A Prelude to Progress: The Evolution of Postsecondary Education for Students with Intellectual Disabilities

by Meg Grigal, Debra Hart, and Sharon Lewis

INTRODUCTION

Given all the recent advances in the field of postsecondary education for individuals with intellectual disabilities, one might assume that this area has well-established common values, strong philosophical foundations, consistent data-driven practices, and widely available existing services. Evidence of this progress abounds. There are now specific provisions supporting college access for individuals with intellectual disabilities in federal law; unprecedented access to some forms of financial aid; and various websites featuring program and resource materials. These are all positive accomplishments and serve as significant markers toward progress.

However, for many young people with intellectual disabilities, these markers have little impact. In fact, they may serve as a frustrating reminder of the paucity of available options. A constant refrain from students with intellectual disabilities is, “I want to go to college, but there is nothing available in my community. Can you help me?” Data from the National Longitudinal Transition Study-2 (NLTS-2) indicate that only 2.3% of out-of-school youth with intellectual disabilities in 2009 were enrolled in any kind of postsecondary education institution (NLTS-2, 2009). These recent findings demonstrate that for the majority of students with intellectual disabilities in our country, college is still not a viable or realistic option.

Therefore, the markers of progress may be misleading, as they reflect the potential for a new reality more than a current reality. We cannot assume that the existence of some research, some online or print resources, and a relatively small number of programs means that the work is done. The progress achieved thus far has allowed our field to begin a conversation that is likely to last a very long time.

At this stage, we should expect to hear conflicting opinions regarding what can and should be possible for students with intellectual disabilities in the context of postsecondary education. If, as Mohandas Gandhi observed, healthy discontent is the prelude to progress, then we are certainly in the prelude phase of this conversation. Developing and implementing evidence-based practices, cultivating common standards with which to measure and research such practices, and generating supportive policies at the federal, state, and local levels will require significant amounts of time and resources.

A HISTORICAL PERSPECTIVE

Not long ago, students with an intellectual disability did not have the right to access a public primary or high-school education, let alone college. In fact, some states had laws that explicitly excluded children with certain types of disabilities, including students with “mental retardation,” from attending public school. In the 1970s, parents in 26 states had to resort to litigation to assert their children’s right to attend public schools (National Council on Disability, 2000). Large numbers of people with intellectual disabilities languished in state institutions where even the most basic needs were barely met. Educational and rehabilitation services were not even considered, certainly not as we know these services today. The medical community often counseled parents to institutionalize their children so they could get the “care” they needed and be “kept safe.”

With the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975 (now known as the Individuals with Disabilities Education Act – IDEA), Congress finally cleared the way for children with disabilities to have the opportunity to learn and to succeed in public school. Initially, the law was about creating access to a free,
appropriate public education as well as access to individualized planning and least restrictive learning environments. In the 35 years since this law passed, expectations for youth with intellectual disabilities to live and work in our communities have been raised. The public education system has responded to these new higher expectations by developing teacher training programs, standards and quality indicators, and regulatory oversight mechanisms. Much of this work was funded by the U.S. Department of Education in the form of personnel preparation, model demonstration, and field-initiated research projects.

Therefore, education policies and practices reflect the knowledge base and values of their time, and provide a foundation for future expansion and innovation. For example, the notions of least restrictive environment, community integration, and individualized planning have been present in disability, special education, and rehabilitation legislation for many years; yet the manner and extent to which these notions have been implemented in practice has evolved significantly over time. Self-contained special education classrooms, sheltered employment workshops, and group homes were at one time “state of the art” in their respective fields of education, employment, and community living. However, as our expectations evolved about what people with intellectual disabilities could achieve in terms of learning, working, and living with people without disabilities, so did our practices.

This view of history allows us to put the current status of postsecondary education access into perspective. The passage of the Higher Education Opportunity Act amendments (PL 110-315) that support access to higher education and federal financial aid for students with intellectual disabilities occurred only recently, in 2008. As with the Education for All Handicapped Children Act, it will take some time for the principles outlined in the HEOA to translate into practice. It will also take some time for the implementation of these practices to mature, becoming more refined and reflective of high expectations. Once again we will need to create standards to guide best practice, training for professionals, and research to identify evidence-based practices and outcomes.

As IDEA evolved to reflect higher expectations for youth with disabilities transitioning out of high school, this new emphasis was reflected in the hundreds of projects funded by the Office of Special Education Programs (OSEP) in the U.S. Department of Education that focused on demonstrating and researching transition practices in the 1980s and 1990s (OSEP, 2010). A similar level of interest in postsecondary education for students with intellectual disabilities, and corresponding investment of funds from federal agencies, will be required to expand the current foundation of practice and to guide future research and policy agendas.

Another pivotal piece of legislation that has had a major impact on the lives of people with intellectual disabilities has been the Americans with Disabilities Act (ADA), which recently celebrated its 20th anniversary. As a result of this legislation, remarkable progress has been made by individuals with disabilities in participating in civic life, accessing educational and professional advancement, and enjoying improved access to a variety of private-sector environments and travel experiences.

The rights of people with disabilities afforded under the ADA (Office for Civil Rights, 2010) must not only continue to be protected, but also be fully implemented. The goals of the law – equality of access across all aspects of adult life, including higher education – need to be fully realized for all people with disabilities, including those with intellectual disabilities. Recently reauthorized, the Americans with Disabilities Act Amendment Act (ADAAA) of 2008 brings with it a broader interpretation of the construct of disability. This may have additional implications for colleges and universities that are seeking to provide access to higher education to people with intellectual disabilities.

CURRENT REALITIES

As we work to broaden postsecondary education access for students with intellectual disabilities, we must use a framework that reflects and adheres to the legislative guidance provided in the Higher Education Opportunities Act. At the same time, we must be mindful that most of the students with intellectual disabilities emerging from high schools today will not be considered “college ready.” In part, this stems from the types of goals written into their IEPs. Students with intellectual disabilities are the least likely to have college listed as goal on their IEP (Grigal, Hart, & Migliore, 2011). Consequently this is also one of the least likely groups of students (along with students with multiple disabilities) to enroll in postsecondary education four years after high school (Newman, Wagner, Cameto, & Knokey, 2009).

Students with intellectual disabilities will not consider college as a realistic option unless the legislative and regulatory language that guides our secondary special education practices more clearly supports this choice. Some very brief language in the preamble to IDEA states that nothing in the law would prohibit a local education agency from using IDEA funds to support students with disabilities in a postsecondary
environment. However, there is no clear support articulated for funds to be used in that manner. The current IDEA regulations do not differentiate between IEP guidelines and transition expectations for students between the ages of 18 and 21. Therefore, school systems may struggle with translating meaningful, socially integrated transition experiences on a college campus for young adults with intellectual disabilities into the standard IEP framework used to guide the delivery of secondary special education services in high school settings.

The current research literature on postsecondary education for students with intellectual disabilities is comprised primarily of descriptive studies, qualitative studies, and some single subject and case studies on postsecondary experiences and outcomes for individuals with intellectual disabilities (Think College, 2010a). There is scant research on evidence-based practices or interventions for students with intellectual disabilities in postsecondary education. Why is this?

One reason is that there is still little existing or consistent practice, let alone evidence-based practice. The programs and services in colleges for students with intellectual disabilities have been created without federal or state legislative or regulatory guidance or funding, and thus can be difficult to compare in a meaningful way. Additionally, up until very recently, there have been extremely limited and somewhat disjointed efforts to fund any kind of research in this area. Despite this, over 168 postsecondary education options for students with intellectual disabilities exist (Think College, 2010b). The existence of these options demonstrates the power and potential of the early grassroots efforts of institutes of higher education, local education agencies, and families to offer people with intellectual disabilities access to college. These efforts have been revolutionary, and in many cases these practices have been groundbreaking. Each of these past efforts should be honored, but also thoughtfully examined in light of the new federal guidelines.

**WHAT COMES NEXT**

Future work in this area should build upon the early efforts of the institutes of higher education, school systems, agencies, and individuals that created opportunities where none existed. Emerging programs can benefit from their collective experience regarding what worked and what didn’t in terms of planning, brokering partnerships, blending resources, and cultivating authentic learning experiences for students with intellectual disabilities.

Part of the next generation of work will be conducted by the colleges and universities that have been recently awarded Transition and Postsecondary Education for Students with Intellectual Disabilities (TPSID) model demonstration grants by the Office of Postsecondary Education in the U.S. Department of Education (see www2.ed.gov/programs/tpsid for the grantees list). These 27 projects across the country provide the field with an opportunity to see the Higher Education Opportunity Act regulations in practice, and to determine the extent to which those practices support successful outcomes for students with intellectual disabilities.

This first federally funded model demonstration program reflecting the new provisions in the HEOA will deepen our understanding of the structures necessary to implement postsecondary education services for students with intellectual disabilities. It will also provide some common measures of the experiences and outcomes of students. Yet sole reliance on the TPSID grants to build our knowledge base around this topic would be short-sighted. As other federal and state agencies or foundations prioritize funds, efforts must be made to engage two- and four-year colleges and universities, vocational and technical colleges, and local education and adult-service agencies in a diverse array of research activities. These efforts will be made more fruitful as additional programs and services are developed and implemented across the country.

The creation of new postsecondary education options for people with intellectual disabilities will depend greatly upon leadership at the state and local level. This will have to include state departments of education, higher education commissions, local school systems, and rehabilitation and disability services agencies. Collaborative efforts among these entities will build and strengthen state networks, and allow for the development of the infrastructure and communication mechanisms needed to foster and sustain new partnerships and services. Our state
and local leaders need to become aware of the resources and opportunities that exist in their states, identify gaps in services, and establish plans to respond to the growing need and desire of their constituents with intellectual disabilities to access higher education.

CONCLUSION

The next decade will be a very exciting time as the range of options for postsecondary education for individuals with intellectual disabilities continues to grow nationwide. We are entering a new phase, when the questions on the table focus less on, “Should students with intellectual disabilities have the option to go to college?” and more on, “How can students with intellectual disabilities have college options?” and “What should these college experiences be comprised of and culminate in?”

These questions will drive the next wave of research, policy, and practice. As we seek to answer them, we will have the chance to apply lessons learned about the impact higher expectations have on outcomes for people with intellectual disabilities to the relatively new arena of higher education. As our vision of what is possible for students with intellectual disabilities expands once more, we will be challenged to move beyond the relative ease of navigating a known path, to face and overcome the difficulties that come with exploring uncharted territory.

REFERENCES


ABOUT THE AUTHORS

Meg Grigal is a Senior Research Fellow with the Institute for Community Inclusion at the University of Massachusetts Boston. She may be reached at meg.grigal@umb.edu.

Debra Hart is Director of Education and Training with the Institute for Community Inclusion at the University of Massachusetts Boston. She may be reached at debra.hart@umb.edu.

Sharon Lewis is Commissioner of the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, Washington, D.C. She may be reached at sharon.lewis@acf.hhs.gov.

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