

Postsecondary Education and Persons with Intellectual Disabilities: An Introduction

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Abstract: Legislation in recent years, including the ADA, IDEA, and the Olmstead Act, has vastly affected the accessibility of postsecondary education for persons with disabilities. This paper presents an overview of that legislation and considers how the resultant supports and services have become more flexible and increasingly tailored to the individual's unique educational needs and academic/professional goals. This paper also examines a sampling of educational models and projects that have been undertaken with the intent of maximizing accessibility and inclusion, and it looks at the various issues concerning supports, policy, financial concerns, and systemic coordination that arise from those models and projects. Finally, the need for future research is addressed, and questions intended to give direction thereto are posed.

Americans of every historical era and demographic group have recognized the role of education in improving the quality of life of the individual as well as sustaining the life of democracy. Adults with disabilities are more than twice as likely as persons without disabilities to live below the poverty line and be financially dependent on government programs or family (U.S. Department of Health & Human Services, 2001). Completion of some type of postsecondary education, including different forms of vocational or technical training and other life-long learning, significantly improve one's chances of participating in gainful and satisfying employment. Engaging in lifelong learning and growth opportu-

nities throughout adulthood is important to one's sense of purpose, personal well being, and financial independence. More and more persons with disabilities are pursuing higher education; in the past twenty years, this population has more than tripled (HEATH Resource Center, 2003; National Organization on Disabilities/Harris Survey, 2003). Further, persons with disabilities entering postsecondary education are making significant improvement in persisting toward successful completion of their program of studies (Harris Survey, 2000; HEATH Survey, 1998; OSERS, USDOE, November 29, 2000). In support of these improvements, disability supports, services, and accommodations are now provided in most types of postsecondary education settings (Kaye, 2000; National Organization on Disabilities/Harris Survey, 2003).

Advances on the part of persons with disabilities have historically followed the passage and amendments of federal policy. Ground-breaking policies include: (1) Public Law 94-142 (reauthorized as IDEA, 1997), which focuses upon quality preparation in secondary school and transition to postsecondary education and employment; (2) the Americans with Disabilities Act (ADA), which focuses upon providing reasonable accommodations to ensure equal access to learning and work environments; and (3) the Rehabilitation Act of 1973, which provides financial assistance and

Development of this paper was completed as part of the Strategic Program of Research for the National Center for the Study of Postsecondary Educational Supports at the University of Hawaii at Manoa, which is a Rehabilitation Research and Training Center funded by grant # H133B980043 from the National Institute on Disability and Rehabilitation Research within the U.S. Department of Education. Opinions and views offered within this paper are those of the researcher involved and the funding agent implies no endorsement. Correspondence concerning this article should be addressed to Robert Stodden, Center on Disability Studies, 1776 University Ave., UA 3-7, University of Hawaii at Manoa, Honolulu, HI 96822. Email: Stodden@hawaii.edu

training support leading to quality employment. These advances have led to the enrollment of students with disabilities in postsecondary education. The different types of self-reported disability in postsecondary education include various degrees of sensory and orthopedic impairments, learning and emotional disabilities, and other physical disabilities. In contrast, those youth experiencing intellectual disabilities have not yet made significant gains toward access and participation in postsecondary education.

Over the past decade, family members of youth with intellectual disabilities have begun to express an interest in seeing their young adults participate in a range of postsecondary education activities (Austin, 2000). Family members, youth, interested community agencies, and educators in secondary and/or postsecondary school settings have collaborated to develop and experiment with a range of postsecondary education models. Family members, foundations or trusts, small amounts of federal demonstration funding, and/or the actions of a few supportive persons on postsecondary education campuses originally supported such opportunities. This paper will present a review of current models of supports for students with intellectual disabilities in postsecondary education with an examination of the dynamics of policies and issues that encourage this growth.

Models of Service and Supports

A number of demonstration projects were funded by the United States Department of Education to experiment with provision of special education services in employment and postsecondary education settings for young adults under IDEA who were between the ages of eighteen to twenty-one and who had intellectual disabilities. Other projects designed specifically for persons with developmental disabilities sought to develop independent living and employment preparation on community college campuses. The aforementioned projects and other developed opportunities have taken different forms depending on the interests and knowledge of those persons involved. Hart, Zafft, and Zimbrich (2003) and the Second Summit Proceedings of 2002 sum-

marized the evolving postsecondary education opportunities:

Substantially separate model. These opportunities are often developed as programs that are separate from the matriculated course of study or curriculum as provided to other persons attending the postsecondary education campus. Such programs are often housed separately, because students with disabilities do not follow a typical schedule and their studies often do not result in a recognized certificate, license, or degree. Students who attend these programs may not interact with the typical student body, nor do they take any standard college courses. The curriculum for students with disabilities is primarily focused on "life skills" development, community-based instruction, and/or rotation through a limited number of on the job employment training slots (e.g., maintenance, food preparation, filing) to gain experience. Such program models are usually staffed by special education teachers or adult disability service providers and often do not involve support personnel from the postsecondary education institution. Generally, funding for these programs is provided through the local education agency or through a private family or corporate trust. Initiators of such programs are typically parents of young people with intellectual disabilities and/or special education personnel from the local school district.

Mixed program model. These opportunities usually include a combination of integrated campus courses of study as well as substantially separate "life skills"/transition programs housed on the campus of a college. Students may interact with the typical student body (e.g., cafeteria, sport events) and may participate in a normal campus schedule. Students with intellectual disabilities may take some college level courses, including elective offerings, in combination with components of a separate curriculum focused on "life skills", community-based instruction, and/or rotation through a limited number of employment slots (e.g., maintenance, food preparation, filing) to gain experience. Parent groups or secondary school special educators working in collaboration with postsecondary education instructors or support persons often initiate these opportunities. The outside sources, local school dis-

tract, and the postsecondary education program may share funding for these models.

Individualized support model. Students participating in this model often receive individualized services, accommodations and supports (e.g., educational coaches, assistive technology) that are needed to ensure access, participation, and progress in a range of college courses, certificate programs, internships, and degree programs. All services and supports are student centered, based on student choices and preferences to access and succeed in courses and activities. Students participating in this model may be matriculated and working toward completion of a course of study resulting in employment or a career move. In individualized models, supports may be initiated by staff within a program area or by a team of persons representing postsecondary training and high school educators, as well as local businesses or employers. In addition, the educational and related supports and services making it possible for youth with intellectual disabilities to participate in these models are often funded by a combination of sources including the postsecondary institution, local businesses, and school districts.

Recent Developments

During the Summer of 2000, the National Center for the Study of Postsecondary Educational Supports at the University of Hawaii at Manoa, brought together a group of youth with intellectual disabilities, family members, and professionals, all interested in exploring and furthering opportunities in postsecondary education. This meeting brought about the creation of National Summits for person with disabilities in postsecondary education. The First Summit (Summit Proceedings, 2000) of the Coalition for Postsecondary Education and Youth with Cognitive Disabilities was held in Portland, Oregon, and was aligned with the National Conference of the Association of Higher Education and Disability. Following the First Summit, numerous meetings were held around the country with family members, youth, and interested professionals to further share opportunities and begin the process of planning a national agenda for this group of youth (TASH, 2001; Pacific Rim Conference, 2002). These meetings generated a

ground swell of interest in postsecondary education opportunities for youth with significant and/or intellectual disabilities.

National interest was peaked by a series of meetings supported by federal agencies and other groups seeking further work in this area. During the summer of 2002, the National Institute on Disability and Rehabilitation Research supported a National Summit on Postsecondary Education and Employment at the National Press Club in Washington DC (National Summit Proceedings, 2002). The meeting had a focus on youth with significant and intellectual disabilities. During the fall of 2002, the Office of Disability Employment Policy of the U.S. Department of Labor sponsored a working roundtable to further explore ways to support postsecondary opportunities. In December 2002, aligned with TASH Conference in Boston, the national coalition held its Second Summit with the sponsorship of the Administration on Developmental Disabilities, the Office of Special Education Programs, and TASH. The summit was organized and conducted with a number of family members, youth with intellectual disabilities, and interested supporters in attendance. Attendees shared the successful experiences of a number of youth with intellectual disabilities in postsecondary education settings, along with a series of papers that had been written supporting this emerging field of study (Second Summit, 2002). The Second Summit also yielded a proceedings summary of the presentations and discussions (Second Summit Proceedings, 2002) as well as a number of products to be shared with family members and others interested in supporting this work.

Finally, the "Students with Intellectual Disabilities and Postsecondary Education Institute: Discussions of Developments in Practice and Policy" was held on September 15, 2003 in Washington DC. This Institute gathered policy makers from Washington DC and leaders in the area of postsecondary education and intellectual disability nationally. Examples of current state of the art practice were displayed and examples of financial barriers and opportunities, regulatory solutions and research implications were discussed. A proceedings manual was also produced as a result of the Institute. Recommendations from the Institute are to be reflected in future Federal pol-

icy initiatives and in priority setting activities. Clarification and endorsement of positions as stated in IDEA 97, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act were issued by federal agency partners. Although the need for policy to support students with disabilities to attend postsecondary education exists, policy history reflects a need and an interest in the development of a wider range of supports and services for students with intellectual disabilities in postsecondary education.

The New Paradigm: Legislative and Policy Changes

Recent key developments in the participation of students with significant and intellectual disabilities in postsecondary education are evident in the context of legislative, policy and program developments. Following the deinstitutionalization movement for people with developmental disabilities in the 1960's and 1970's, supports and services for people with disabilities often were delivered and remained in the context of the medical model, then evolved to the community supports model after strong advocacy by families of children with developmental disabilities (Bradley, 1990). In 1990, key elements of the definition of mental retardation were identified by the American Association of Mental Retardation around the constructs of capability, environment and functioning level. The New Paradigm describes the "fit" of individual capacities within the structure and expectation of the individual's personal and social environment. It is a distinct departure from the medical diagnosis and treatment of the previous medical model; the New Paradigm empowers persons with disabilities and their supporters. Originating as a part of the self-determination movement for people with disabilities and their desire for civil rights and independent living, new advocacy has spurred the creation of new models of supports and services and the development of increasing control over supports by all individuals with disabilities. Supports and services have become more flexible in response to "consumer choice" and are increasingly tailored to individual needs and desires. The New Paradigm reflected the values that formed the basis of several ground-

breaking legal decisions leading to the development of supports and services for people with intellectual disabilities in postsecondary education. Following is a review and discussion of pertinent federal policy and legal decisions.

The ADA of 1990, STAT. 327 transformed the self-determination and empowerment movement undertaken by persons with disabilities into federal legislation. The ADA protects civil rights by providing the tools for people with disabilities to self-advocate in various public settings, including postsecondary education. The ADA shifts the responsibility for making decisions about their services and supports to individuals with disabilities by requiring them to identify their disability and negotiate their accommodations, in stark contrast to the experience under the Individuals with Disabilities Education Act (IDEA) of special education secondary students. Under IDEA '97, which governs the provision of services and supports to secondary school students, it is the responsibility of the Local Education Authority to identify special needs students and to provide adequate services for them while parents negotiate services under an Individualized Education Plan (IEP). During the transition period from secondary school to postsecondary education, the student is expected to self-advocate, thus taking on the former role of the parents (Stodden, Jones, & Chang, 2002). Under the ADA, which governs post school life, individuals with disabilities have rights, which encompass access to transportation, communication, and access to public buildings and information.

IDEA '97 (PL 105-17) (1997) has a long history with its roots in the Equal Education of the Handicapped Act of 1975 (PL 94-142). The result of this law, its amendments, and reauthorization is that over one million children have been educated in public school settings instead of residing in institutions. IDEA '97 ensures that teachers, parents, and young persons with disabilities are involved in planning the education of youth with disabilities. Such planning provides opportunities for youth with intellectual disabilities by supporting a discussion of access to the typical curriculum and preparation for and transition to postsecondary education. Nationally, schools are attempting to support youth with

intellectual disabilities to adhere to a standards-based curriculum with outcome accountability with the transition planning process for these youth (Smith, Stodden, James, Fisher, & Pumpian, 1999). Some schools have successfully restructured by forming a whole school design which includes all students while coping with heterogeneous grouping, curricular design, multiple methods of assessment and new roles for teachers (Jorgensen, 1999).

One area of IDEA '97 that indirectly affects the access to and participation of students with disabilities in postsecondary education is the inclusion of all students in standardized assessments and performance goals. Adherence to general education curriculum goals and assessments results in increasing expectations for students with intellectual disabilities and often has a positive effect on their performance (Sax & Thoma, 2002). Transition planning requirements in IDEA '97, including planning for postsecondary education, directly affects students with intellectual disabilities in their secondary school preparation because it is applicable to all students regardless of the extent of their disability. This language opens the door for transition planning for postsecondary education as early as age 14, so that students, families, and teachers may plan their secondary curriculum to reflect desired post school outcomes (Fisher, Sax, & Pumpian, 1999; Sax & Thoma). It is essential in this planning to identify the desired future environments with the input of students with intellectual disabilities during the transition planning process.

The IDEA '97 directly affects students in the area of ensured access to the general curriculum for all students as part of the "least restrictive environment" clause, which mandates that students be included with non-disabled peers in general education settings to the extent possible. These heterogeneous settings necessarily focus on an instructional design that accounts for the needs of the student and supports with varying levels of ability and disability. Strategies such as universal design, person-centered planning, the use of technology, and slight modifications to the culture of the classroom have been effective techniques in facilitating the inclusion of students with intellectual disabilities in academic settings

(Wehmeyer, Sands, Knowlton, & Kozeleski, 2002). Several other benefits result from the inclusion of students with intellectual disabilities in more heterogeneous settings. Among the most beneficial, perhaps, is that as students with intellectual disabilities are being included in academic classes in secondary schools, they are also being included in the social life and climate of the school. They are participating more and more in typical activities and are exposed to the natural behavior of other teenagers. Through making friends and acquaintances and thereby increasing their social networks and skills, they are afforded the opportunities to understand typical behaviors of teens without disabilities and to ultimately decrease stigmatizing behaviors that would likely separate them as adults (Fisher, Pumpian, & Sax 1998; Gilberts, Agran, Hughes, & Wehmeyer, 2001; Schnorr, 1991). Students with intellectual disabilities should always be expected to take part in the general education curriculum and prepare for post-school experiences with an array of choices identical or similar to those of typical students (Flavey, Eshilian, & Rosenberg, 2001; Jorgensen, 1999; Smith et al., 1999).

Inclusion in typical adult life is now supported legally. The Olmstead Decision (1999) or Olmstead vs. LC is a historic Supreme Court decision that encourages states to re-evaluate the manner in which they deliver publicly funded long-term care services to people with disabilities. Previous to this decision, a strong bias in Medicaid (the Medical Model) funding had the effect of increased funding to large congregate institutions, such as nursing homes and institutions for individuals with mental retardation. Often, individuals could only receive their needed and desired services in these settings. The Olmstead Decision ruled that it is a violation of the Americans with Disabilities Act to discriminate against individuals with disabilities by providing services only in institutions when they can be served in a community-based setting. As a result, each state developed a plan to comply with the decision. Currently, states and consumer advocacy groups are designing ways to deliver supports and services in the community with federal Medicaid monies redirected from institutions. In some states, community care system-change efforts are underway to

redesign the service delivery system with the funding of federal implementation grants.

The following results can be discerned from the Olmstead decision: 1) more people are moving out of institutions; 2) an improved capacity is present in the community for the provision of personal care; and 3) community based supports and services once available only in large congregate settings are now available to individuals in their own homes, schools, and communities. Supports and services are being developed which optimize models of choice and self-determination (Fox-Grage, Folkemer, & Lewis, 2003). Olmstead is a further example of the New Paradigm as applied to community supports and services for individuals seeking residential and community supports. In summary, these key legislative and policy developments have set the stage for students with intellectual disabilities to receive the assistance they need to both thrive independently within the general community and to participate in postsecondary education.

Issues Concerning the Provision of Supports and Services in Postsecondary Education

Despite these areas of progress in the areas of legal and social policy, significant complications remain in supports and service delivery. Barriers exist for persons with disabilities in the areas of family initiated support, postsecondary educational settings, as well as in the provision of government-funded support services (AYPF & CEP, 2002). Although IDEA '97, the ADA, and the Olmstead Decision are strong federal policies, there is still not the coordination between agencies necessary for a seamless transition of youth with disabilities from secondary school to postsecondary education. As students with intellectual and other significant disabilities prepare for and enter postsecondary education they still face basic issues that will be discussed in the next section.

Issues in the Provision of Family Initiated Supports

Historically, families have been successful at advocating for and creating natural and basic supports for their children and youth with

intellectual disabilities in general. Most notably, the 1950's Arc Movement created community based advocacy, networks and supports for families with children with mental retardation. Parents and families continued their advocacy for the passage of the Equal Education of the Handicapped Act P.L. 94.142, now IDEA '97. This advocacy for neighborhood and inclusive education has defined special education for the past 30 years.

Under IDEA, parents have the right and responsibilities to define and approve of their child's education through the development of an Individualized Education Plan. This historical role is in contrast to the implementation of Family Educational Rights and Privacy Act (FERPA), a Federal law that protects the privacy of student educational records. FERPA gives parents certain rights with respect to their children's education records (20 U.S.C. § 1232g; 34 CFR Part 99). These rights transfer from the parents to the student when he or she reaches the age of 18 or attends a school beyond the high school level. The law restricts the viewing and copying of educational and other records of students without their express permission. Typical families pass through developmental stages, "launching" is the stage that marks the transition from secondary education to postsecondary education. During this time, parents of students with disabilities relinquish their legal role of advocate for students with disabilities (Whelley & Graf, 2002). Now, they support their youth in the "dignity of risk" that adult life brings but build in assurances for safety through the depth of social networks and individually targeted planning. They can also advocate for the resources needed to support their youth's choices.

However, many families with members with intellectual disabilities are fearful in the launching period. They want to protect their sons and daughters from the risks of the greater world and limit them by choosing self-contained and protected programs. Many families feel the loss of the entitlement of services provided through IDEA '97 as an abrupt change in the transition to adulthood. The result is a choice by parents to protect their youth in the face of a dearth of post-school supports and often ill-prepared youth (National Center for the Study of Postsecond-

ary Educational Reports, 2001; Whelley, Hart, & Zafft, 2002).

Policy Implementation Issues: Financial and Regulatory Concerns

College is expensive for every student and the financial burden is often greater for students with intellectual disabilities and their families. Accessing financial aid may be difficult because award packages are typically contingent upon the student's meeting a minimum credit requirement per semester. So students with disabilities often must forfeit financial assistance while at the same time extending the number of semesters. Making matters worse, students with disabilities may actually run out of eligible semesters for grant qualification. Additionally, work-study opportunities may be limited due to the need to focus on finding, coordinating and using accommodations in daily living and studies. In fact, in postsecondary education there are disincentives to be employed in work-study programs. This work may be counted as current or future income by Vocational Rehabilitation or Social Security Insurance programs, thereby decreasing that benefit. Typically, college financial aid officers are often unaware of the unique and compounding issues that face students with disabilities (National Council on Disability, 2003; Youth Advisory Council, 2003).

Without ready access to financial aid or to work study, students with intellectual disabilities are left to fund their college education on their own. A family fortunate enough to be in a position to do so can create a college fund and/or a savings account for a child with disabilities, as is done for any other child. Less burdensome (and potentially class-segregating) alternatives could be available through creative policy development, such as an expansion to the federal financial aid program, governed by the Higher Education Act. Financial Aid officers in postsecondary education require more discretion in extending eligibility to students with disabilities based upon the needs of their disability. Supplemental grants should be offered in place of work-study or other types of higher education assistance. Funds should be made available for tuition, textbooks, support service and assistive technology. Deferments to loan payments should

also be available due to disability (Youth advisory Council, 2003). These policy adjustments would decrease the financial burden for students with disabilities, thereby increasing their opportunities in attending postsecondary education.

Issues for Students with Intellectual Disabilities in Postsecondary Education

Individuals with intellectual disabilities, their families and personnel report that it is critical that the faculty and staff have a supportive and problem-solving attitude. Second, some students may require supports not available at an institution of higher education (i.e., physical therapy, individualized transportation, adaptive equipment or personal assistants). Further, it is the responsibility of the young person with intellectual disabilities, not the schools', to self-identify as a person with a disability and disclose the nature and needs of their disability. Students with intellectual disabilities must begin to learn to self-advocate at an early age. Students must learn what their disability is, what accommodations they want, what their rights are and how to negotiate for their rights and accommodations. The supports that they need may not be available at their postsecondary educational institution or local community leading to further complications.

Issues of Coordination and Management of Supports and Services

Supports and services in postsecondary education should be delivered in a coordinated manner and often are not (Whelley et al., 2002). Rather, the procurement of services amounts to a confusing and daunting task, even for the professionally employed case manager. It is even more difficult to coordinate supports and services for students with intellectual disabilities, as the nature of coordination may be more complex than other students with disabilities.

A component of coordination is alignment of required supports and services from the institution of higher education and with Vocational Rehabilitation Agency, Medicaid, medical insurance and the Developmental Disabilities service unit of the state is also in

order. Service gaps occur as students exit high school and/or turn 18 years old or 21 years old. There are similar overlaps in service related to these transition points. The array of discrete agencies which replace IDEA in the post-school sector have varying eligibility requirements, capacities, and quality and length of service. Students and families, particularly of youth with intellectual disabilities, are profoundly impacted by this lack of coordination after IDEA entitlement ends, and they generally require assistance to learn to manage their supports. Individuals, with family support, are attempting to go to college without systematic change and are struggling to overcome the barriers created by the lack of coordination of educational and related services.

Discussion and Need for Further Action

Secondary school preparation and transition of students with intellectual disabilities is critical for their success in later postsecondary education and other post-school roles. IDEA '97 directs the manner in which to include students with intellectual disabilities in typical secondary curricula. Taking full advantage of this law can prepare students with intellectual disabilities for success in postsecondary education as described above. However, teachers and secondary personnel need to go beyond basic compliance with IDEA '97 by investigating postsecondary education options in their local geographic area and inviting postsecondary educators to the IEP of students who desire a postsecondary education experience. Individual planning such as MAPS or PATH can help to identify the student's future desires and goals.

The shift to preparation for postsecondary education has implications for secondary teachers, administrators and for families. First, all need to adjust their expectations of the student with intellectual disabilities. Emerging information on the success of students with intellectual disabilities during and after postsecondary education is available (Zafft, Hart, & Zimbrich, 2004). Ample evidence exists to show that students with intellectual disabilities are capable of postsecondary material when given appropriate preparation, transition, assistance, and supports or services.

Attitudes toward and expectations of stu-

dents with intellectual disabilities attending postsecondary education bring its own set of challenges as well. Faculty members are obligated to adapt their teaching strategies to a variety of learning styles. Supports external to the postsecondary setting must be flexible and well coordinated to meet the individual needs of the student. A systemic adjustment in financial aid with accommodations in course loads, particularly for students with intellectual disabilities, is necessary. Given the attention and focus upon this area of study over the past three years, the following issues have evolved as important to those building postsecondary education opportunities for youth with intellectual disabilities:

- What is the satisfaction of available postsecondary services for the family?
- What are the processes for the delivery of postsecondary education and supports to students with intellectual disabilities?
- How do these processes affect families, teachers, school administrators and postsecondary personnel as well as other stakeholders?
- What are the policy changes and regulatory issues needed to facilitate the participation of youth with intellectual disabilities in postsecondary education?
- What are the funding bases for the future programs or opportunities?
- What are the interagency funding alterations that may facilitate the education of youth with intellectual disabilities in postsecondary education?
- What are the desired outcomes or results of the programs or opportunities for youth with intellectual disabilities and their family members?

The answers to these questions seem to have an influence upon the manner in which the postsecondary education program or opportunity is originated, approached, and developed. In turn, answers to these questions influence (1) the approach taken to develop and provide supports, services and/or accommodations for the student with intellectual disabilities, and (2) the alignment and coordination of educational services and supports with related services provided by a range of agencies including those related to health,

housing, and transportation. This is a new and emerging area of service and study. Although substantial issues remain in the preparation, service approach, coordination of supports and funding, the current progress in this area of study is promising.

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TITLE: Postsecondary Education and Persons with Intellectual
Disabilities: An Introduction
SOURCE: Education and Training in Developmental Disabilities 39
no1 Mr 2004
PAGE(S): 6-15
WN: 0406208151002

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