

Neurodiversity in Higher Education: Library and Information Science Educators Address the Learning Needs of Students with Intellectual Disabilities

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ABSTRACT

Research-based evidence is needed to raise awareness of the need for full equity and representation of individuals with disabilities in higher education including students with intellectual disabilities (ID). This research presents details in American law related to individuals with disabilities, describes intellectual disability according to widely recognized authorities, discusses implications for standards for inclusive education, identifies existing postsecondary education (PSE) course and program types, and addresses library and information science (LIS) educators' opportunities for preparing graduate library students in serving and instructing individuals with ID in higher education. Suggestions for future research to further investigate the information needs of stakeholders who impact the success of PSE students with ID including individuals with ID; parents; K-12 teachers, counselors, and support staff; PSE administrators, faculty, and support staff; legislators and policymakers; government service providers, and community leaders and groups, as well as continued research to investigate how LIS educators are involved in teaching graduate library students to instruct and support the education of PSE students with ID.

ALISE RESEARCH TAXONOMY

information literacy; curriculum; standards; academic libraries; social justice

AUTHOR KEYWORDS

intellectual disabilities; higher education; postsecondary education; disability services; instructional librarian; inclusion

INTRODUCTION

A relatively short time ago, high school graduation and transition to undergraduate college and university programs were experiences obscure to many individuals with intellectual disabilities (ID). As a result of new protections in American law (Individuals with Disabilities Act, 2004), which were followed by additional clarification of the definition of postsecondary education student with ID in the Higher Education Opportunity Act of 2008, diversity grew in higher education due to increased enrollment by individuals with ID (Grigal, Hart, & Weir, 2013; Plotner & Marshall, 2014). (*Higher education* is defined as educational opportunities provided through colleges and universities.) The idea of neurodiversity in higher education (Grant, 2009) ushered in new implications for how institutions of higher education include individuals who experience intellectual differences. Programming must be designed for all eligible individuals, which includes individuals with characteristics considered to be diverse such as race, ethnicity, nationality, gender, sexual orientation, religion, age, socioeconomic status—and ability. In this new higher education environment, everyone benefits from what traditionally underrepresented groups or groups once absent bring to the learning environment.

There is evidence from a 2018 survey disseminated through email and social media of “a trend within library graduate education that is exclusive to teaching library graduate students practically and adequately about disability and accessibility” (Pionke, 2020, p. 266). Based on the study’s survey responses by current graduate students, Pionke found that library graduate education students want better graduate education curriculum and instruction to prepare for serving and supporting individuals with disabilities. In response to Pionke’s findings from the LIS field and to address the universal need for continued full equity and representation of students with ID in higher education, this exploratory analysis of research was designed to produce findings that will inform and accelerate teaching and supporting all individuals who attend higher education, particularly individuals with ID, which may result in the restructuring of educational environments.

Today’s higher education policies and procedures have significant implications for faculty teaching and student learning experiences for students with ID (Ryan, 2014; Thoma, 2013). When writing about the educational needs of individuals with ID, Kelley and Westling (2019) state that educational programming beyond high school known as *postsecondary education* (PSE) programs “are not two-year vacations, respite care, or full-time activity centers” (p. 5), and in contrast, “a postsecondary education program for individuals with ID should intentionally provide the structure, support, and learning opportunities that will be success-oriented and lead to greater independence as an adult” (p. 5). Unlike when educating students without diagnosed disabilities, for the benefit of students with ID higher education policies and practices must embrace institutional collaboration with social service agencies and/or school districts to identify, collect, and analyze student evaluation data. According to Plotner and Marshall (2015), PSE programs must collaborate with adult agency partners when planning and delivering courses to improve the likelihood that knowledge and skills gained during PSE will lead to appropriate employment outcomes for students with ID. Sheppard-Jones, Kleinert, Druckemiller, and Ray (2015) further point out that even when adults with ID complete PSE programs, they often require ongoing supports through state and federally funded developmental disabilities waivers.

RESEARCH QUESTIONS

To fill gaps in educators' imagination and understandings of PSE students with ID, this research highlighted relevant facts and published examples for instructing and supporting students with ID while answering these research questions: What is intellectual disability? How common is it for individuals with ID to attend PSE programs? What are standards, quality indicators, and benchmarks for inclusive higher education for individuals with ID? How are LIS educators leading change at institutional and program levels for the benefit of students with ID?

INTELLECTUAL DISABILITY

According to the American Association of Intellectual and Developmental Disabilities (AAIDD) frequently asked questions website, “[i]ntellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behavior, which covers a range of everyday social and practical skills. The disability originates before the age of 18” (AAIDD, 2019, para. 1). Further, according to the AAIDD website, the term *intellectual disability* (ID) denotes the same population once labeled *mentally retarded* (MR). It has taken time for MR language to disappear in legislation, regulations, titles of academic programs and professional organizations, and as used by the public. Unlike the diagnosis of MR, ID is not determined by an IQ test, but instead, ID is diagnosed by a complex assessment in the areas of intellectual functioning and adaptive behavior, which includes an assessment of conceptual skills, social skills, and practical skills. This present research reveals that individuals with ID may also be identified as having non-verbal learning disabilities (Russell, 2020); learning disabilities, attention-deficit hyperactivity disorder, and/or behavioral/emotional disorders (Bakken & Obiakor, 2020; Grigal, & Papay, 2018), or Autism Spectrum Disorder (Cox, Thompson, Anderson, Mintz, Locks, Morgan, Edelstein & Wolz, 2017).

In 2006, Hart, Grigal, Sax, Martinez, Madeleine, and Will reported that education after high school had become an opportunity for an estimated 2,000-3,000 students with ID annually who were eligible for PSE opportunities. Education after high school for this population is extremely important given the research indicating that when compared with their peers, individuals with ID typically earn less, are engaged in lower skills jobs, experience higher rates of poverty, and have limited access to employee benefits (Stodden & Dowrick, 2001; Wagner, & Newman, 2015). Decreasing the high number of unemployed individuals with ID must be a matter of serious concern for all PSE educators, including library and information science educators, who have a stake in the future of higher education. Promising findings by Sannicandro, Parish, Fournier, Mitra, and Paiewonsky (2018) in a quantitative study of 2008-2013 Rehabilitation Services Administration 911 files indicate that PSE was associated with increased employment, increased weekly earnings, and decreased reliance on Supplemental Security Income. Other promising findings are reported by Qian, Johnson, Smith, and Papay (2018) who conducted a quantitative study of community and technical college students with ID. They found that predictors associated with paid employment outcomes were participation in inclusive classes and campus events; prior paid work experience; and participation in volunteering and/or community services.

Under the IDEA (2004), which mandated equity, accountability, and excellence in education for individuals with disabilities, two- and four-year public and private institutions of

higher education provide programs with federal support for high school graduates with ID, age 18 to 22 (Hart, Grigal, Sax, Martinez, Madeleine, & Will, 2006; Grigal, Hart, & Weir, 2013; Sannicandro, 2016; Sannicandro, Parish, Fournier, Mitra, and Paiewonsky (2018). PSE programming for individuals with ID is a response to advocacy predominately by parents who want information and guidance, safety, and a focus on employment for their children (Griffin, McMillan, Hodapp, 2010) and other disability advocates who maintained that federally funded institutions must open their doors to enable individuals with disabilities to benefit from their right to education until their 22 birthday. Until recently when postsecondary programs for individuals with ID emerged, many individuals with disabilities had no choice for where to receive education services guaranteed in the law expect to remain in high school. For individuals with intellectual and physical disabilities, remaining in high school until their 22nd birthday was typically considered unacceptable when compared to typical peers who at age 18 exit high school immediately following senior high graduation. The bottom line has been that even though an option was staying in high school for three more years, it was not an acceptable option for most.

INDIVIDUALS WITH INTELLECTUAL DISABILITY AND PSE PROGRAMS

According to the U. S. Department of Education, National Center for Educational Statistics (NCES, 2019), *Digest of Education Statistics*, 2017 (NCES 2018-070), Chapter 3, in 2015-16, 19 percent of male students and 20 percent of female students in PSE reported having a disability, including ID. NCES (2019), reports that between 2000 and 2017, total undergraduate enrollment in degree-granting postsecondary institutions was 16.8 million students. To determine how many colleges and/or universities offer PSE programs and in which areas of the United States programs are located, the researchers analyzed the ThinkCollege.net website, which is a project of the Institute for Community Inclusion at the University of Massachusetts Boston funded by grants from the Office of Postsecondary Education, US Department of Education. We found that there are currently adult learning PSE opportunities for individuals with ID in 49 states. Opportunities are in an array of college and university course types attended by students with and without disabilities including non-degree programs (60), certificate programs (169), and other combinations (56) of options for a non-degree, certificate, and degree programs. In light of the U. S. Department of Education, National Center for Educational Statistics (2019), *Digest of Education Statistics*, 2017 (NCES 2018-070), Chapter 2, 2015-16, which reports that in the U. S. there are 1,579 2-year colleges, and 3,004 4-year colleges, the number of PSE programs for students with disabilities is small when compared to the number of U. S. colleges and universities.

Individuals with ID are also eligible for community-based programs designed to provide environments where experiential learning can occur. Community-based programs, while useful social environments are not an alternative to PSE. Wintle (2015) studied community-based programs to determine what steps these programs take to prepare students with ID to participate in PSE programs. Also, the study revealed that students with ID preparing for PSE programs were those who could function in a school setting without disruptive behavior; had medium needs; had a circle of support that included parents, caregivers, and community members; were able to provide own self-care, and had educational and career aspirations. Additional key findings in the Wintle study were that individuals with ID need focused instruction to build

literacy skills; copy and/or take notes and complete worksheets; literacy skills for reading, and literacy skills for building recall and summary skills. To be prepared for college and/or university experiences, it was also concluded in the Wintle study that individuals with ID preparing for PSE need opportunities to observe actual academic activities at the university.

STANDARDS FOR INCLUSIVE HIGHER EDUCATION

According to Grigal, Hart, & Weir (2012), the *Think College Standards for Inclusive Higher Education* created at the Institute for Community Inclusion at the University of Massachusetts Boston provide a framework for a model PSE program and guidance for facilitating participation for students with ID on college campuses. Their model includes eight key elements: academic access, career development, campus membership, self-determination, alignment with college systems and practices, coordination and collaboration, sustainability, and ongoing evaluation. Grigal et al. (2012) assert that students with ID need access and support to participate in college and university organizations and residential life facilities; to participate in co-curricular activities such as student organizations, practica, and service-learning opportunities, and to use technology devices for communication and completing assignments. Also, individuals with ID need to engage in social activities with students without diagnosed disabilities who serve as role models and natural supports. The current transformation to more diversity in higher education environments together with the use of the *Think College* standards suggest many implications and opportunities for LIS educators to educate and prepare graduate library students for roles and responsibilities identified by Benjes-Small and Miller (2017) as an instructional librarian who wears the hats of designer, teacher, teaching partner, advocate, project manager, coordinator, and a lifelong learner.

The *Think College* (Grigal, Hart, & Weir, 2012) standards alongside the Association of College and Research Library's (ARCL) *Framework for Information Literacy for Higher Education* (2016) provide an outline (Table 1) for identifying examples of information literacy abilities to include as positive learning outcomes for students with ID. These learning outcomes reflect Think College basic premises and the six ARCL frames, which are centered on the premise that information authority is constructed and contextual; information creation as process; information has value; research as inquiry; scholarship as conversation; and searching as strategic exploration.

Think College Standards (2012)

ARCL Framework (2016)

	I can with assistance:
Academic Access	interpret course descriptions and select courses of personal interest.
Career Development	compare and contrast descriptions of jobs and careers.

Campus Membership	inquire and communicate about joining campus organizations.
Self-Determination	retrieve and read authoritative sources to make life choices.
Alignment with College Systems	access and use technology and digital materials.
Coordination and Collaboration	complete applications for internships and practicum.
Sustainability	select and use appropriate sources about funds for tuition and other costs.
Ongoing Evaluation	analyze assignment and course evaluation data.

Note: Based on the *Think College Standards for Inclusive Higher Education (2012)* created at the Institute for Community Inclusion at the University of Massachusetts Boston, and the Association of College and Research Library's *Framework for Information Literacy for Higher Education (2016)*.

Table 1. Teaching Library Graduate Students about Inclusive Learning Outcomes for Postsecondary Students with Intellectual Disabilities

As this outline reveals, graduate library students should be prepared to respond to students with ID who are learning measurable academic, cognitive, and technical skills relevant to participation in college, jobs, and careers. Most certainly, today's academic librarians should be prepared in a variety of strategies to instruct and facilitate information literacy learning for students with ID in response to widely accepted standards for inclusive education. Moreover, in academic libraries there are spaces that should be arranged to reduce student intimidation, anxiety, and uncertainty about obtaining reference services; using public access computers, and studying and taking exams in a space that is free from major distractions yet open to the mainstream activities of all students. It is increasingly common for Centers for Listening, Speaking and Writing to be located in academic library buildings and for centers to make available both library faculty instructors and informed student assistants. Academic librarians are prepared to learn from subject faculty about various aspects of course content, assignments and projects modified for students with ID, and they can serve as an instructor present in the library to communicate with the student. Academic libraries are spaces where there is clear signage, visible organization and placement of materials, and library personnel whose responsibility it is to anticipate students' questions, preferences, and needs and to respond appropriately.

When students with ID use the library in-person and then need guidance in accessing needed public or personal transportation, academic library personnel can answer questions and

assist in facilitating bus, taxi, ride-sharing, and other naturally occurring transportation options. Academic librarians can guide and facilitate students' access and communication with disabilities services provided by that college or university office. In addition to library orientation sessions and tours, academic librarians can provide personal instruction or instruction in small groups about the use of needed technology such as personal devices to text, email, and access electronic resources and platforms for instruction. Individuals with ID along with their peers can use the library for meeting with mentors, tutors, and campus ambassadors. And, like Hall, Meyer and Rose (2012) suggest, academic librarians are well-positioned to provide education and training to college and university faculty on universal design, a research-based framework and principles (Burgstahler, 2015) for development of learning environments that accommodate individual learning differences, which are now referred to by name in IDEA (2004) and other U. S. laws. Academic librarians can also provide parents and guardians access to information and resources about intellectual disabilities and about their rights to participate in their student's PSE programs.

LIS EDUCATORS LEAD CHANGE AT INSTITUTIONAL AND PROGRAM LEVELS

A review of published literature reveals that libraries continuously improve physical access to library spaces and some academic libraries are actively and directly involved in addressing the learning needs of students with ID. For example, Albertson and Whitaker (2011) report that a LIS master's student service-learning project provided access to technology and training contributing to personal empowerment in individuals with ID as master's students gained insights about the learning needs of individuals with ID. Anderson (2018) reported evidence that librarians' awareness of ASD through educational opportunities is the first step in tailoring the library environment, providing access to resources, and creating special interest group opportunities for social interactions for individuals who are otherwise typically alone.

Brannen, Milewski, and Mack (2017) reported that the University of Tennessee (UT) Knoxville formed an Assistive Technology and Accessibility Committee with the mission to assess and make recommendations about UT Libraries' practices for serving college students with disabilities using library-owned instructional materials and technologies. They also recommend incorporating universal design principles when planning for library instruction and outreach to college students with ID. Conner and Plocharczyk (2019; 2020) provide evidence that the academic library can successfully offer book clubs to provide environments for learning and socializing for college students with ID. Kowalsky and Woodruff (2017) created and published a guide for creating inclusive library environments. Murphy, Amerud, and Corcoran (2019) report that although partnerships between academic libraries and institutions' disability services vary across North America, it is encouraging that inter-unit partnerships exist to provide opportunities for enhanced student services and learning supports promoting success for individuals with ID.

SUMMARY

The purpose of this research was to communicate research-based evidence to raise awareness of the need for continued full equity and representation of individuals with disabilities

in higher education including students with ID. This research presents details in American law related to individuals with disabilities, describes intellectual disability according to widely recognized authorities, discusses implications for standards for determining learning outcomes in inclusive education, and addresses LIS educators' opportunities for leadership in teaching graduate library students. When compared to the total number of U. S. two- and four-year colleges and universities, this research indicates that the growth of PSE programs for individuals with ID disappointingly remains remarkably low.

Moeller (2019), cautions that “[i]n the United States, current conversations within higher education and academic librarianship around resilience and professionalism create additional barriers to inclusion and exclude the lived experiences of those with disabilities” (p. 456). She points out that “libraries must enact structural change to create and promote a culture of inclusion and equity for both library users and library workers” (p. 456). In teaching about developing culturally competent library professionals, Cooke (2017) pointed out that the tendency toward a passive acceptance of using a “one-size-fits-all approach to services” (p. 48) has in the past too often been the case. These noted failures and/or refusals can be addressed and overcome in many important ways as this research emphasizes when LIS educators prepare graduate library students for instructing and serving students with ID. This research emphasizes that academic librarians must be informed and proactive in using information and providing instruction and services in a manner that is easily understood by individuals with ID, their faculty members, educational service providers, and their parents or guardians who choose to participate.

The present analysis of research provided significant evidence for promoting the long past-due transformation away from a deficit model of disability wherein human conditions are viewed as a deficit or problem to be solved or eliminated through medical and/or educational interventions. The idea of neurodiversity in higher education (Grant, 2009) has implications for how institutions intend to include students. The use of the concept of neurodiversity embraces the premise that learning differences among people are the result of naturally occurring variations and that all human brains learn differently. Therefore, supporting neurodiversity in higher education should be the goal, not the exception.

In addition to answering identified research questions, this research identified the need for future research that will address stakeholders who impact the success of PSE students with ID including individuals with ID; parents and faculty members; K-12 teachers, counselors, and support staff; PSE administrators, faculty, and support staff; legislators and policymakers; government service providers, and community leaders and groups. Future research should also address how higher education offices for disability services address the inclusion/exclusion of students with intellectual disabilities. The present research also made clear that LIS educators have opportunities to teach professional librarians to be knowledgeable, compassionate, and competent higher education leaders and providers of information literacy instruction, and information resources and services to all PSE students including individuals with ID. Future research should continue to investigate graduate library students' impression of their preparation for serving individuals with disabilities and how practicing libraries are involved in the education of PSE students with ID.

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