers and student affairs practitioners to take notice and observe whether people with intellectual disabilities exist on their campus. I ask student affairs practitioners to think about how they can promote having of inclusive programming for people with intellectual disabilities on their campus. Why are people with intellectual disabilities integrated in primary and secondary schools through Individual Education Plans (IEP) and special education teachers? Why can't we commonly follow a similar model in higher education?

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