Postsecondary Education for Students with Intellectual and Developmental Disabilities: A Critical Review of the State of Knowledge and a Taxonomy to Guide Future Research

This Policy Research Brief reviews the state of knowledge and research practice in the emerging field of postsecondary education for students with intellectual and other learning-related developmental disabilities. The Brief concludes with a proposed taxonomy to better organize and structure research and program descriptions in support of an improved knowledge base. The review was conducted by Mary McEathron and Trisha Beuhring of the Evaluation Group at the University of Minnesota’s Institute on Community Integration. Support for the review was provided by the National Institute on Disability and Rehabilitation Research through funding for the Research and Training Center on Community Living. For further information contact Mary at mceat001@umn.edu or (612) 624-1450.

Introduction

Postsecondary education (PSE) has long been considered a pathway to community inclusion, independent living, and competitive employment for persons with intellectual and developmental disabilities (IDD), just as it has been for the general population. PSE for persons with IDD is on the cusp of substantial growth, thanks to new federal legislation and a major grant initiative that will make higher education more available, inclusive, and supportive (see Higher Education Opportunity Act, 2008; Weir, et al., 2011; Office of Postsecondary Education, 2010). To realize the potential afforded by these new commitments, research needs to keep pace with emerging practice.

In November 2009, the National Institute on Disability and Rehabilitation Research (NIDRR) and the Office of Postsecondary Education (OPE) in the U.S. Department of Education hosted a State of the Science Conference on Postsecondary Education for Students with Intellectual Disabilities. The consensus at that conference was that the field was at a critical juncture. Knowledge about the characteristics of current programs, their participants and their outcomes was viewed as far too limited to determine to what extent, in what areas, and for what reasons PSE may be yielding benefits for persons with IDD. In noting the need for an improved knowledge base, a taxonomy or classification scheme that could be used to describe PSE programs in a way that furthers an understanding of them was viewed as an important early stage to systematic research (State of the Science Conference Proceedings, 2009).

In the summer of 2010, a team of researchers from the University of Minnesota began work on a taxonomy for the field based on these identified needs.

They reviewed current knowledge and research practice to establish the components of a taxonomy that would sufficiently and accurately describe the characteristics of students with IDD, the programs they attended, the diversity of program goals, and the diversity of activities and experience related to achieving program goals. In the process, the review identified untested assumptions, critical gaps in knowledge, and inconsistencies in the definition of key terms. The taxonomy was designed with both the available information and these unresolved issues in mind.

State of the Field

Review of Existing Programs

Information on PSE programs for persons with IDD has been summarized in two comprehensive literature reviews, one...
covering the 1970’s through 2000 (Neubert et al., 2001) and the other covering 2001 through 2010 (Thoma et al., 2011). A new resource, the Think College database (http://thinkcollege.net), also provides information on active PSE programs around the country. These are informative sources for the current state of programming; however, they are limited in their ability to provide information about the state of knowledge regarding PSE for persons with IDD or taxonomical organization for past and future research on the topic. This section briefly describes those resources.

Programs Identified in Literature Reviews

The first comprehensive literature review (Neubert et al., 2001) found only 13 PSE programs designed for individuals with intellectual and other significant disabilities in peer-reviewed journal articles published between 1972 and 2000. The second (Thoma et al., 2011) identified 47 studies published during the subsequent decade. While most were descriptive studies, less than half reported enough information on student and program characteristics to be useful in developing the taxonomic model. Both reviews acknowledged that many more programs existed than were covered in journal articles, technical reports or on Web sites.

Think College Program Database

The Think College database contains information on active PSE programs that enroll individuals with IDD (see http://thinkcollege.net). The information in the database was obtained in 2009 through a national survey of PSE institutions conducted by the Institute for Community Inclusion at the University of Massachusetts Boston. The Web site notes that it is not an exhaustive list, containing only those institutions that completed the survey. In November 2010, it provided information on 139 PSE programs for youth with IDD. However, the Think College database had significant limitations for understanding the nature of existing PSE programs because the entries varied considerably in type, detail, and accuracy. For example, key terms, such as “mild intellectual disability” and “fully inclusive education” were used inconsistently. In addition, a quarter of the responding programs were concentrated in four of the country’s largest states (California, Pennsylvania, Ohio, and Texas). This raises questions about the comprehensiveness and representativeness of responding programs.

Issues in the Research Literature

Examination of the studies cited in the literature reviews was conducted to determine additional elements — such as characteristics of enrolled students, contextual factors, and intended outcomes — that would inform the development of a taxonomy that could capture and classify the full range of PSE programs for students with IDD. It was difficult to draw conclusions, however, because published research on the effectiveness of PSE for persons with IDD relies largely on single-case studies or qualitative analyses of small samples (see Hughson, Moodie & Uditsky, 2006; Neubert et al., 2001; Thoma et al., 2011). As a result, there are major gaps in knowledge, inconsistencies in how samples and programs are defined, and untested assumptions about the benefits of PSE for persons with IDD. This section provides a brief summary of some of the issues, and their implications for creating a solid research foundation on PSE programs for students with IDD.

Characteristics of the Study Population

Although current definitions of disability focus on function rather than categorical diagnoses (WHO, 2001) it is important to acknowledge that degree of intellectual disability is associated with differences in the PSE experience of individuals, the supports required, and the range of desired and potential outcomes. There is added relevance because of a disparity in how the term “intellectual disability” (ID) is understood in clinical, educational and social service settings, and how the term is used in PSE research studies.

The narrow definition of ID cited by medical, psychological, and IDD professional groups (e.g., AAIDD, 2010; DSM-V, 2010; Merck’s Manual, 2010; NICHCY, 2010) is a profile of skill assets and deficits (formerly labeled mental retardation) including: (a) intellectual deficits that are at least two standard deviations below the general population average on a standardized measure of intellectual functioning (generally an IQ of 70 or below); and (b) concurrent limitations of two or more standard deviations in at least two areas of adaptive functioning — conceptual skills (communication, language, time, money, academic); social skills (interpersonal skills, social responsibility, recreation, friendships); and/or practical skills (daily living skills, work, travel). By contrast, PSE research studies typically recruit heterogeneous samples that include persons for whom ID is a secondary feature of unspecified severity, including Autism Spectrum Disorder, epilepsy, cerebral palsy, “significant disabilities,” and “significant learning disabilities” (e.g., Anderson & Fraser, 2008; Hart et al., 2004; Migliore & Butterworth, 2009; Neubert, Moon & Grigal, 2004; Wei, 2004; Zafft, Hart & Zimblich, 2004; also see Neubert et al., 2001, and Thoma et al., 2011). This means the study samples are likely to include students with “borderline” to normal intellectual ability and higher levels of adaptive functioning overall than is typical of individuals in clinically defined ID groups.

This heterogeneity matters because students with different profiles face different challenges in the PSE setting. For example, students with narrowly defined ID are challenged academically in the area of their core disability (but may have normative social skills), while individuals with Autism Spectrum Disorder are challenged socially in the area of their core disability but may have normative
intellectual ability. Such different profiles can carry quite different demands for accommodation and individualized supports. They are also likely to be associated with different social, independent living, academic, and employment outcomes. Thus using a broad definition of "intellectual disability" in PSE studies, without specifying the characteristics of the research sample, can make it difficult to learn what works, what doesn’t work, with whom and why. It raises questions about the generalizability of PSE-related outcomes to youth and young adults with clinically-defined ID, especially those with different degrees of intellectual impairment.

This impression also invites misunderstanding when clinicians, advocates, and policy makers — operating from a formal understanding of ID — are informed that positive outcomes in community inclusion, independent living, academics, and competitive employment are attributable to a PSE program for students with intellectual disabilities when the program includes only a subset of students whose intellectual limitations are as significant as consumers of ID, especially those with different degrees of intellectual impairment.

Characteristics of Postsecondary Institutions

Programs at two-year community and technical colleges differ from programs at four-year institutions in multiple ways, including affordability, enrollment policies (open versus selective admission), academic emphasis (vocational versus general education), range of disciplines offered, depth of course offerings, extent of disability support services, and diversity of the social context (intellectual abilities of peers, independent living options, etc.). There is also variability within categories of two-year and four-year institutions (e.g., technical and community college programs typically have very different goals). The variability overall in the educational, vocational, social, and independent living activities among programs makes type of institution a potentially important contextual factor.

Selection Biases

Institutional context has an influence on who is enrolled as well as on program characteristics, and selection factors introduce biases that must be taken into account when describing and evaluating outcomes of different programs. Most two-year community and technical colleges have open enrollment, so self-selection factors (e.g., motivation, interest, perseverance, severity of IDD) influence both PSE-related outcomes (e.g., who obtains a certificate, who drops out) and the ultimate outcomes that PSE presumably impacts (e.g., who obtains competitive employment). Programs at four-year colleges and universities compound these self-selection biases with institutional selection biases. The students they admit are typically selected for success. One program, for example, selects students with IDD who have a profile of personal and family strengths: highly motivated, behaviorally non-disruptive, sufficient social skills to fit in, appropriate academic preparation, and strong family support. Whatever the criteria, as few as 15% to 20% of applicants are accepted in some university programs designed for persons with IDD. Strive University, for example, accepted only 10 out of 68 applicants with IDD one year, based on a competitive application process (see Schmidt, 2005). MasonLIFE tells applicants that only 20% are typically accepted each year (MasonLIFE, 2011). Selective admission policies greatly improve the students’ chance of success but severely limit the generalizability of program outcomes to youth with IDD who do not meet their highly selective admission criteria.

Evidence about who typically succeeds at which type of institution, and why could have a major impact on policy and practice, ultimately improving the person-program fit and the program-institution fit. Evidence on which factors contribute to self-selection biases and to selective admission decisions might also be used to design PSE-preparation programs that will improve the likelihood of success at both types of institutions. Consequently, personal characteristics and family context must be incorporated into a taxonomy for PSE research to capture such potentially influential moderating variables.

Study Samples

The existing literature indicates that PSE programs for persons with IDD typically enroll a relatively small number of students per year (see Hughson et al., 2006; Neubert et al., 2001; Thoma et al., 2011). Many assume this is due to the low prevalence of intellectual disability in the general population, which ranges from 1% to 2% depending on age cohort and the operational definition of intellectual disability (see Larson et al., 2001; Merck’s Manual, 2010; NICHCY, 2010). Even using the most conservative estimates, if the number of applicants reported by Strive University and MasonLIFE are representative of what other institutions experience (i.e., 50 to 70 applicants per year), then the size and number of PSE programs that offer the personalized supports needed by students with IDD are insufficient to meet the demand.

That may change over time, as the new legislation and grant-supported investment in demonstration projects makes PSE for persons with IDD both more affordable and more widely accepted (see HEOA, 2008; OPE, 2010). Meanwhile, small heterogeneous samples will continue to present challenges to improving the research foundation that informs practice. Progress will require an ongoing dialogue between practitioners and researchers, including creative solutions in measurement, qualitative analysis, and statistical hypothesis testing. The literature includes some examples that could be used as a starting point, such as case-specific reporting of links between PSE program activities and outcomes (see Hughson et al., 2006; Noyes and Saxe, 2004; Saloviita, 2000) and the use of interviews to determine
whether employers considered, or even knew about, the student's PSE experience when making an employment decision (see Hughson et al., 2006).

Employment Outcomes

Improved employment opportunities are one of many reasons that people seek higher education (Baum & Ma, 2007). Employment has also been identified in federal statutes as a key goal for persons with IDD (see EEOC, 2010; HEOA, 2008). However, the few PSE studies that have reported employment-related outcomes typically relied on samples that were very small or that were large but highly heterogeneous. Few of the small studies reported case-specific qualitative results, while large studies typically aggregated outcomes for their heterogeneous samples rather than breaking results out by type or severity of IDD. As a result, there is no way to determine from the literature whether there are employment benefits associated with PSE, and if so for whom and to what extent. Nor is there any way to determine which program characteristics are associated with positive employment outcomes.

What the limited available data suggest is that the relationship between PSE and employment may be more modest than what is seen in the general population. For example, the only PSE study that included a comparison group (Zafft et al., 2004) found no statistically reliable differences in employment outcomes between a heterogeneous sample of 20 adolescents with IDD who received some PSE and a matched group of 20 adolescents with IDD who did not. The single exception was within the small subset of youth who had received PSE and also found a job: They were more likely to be in competitive than sheltered employment. It was not clear, however, whether finding a job in the first place was related to their PSE experiences or to differences in personal characteristics (e.g., motivation, family support, type or severity of IDD).

Secondary analyses of large datasets have also been inconclusive, in part because they compare intact groups that are subject to intense self-selection biases. In one study of national Vocational Rehabilitation (VR) data, for example, the 1.5% of youth with IDD who completed a PSE program included many who earned a B.A., M.A., or higher (Migliore & Butterworth, 2009). Thus it is not reasonable to treat the higher earnings of an intensely self-selected subgroup as evidence that PSE alone improves employment outcomes for youth with IDD.

That positive employment outcomes may be attenuated when PSE is included in the rehabilitation plan, rather than left to self-selection, is illustrated by a VR study in Maine. Among persons with all types of disabilities, the 20% of individuals who received some PSE services as part of their individualized employment plan did not, as a group, have appreciably better employment outcomes in the short term or long term than persons with disabilities who did not receive any PSE services at all (Anderson & Fraser, 2008). This despite the fact that they were more likely to have physical than intellectual disabilities, were in VR longer, and cost more to serve. But, again, the lack of information about how much PSE they received, and differences in personal characteristics, makes it difficult to interpret the weak relationship between PSE and employment outcomes.

As these studies illustrate, research needs to identify how employment outcomes vary for students with different profiles of personal characteristics, including motivation and the degree of intellectual disability. Research must also attend to differences in the PSE experience (e.g., length of program participation and type of coursework) and its association with employment outcomes. As in the general population, it is possible that there is a threshold below which no benefit is seen. Finally, a better understanding of the relationship between PSE and employment will require an assessment of how PSE impacts social skills, mental health, independent living skills and other areas of adaptive functioning that serve as moderators (qualifiers) or mediators (conduits) of PSE's impact on employment.

Defining Activities and Outcomes

Another fundamental barrier to understanding the effects of PSE are the inconsistencies in definitions of employment, independent living, community inclusion and other PSE-related outcomes, when such outcomes are addressed at all. Without some level of consistency, it is not possible to compare outcomes across studies or conduct meta analyses to establish links between program activities and various outcomes for persons with IDD. For example, there is no consistency across studies in the indicators used to assess employment outcomes. Researchers have variously looked at lag time until employed, type of job, amount of employment, duration of employment, amount of remuneration, amount of job-related supports, career potential, supplemental or replacement income, and reasons for unemployment. While these are all informative, the relationship between PSE and employment outcomes may look different depending on which indicator is used. For example, Smith and Lugas (2010) reported that youth with autism were more likely than youth with other intellectual disabilities to find a job upon exiting VR, but they worked fewer hours and earned less. As a result of such complex findings, recent studies have cautioned about the need to report multiple indicators to get a complete picture of how PSE is related to employment (Domin & Migliore, 2010; Smith & Lugas, 2010; also see Anderson & Fraser, 2008). Even more helpful would be the use of indicators that reveal whether PSE was causal or merely a correlate of those outcomes. For example, did the employer consider, or even know about, the individual's PSE experience; was the job in the student's academic field of study; did social skills play a role in obtaining and retaining a job (see Hughson et al., 2006)?

There is a comparable inconsistency in defining PSE program characteristics and activities. "Inclusion," for example, has been variously defined as simply being on campus, as the instructor giving equal attention to students
with IDD as to those without disabilities, and as the percent of time spent in classes with students without intellectual disabilities. In sum, a body of research cannot be meaningfully aggregated until there is considerably greater consensus and consistency in how key program characteristics, activities, and outcomes are defined in practice.

Unintended Consequences

The transition into PSE is stressful for the general college population (see Gabriel, 2010), so it should not be surprising that adjusting to the social pressures of PSE and adult living are also stressful for college students with disabilities (Webb et al., 2008). The importance of taking the potential for unintended negative outcomes into account is underscored by evidence that youth with IDD are more likely than those in the general population to experience emotional, behavioral, medical, or psychiatric disorders (NICHD, 2010). Although the issue has not been researched yet in PSE for youth with IDD, a growing body of literature in other fields has convincingly demonstrated that social, educational, and mental health programs produce varied and sometimes unintended outcomes that need to be better understood through research (e.g., Ashcroft et al., 2003; Dishion et al., 1999; McCord, 2003).

Cost/Benefit Tradeoffs

The only available evidence on cost/benefit tradeoffs is mixed, limited by a failure to take into account the amount of PSE completed, long-term employment outcomes, and the role of personal characteristics, such as motivation and the profile of functional strengths and deficits of the participating individuals with IDD. It is possible that structured programs for persons with IDD, such as those being developed under the Transition and Postsecondary Programs for Students with Intellectual Disabilities initiative (Office of Postsecondary Education, 2010) will lead to clear evidence of improved outcomes. Whether the improved outcomes will be sufficient to offset the additional costs of a structured program is a return-on-investment question that the field needs to answer in order to maintain the support of administrators and policymakers. This is particularly true for programs at four-year institutions, where tuition and campus residential costs can exceed $50,000 per year (Schmidt, 2005).

Offsetting savings that flow from PSE-related improvements in employment (a pathway to independent living and economic self-sufficiency), as well as improved mental health and adaptive functioning (quality-of-life indicators with implications for employment success and reduced treatment costs), do not have to be substantial in the short term in order to pay back the investment in PSE over a youth's lifetime, perhaps in multiples of the original expenditure (see Aos et al., 2004; Cohen, 1998). However, the financial return on investment does need to apply — or have the potential to apply — to a sufficient number of youth with IDD to make long term investments in PSE programs worthwhile from a policy standpoint.

Policy implications may be unexpected (Aos et al., 1998, Table 1). For example, programs at two-year community and technical colleges might have poorer outcomes than programs at four-year colleges and universities, but better return on investment and external validity because their tuition is less, they take half the time to complete, and their students are more representative of the population of persons with IDD as a whole. A more in-depth examination of existing programs and longitudinal research are needed to test these hypotheses.

2009 Conference Proceedings

The 2009 State of the Science Conference brought together researchers, professionals, and advocates from around the country to discuss the current state of the field and what was needed to move the field forward. At the request of, and with support from, the National Institute on Disability and Rehabilitation Research (NIDRR), a thematic analysis of the official conference transcripts was conducted to identify components and characteristics of students and programs that would be useful in building a taxonomy for research on PSE for students with IDD. Of the 13 issue categories identified, three dominated the discussions: (1) characteristics of students (i.e., personal skills and characteristics, type of disability, other demographics, self-determination, matriculating or not, guardianship, level of disclosure, and International Classification of Functioning with focus on context); (2) outcomes (i.e., student outcomes ranging from social skills to employment, and the links among outcomes; student personal goals versus program goals; what to measure and how; changes in other students; return on investment; and factors that impede measuring outcomes, such as the need for data on long-term outcomes and negative outcomes, variability of programs and students, and lack of apparent connection between program activities and desired outcomes); and (3) system or environmental factors (institutional policy, state policy, funding; mechanism or rationale for creating a program; connection with current program and resources; overall factors; and disability field).

Participant comments echoed limitations observed in the research literature and underscored the importance of designing a taxonomy that captures interactions among student characteristics, contextual factors, and program characteristics as well as the importance of measuring a broad range of potential outcomes.

An Ecological Model of Disability

Both the literature review, and the analysis of the 2009 State of the Science Conference proceedings, highlighted the role of individual and contextual factors in determining how students with different personal characteristics may fit with various programs, and how
different programs may fit with various types of institutions. This is in the tradition of an ecological model of human development that has guided research on social science and educational interventions for decades (e.g., Baum & Lynggaard 2006; Bronfenbrenner, 1989, 2006). The same perspective is reflected in the international definition of disability (WHO, 2001).

The ICF is a system for classifying components of disability and functioning that differs from classic diagnostic systems in three ways. Rather than provide a single-focus categorical diagnosis, it provides a comprehensive profile of the individual’s abilities/disabilities and functional strengths/deficits, taking severity into account. Second, like Bronfenbrenner’s ecological model of normative development, the profile is viewed as an interaction between personal characteristics and contextual influences that range from family, peers, and community to the influence of cultural attitudes and expectations (see Figure 1). Also like Bronfenbrenner’s model, the profile is viewed as dynamic over time rather than as static.

This theoretical perspective on disability as a dynamic profile is better suited to the current state of research on PSE and other interventions for persons with IDD (see the social-ecological model introduced in Calkins et al., 2011, and the social model of disability in Hughson et al., 2006). The profile concept is also a better fit for the heterogeneous samples that typify the literature in this area, where IDD is sometimes the core disability (i.e., a clinically defined intellectual disability) but more often is a secondary characteristic that is likely to include marginal to average intellectual functioning (e.g., “high-functioning” autism, cerebral palsy, epilepsy, “significant learning disabilities”).

In addition, the dynamic interplay between person and context is a better characterization of the importance of academic preparation, individualized supports, and the potential for modifying outcomes for persons with IDD so that they might live more independently, participate more fully in inclusive educational and community settings, and reap some of the employment and quality-of-life benefits that are reported for their peers without disabilities who enter and complete a postsecondary college or university program. In keeping with this schema, the authors have used an ecological model of disability to define both the elements of the proposed taxonomy and hypotheses about links among the elements.
PSE Taxonomy

A more standardized approach to PSE research and program description, as provided by a taxonomy, is essential to creating a coherent knowledge base for the emerging field of PSE for persons with IDD. The preceding review of existing programs, analysis of the research literature, and thematic analysis of discussions at the 2009 State of the Science Conference was used to develop a proposed taxonomy. In addition, a limited round of interviews was conducted with program directors and leaders in the field to obtain feedback on the taxonomy.

The proposed PSE Taxonomy is composed of three interconnected parts: (1) a taxonomic diagram illustrating connections among program elements; (2) a prototype database that parallels the taxonomic diagram that will be populated with data from PSE programs in the field; and (3) an overall program model illustrating connections among student characteristics, program activity domains, and outcomes. The taxonomy incorporates the major activities and outcomes discussed in the field. Consistent with current practice in PSE programs, it is applicable to heterogeneous samples of students for whom intellectual deficits may be either the primary or secondary disability. The taxonomy is embedded in an ecological theory of disability that is consistent with the international view of disability as a dynamic interaction between personal characteristics and contextual influences (WHO, 2001). Finally, it complements current approaches of theory-driven program evaluation which use logic models to specify hypothesized links among program activities and desired outcomes (see Chen, 1990).

The taxonomy’s value for future research lies in (1) focusing attention on how PSE programs cluster based on shared characteristics; (2) identifying hypothesized links between program activities and an array of student, family, institutional and societal outcomes; and (3) determining how individual and contextual factors may modify program effectiveness. The taxonomy provides a framework for organizing information about PSE programs for persons with IDD in order to create an evidence base on key elements of PSE programs, links between program activities and program outcomes, and individual and contextual factors that are associated with outcomes.

Program Elements of the Taxonomy

The proposed taxonomic diagram is shown in Figure 2. Once fully developed, the taxonomy could be used to identify and clarify which elements are present in a program and how those elements are being implemented. For example, programs could be grouped by characteristics of persons with IDD they serve, the degree of person-centered planning they provide, or the type of institution in which they are housed. Within each grouping or classification, programs may have any combination of academic, vocational, social, or independent living activities. Variability within elements or activity domains can also be determined, such as whether independent living activities are implemented via dormitory experiences, off-campus living arrangements with roommates, or other arrangements. By delineating those variations, we would be better able to classify or group different types of PSE programs.

Clustering programs based on similarities and differences would help move the field forward in several ways. Ideally, all PSE programs attend to the four domains — academic, vocational, social and independent living — identified in the Higher Education Opportunity Act (2008) as goals of PSE for persons with ID or other significant cognitive disabilities. However, reviews of research and program descriptions indicate these domains are not all evident in many of the existing programs. Still, much can be learned from these less-than-comprehensive programs. Clustering programs based on the domains they do incorporate into their model, and clarifying the specific activities that define each domain, will help reveal which program elements are important to obtaining which PSE outcomes, and whether there is synergism among the activity domains.

Clustering also provides testable hypotheses about how different program structures affect outcomes. Similarities among programs within a cluster will indicate where it may be appropriate to combine samples or compare outcomes (as in the case of meta analyses). Differences among clusters may reveal how contextual factors are placing limits on what a PSE program can offer persons with IDD (e.g., inclusive on-campus housing is seldom an option at two-year institutions). Finally, the elements of the taxonomy provide a common frame of reference for summarizing program characteristics so that counselors, families and self-advocates can make a more informed decision about which cluster of programs is likely to offer the best person-program fit.

Table 1 presents hypothetical programs in a table format to illustrate how groups of PSE programs might cluster according to whether they are housed in two-year versus four-year institutions. Like the literature review and comments made at the 2009 State of the Science Conference, these hypothetical profiles suggest that the institutional context in which a PSE program is housed will have a major impact on the nature of the PSE experience. Outcomes like employment and social inclusion may vary as a result. Of course, whether outcomes vary depending on the type of institution in which the PSE program is located has not yet been studied. Future research regarding how contextual and other factors modify program outcomes will permit refinements in the PSE Taxonomy based on factors of demonstrated importance.

Hypothesized Links Within the Taxonomy

Identifying similarities and differences among PSE programs based on their activities and characteristics is not in
itself of particular value for moving the field forward. Its value derives from contributing to identifying testable hypotheses about causal relationships among program elements and program outcomes. That is the purpose of the third part of the taxonomy, the proposed PSE Program Model (Figure 3).

Within a given cluster of programs, it should be possible to identify a common set of hypothesized links that can be tested in each cluster’s constituent programs. The strength of research support for a causal relationship would be determined in part by the extent to which similar programs obtain similar outcomes after controlling for incidental differences in their student population, families, institutional policies, geographical location, and so forth. A search for individual and contextual factors that moderate (qualify) program outcomes will be indicated if the hypothesized link between activities and outcomes receives inconsistent support across programs within a cluster. Comparing employment and other outcomes across different clusters of programs will help identify what is, and what is not, a valuable element of PSE programs for persons with IDD.

The PSE Program Model can be helpful in other ways. It encourages researchers to specify their assumptions about expected relationships among the elements and outcomes. For example, it is a testable hypothesis whether improved social skills lead to improved employment outcomes as well as to greater integration into the community. The model also specifies an order in how clusters are defined, as indicated by branches in the diagram. The order of importance for distinctions among programs is itself a testable hypothesis. For example, the hypothesized importance of clustering two-year and four-year programs is made explicit in Figure 2, where it is presented as the first branch, or major decision point, for entering students with IDD. Subsequent research may indicate that the type of institution is not that important, say by demonstrating that outcomes do not vary much between two- and four-year institutions. Alternatively, future research may reveal that different institutional settings generally promote very different sets of outcomes. Thus, determining the importance of institutional setting in determining activities and outcomes could have a dramatic impact on the direction of PSE programs for persons with IDD in the future.

Documenting Evolution of Programs and the Field

A final advantage of a taxonomy is that it can serve as a framework for thinking through program refinements in response to evaluation outcomes. Should elements be added to the program’s logic model or deleted? Should additional links be considered and tested? Should the program consider adding some activities and dropping others based on the growing body of research about what works and what doesn’t work? The proposed PSE Taxonomy itself can be, and presumably would be, revised over time to reflect growing knowledge in the field about which elements of PSE

---

**Table 1. Hypothetical Clustering of Programs Based on Program Elements**

<table>
<thead>
<tr>
<th>Program Name</th>
<th>Institution</th>
<th>Entrance/Application</th>
<th>Source of Supports</th>
<th>Person Centered Planning</th>
<th>Individualized Supports</th>
<th>Academic Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2-Year</td>
<td>4-Year</td>
<td>Other</td>
<td>Open Enrollment</td>
<td>Competitive</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Program Inclusion Staff</td>
<td>Disability Services</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>External</td>
<td>Degree of:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Degree of:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Courses w/ Non-disabled Students</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Courses w/ Disabled Students</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>College Readiness Courses</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program</th>
<th>2-Year</th>
<th>4-Year</th>
<th>Other</th>
<th>Open Enrollment</th>
<th>Competitive</th>
<th>Program Inclusion Staff</th>
<th>Disability Services</th>
<th>External</th>
<th>Degree of:</th>
<th>Degree of:</th>
<th>Courses w/ Non-disabled Students</th>
<th>Courses w/ Disabled Students</th>
<th>College Readiness Courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>10</td>
<td>10</td>
<td>25%</td>
<td>75%</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>7</td>
<td>8</td>
<td>50%</td>
<td>50%</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>3</td>
<td>4</td>
<td>50%</td>
<td>50%</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>100%</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

**Table 2. Hypothetical Clustering of Programs Based on Social Domain**

<table>
<thead>
<tr>
<th>Program Name</th>
<th>Social Domain</th>
<th>Independent Living Domain</th>
<th>Vocational Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Social Skills</td>
<td>Other Independent Living</td>
<td>Vocational Courses</td>
</tr>
<tr>
<td></td>
<td>Courses</td>
<td>Dormitory</td>
<td>Courses</td>
</tr>
<tr>
<td></td>
<td>Clubs /Sports</td>
<td></td>
<td>Courses</td>
</tr>
<tr>
<td></td>
<td>Peer Interaction Opportunities</td>
<td></td>
<td>Courses</td>
</tr>
<tr>
<td></td>
<td>Life Skills Courses</td>
<td></td>
<td>Courses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Courses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Courses</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program</th>
<th>Social Skills Courses</th>
<th>Other Independent Living</th>
<th>Vocational Courses</th>
<th>Internships</th>
<th>Job Shadowing</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>V-VC (Credits)</td>
<td>V-I</td>
</tr>
<tr>
<td>B</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>V-VC (Credits)</td>
<td>V-I</td>
</tr>
<tr>
<td>C</td>
<td>X</td>
<td>7</td>
<td>X</td>
<td>V-VC (Credits)</td>
<td>V-I</td>
</tr>
<tr>
<td>D</td>
<td>X</td>
<td>2</td>
<td>X</td>
<td>V-VC (Credits)</td>
<td>V-I</td>
</tr>
</tbody>
</table>
Figure 3. Overall Program Diagram

PSE Program at:
- 2-Year Institution
- 4-Year Institution
- Other Institutions

Program Activities Affect These 4 Domains:
- Independent Living Domain
- Social Domain
- Academic Domain
- Vocational Domain

Student Outcomes:
- Lifelong Friendships
- Improved Social Skills
- Development of Independence
- Greater Self-Determination
- Completion Certificate or Degree
- Analogous PSE Experience
- Rewarding Employment

Institutional/Other Outcomes:
- Change in Faculty
- Change in Other Students
- Change in Peer Volunteers
- Change in Family
- Change in Institutional Policy

Long-term Potential Outcomes for Students:
- Long-Term Economic Benefits
- Better Health and Longevity
- Improved Emotional Wellbeing
- More Participation in Civic Life

Individual Factors That Can Influence Outcomes:
- Academic Preparation
- Type/Severity of Disability
- Motivation

Contextual Factors That Can Influence Outcomes:
- Family Resources
- Parental Support
- Institutional Policy
- Effective Transition Planning

Student with ID/DD
programs for persons with IDD are essential, what types of programs cluster and their importance as decision points, which links between activities and outcomes have (or lack) research support, and the role that personal and contextual factors such as type of IDD, family support, and institutional policy play in moderating (qualifying) PSE program outcomes.

Conclusion and Next Steps

This Policy Research Brief proposes an organizational framework for understanding the characteristics of PSE programs for persons with IDD and the relationship of those characteristics to outcomes. The adoption of such a taxonomy could increase understanding of the variety of PSE program models for persons with IDD, provide a basis for comparing outcomes across program sites, and provide a framework for future research. Using the taxonomy to cluster programs and identify testable hypotheses will invite researchers to consider new research questions that will lead to improvements in PSE programs, in person-program fit, and in program-institutional fit. As new evidence accumulates, the PSE Taxonomy itself can be modified to reflect the growing state of knowledge about whether and how various PSE programs contribute to improving the lives of persons with IDD.

A stronger research literature will provide program developers and advocates with a better foundation on which to build effective PSE programs for persons with IDD. It will provide families and self-advocates with the information they need to determine the optimal person-program fit. Eventually, evidence of return on investment will be available to help inform judgments about how to balance the complex needs of the persons with IDD and their families against the opportunities afforded them and the costs associated with those options. Some next steps towards that goal are proposed below.

Test of the PSE Taxonomy

A key next step in the process is to refine the proposed PSE Taxonomy based on information collected from a diverse set of existing PSE programs for persons with IDD. It will be important to include two-year and four-year programs that are inclusive, mixed, and substantially separate to ensure that the taxonomy is useful for describing past and current programs as well as programs under development. Once completed, an evaluation of the usefulness of the PSE Taxonomy needs to be conducted, guided by the following overarching questions: (1) the extent to which it can be used to identify meaningful similarities and differences among programs; (2) the extent to which it can be used to identify distinct clusters of programs (defined as programs within a cluster being similar to each other and different from programs in other clusters); and (3) the extent to which the type of institution — two-year community/technical college versus four-year university — defines two major clusters of programs with major policy and practice implications for the field. A tested PSE Taxonomy, including answers to the three evaluation questions that illustrate how it can be used, will then need to be shared, and continually re-evaluated to ensure that it provides a useful and widely accepted framework for guiding future research and evaluation of PSE programs.

Consensus on Research Issues

Given the embryonic nature of the field, and the lack of consensus on essential descriptors for programs, clientele, and outcomes, another key step would be to convene experts and opinion leaders on PSE for persons with IDD for the purpose of reaching consensus on operational definitions for: (1) key descriptors of sample characteristics (such as “intellectual disability”); (2) key descriptors of program characteristics and activities (such as “inclusive,” “individualized supports,” and “person-centered planning”); and (3) key outcomes and indicators for assessing the impact of PSE on persons with IDD (such as “employment,” “community inclusion,” and “independent living”). A consensus document, produced by leaders in the field, would benefit both researchers and practitioners. Following agreed-upon definitions for describing samples and programs, and incorporating a core set of outcomes and indicators into research and evaluation studies, would facilitate comparisons across studies. Such comparisons could help determine which elements of PSE programs are the most important, how personal characteristics and family or institutional context affect outcomes, and the strength of relationships between different models of PSE and an array of outcomes in this target population. An expert consensus could be particularly useful for the 27 demonstration programs funded by the Office of Postsecondary Education (OPE) in October 2010 as they work to identify a core set of outcomes and indicators that will best fit their programs’ goals. The end result could be more useful information for counselors, families, and self-advocates with IDD as they compare programs and determine their ideal person-program fit.

Longitudinal Studies

Many of the research questions posed in this brief can only be answered satisfactorily by longitudinal comparison-group studies of PSE program outcomes for individuals with IDD. Moreover, a minimum of three to five years of follow-up data on outcomes is needed to provide a meaningful foundation for cost/benefit analyses (Aos et al., 2004; CSPV, 2010), especially since there is some indication that long-term benefits of PSE for persons with disabilities may be detected even when short-term benefits are not (see Anderson & Fraser, 2008). Consequently, another step in moving toward a substantially improved knowledge base would be to use
the finalized PSE Taxonomy, and the consensus guidelines on research issues, to design a model longitudinal study. As a complementary step, designing longitudinal follow-up studies of persons with IDD who participate in the 27 demonstration projects in the Transition and Postsecondary Programs for Students with Intellectual Disabilities initiative (Office of Postsecondary Education, 2010), and organizing the information gathered from these projects, would enable the field of PSE for persons with IDD to make substantial progress, in both research and practice, over the next five to ten years.
References


Anders, N. & Fraser, K. (February 2008). Research summary: Postsecondary service use and outcomes among Maine Division of Vocational Rehabilitation clients. Available from nandero@usm.maine.edu


Impact: Feature Issue on Postsecondary Education and Students with Intellectual, Developmental and Other Disabilities (2010). Even though the majority of high school students with disabilities identified participation in postsecondary education as a goal for their adult lives, only about 3 in 10 have taken classes since completing high school (National Longitudinal Transition Study-2). And among those with the lowest rates of participation are students with intellectual disabilities. This Impact issue explores what we know, and what we still need to know, about supporting increased participation of students with disabilities—especially those with intellectual disabilities—in postsecondary education, and why that participation is important. It includes articles from families, young adults with disabilities, and professionals. Cost: Free online at http://ici.umn.edu/products/impact/233. Print copies are also available (first copy free, each additional $4) from the Institute's Publications Office at (612) 624-4512 or icipub@umn.edu.

Impact: Feature Issue on Employment and Women with Disabilities (2008). Why is work important to women with disabilities? And why do fewer women with disabilities participate in the workforce than men with disabilities or women without disabilities? These are two of the questions explored in this Impact issue. Because having meaningful, valued work is such an important part of life, this Impact encourages readers to hold an expansive vision of what’s possible for women with disabilities in the employment arena, and offers strategies, resources, and inspiration to realize that vision. Cost: Free online at http://ici.umn.edu/products/impact/111. Print copies are also available (first copy free, each additional $4) from the Publications Office at (612) 624-4512 or icipub@umn.edu.

Earning a High School Diploma Through Alternative Routes (NCEO Synthesis Report 76) (2010). By M. Thurlow, M. Vang, & D. Carmier. Earning a standard diploma has increased in importance during the past several years. Not only is it a document that improves post-school outcomes, but it also has become a part of the Elementary and Secondary Education Act (ESEA) accountability system at the high school level—with the required graduation rate including only those students who have earned a regular/standard high school diploma or higher. Complicating matters in several states is the addition of an exit exam requirement to the traditional coursework requirements. The addition of a testing requirement to other requirements for earning a standard diploma is a challenge for students who do not perform well on assessments. Many, but not all, of these students have disabilities. This report from the Institute’s National Center on Educational Outcomes is based on a study examining the alternative routes to passing the high school exit exam that were available during the school year 2008-09 to students to earn a standard high school diploma. It examines alternative routes in the 26 states with active or soon-to-be active exit exams, and documents the alternative routes available for all students and those specifically for students with disabilities. Cost: Free online at http://www.cehd.umn.edu/nceo/OnlinePubs/Synthesis76/Synthesis76.pdf.


Residential Services for Persons With Developmental Disabilities: Status and Trends Through 2009 (2010). Edited by K. C. Lakin, S. A. Larson, P. Salmi, & A. Webster. This report from the Institute’s Research and Training Center on Community Living presents statistics by state for the fiscal year ending June 30, 2009, with long-term trends, on residential services, settings, populations and expenditures for persons with developmental disabilities in state, nonstate and Medicaid-funded residential programs in the U.S. Resident characteristics, movement and staffing patterns in large state residential facilities are included. Cost: Free online at http://rtc.umn.edu/docs/rsp2009.pdf. To request a free print copy, contact Amanda Webster at (612) 626-0246 or webs0078@umn.edu.

Transition Services for Students Aged 18-21 with Intellectual Disabilities in College and Community Settings: Models and Implications of Success (NCSET Information Brief) (2006). By M. Grigal, A. Dwyre, & H. Davis. Published by the Institute’s National Center on Secondary Education and Transition, this brief provides an overview of some successful models of transition services being implemented in postsecondary settings, describes one such model implemented by the Baltimore City Public School System in three local colleges, and presents some of the implications and strategies for success of this model. Cost: Free online at http://www.ncset.org/publications/viewdesc.asp?id=3395.

Related Institute Publications

The following other resources published by the Institute on Community Integration may be of interest to readers of this Policy Research Brief.

- Impact: Feature Issue on Postsecondary Education and Students with Intellectual, Developmental and Other Disabilities (2010). Even though the majority of high school students with disabilities identify participation in postsecondary education as a goal for their adult lives, only about 3 in 10 have taken classes since completing high school (National Longitudinal Transition Study-2). And among those with the lowest rates of participation are students with intellectual disabilities. This Impact issue explores what we know, and what we still need to know, about supporting increased participation of students with disabilities—especially those with intellectual disabilities—in postsecondary education, and why that participation is important. It includes articles from families, young adults with disabilities, and professionals. Cost: Free online at http://ici.umn.edu/products/impact/233. Print copies are also available (first copy free, each additional $4) from the Institute's Publications Office at (612) 624-4512 or icipub@umn.edu.

- Impact: Feature Issue on Employment and Women with Disabilities (2008). Why is work important to women with disabilities? And why do fewer women with disabilities participate in the workforce than men with disabilities or women without disabilities? These are two of the questions explored in this Impact issue. Because having meaningful, valued work is such an important part of life, this Impact encourages readers to hold an expansive vision of what’s possible for women with disabilities in the employment arena, and offers strategies, resources, and inspiration to realize that vision. Cost: Free online at http://ici.umn.edu/products/impact/111. Print copies are also available (first copy free, each additional $4) from the Publications Office at (612) 624-4512 or icipub@umn.edu.

- Earning a High School Diploma Through Alternative Routes (NCEO Synthesis Report 76) (2010). By M. Thurlow, M. Vang, & D. Carmier. Earning a standard diploma has increased in importance during the past several years. Not only is it a document that improves post-school outcomes, but it also has become a part of the Elementary and Secondary Education Act (ESEA) accountability system at the high school level— with the required graduation rate including only those students who have earned a regular/standard high school diploma or higher. Complicating matters in several states is the addition of an exit exam requirement to the traditional coursework requirements. The addition of a testing requirement to other requirements for earning a standard diploma is a challenge for students who do not perform well on assessments. Many, but not all, of these students have disabilities. This report from the Institute’s National Center on Educational Outcomes is based on a study examining the alternative routes to passing the high school exit exam that were available during the school year 2008-09 to students to earn a standard high school diploma. It examines alternative routes in the 26 states with active or soon-to-be active exit exams, and documents the alternative routes available for all students and those specifically for students with disabilities. Cost: Free online at http://www.cehd.umn.edu/nceo/OnlinePubs/Synthesis76/Synthesis76.pdf.


- Residential Services for Persons With Developmental Disabilities: Status and Trends Through 2009 (2010). Edited by K. C. Lakin, S. A. Larson, P. Salmi, & A. Webster. This report from the Institute’s Research and Training Center on Community Living presents statistics by state for the fiscal year ending June 30, 2009, with long-term trends, on residential services, settings, populations and expenditures for persons with developmental disabilities in state, nonstate and Medicaid-funded residential programs in the U.S. Resident characteristics, movement and staffing patterns in large state residential facilities are included. Cost: Free online at http://rtc.umn.edu/docs/rsp2009.pdf. To request a free print copy, contact Amanda Webster at (612) 626-0246 or webs0078@umn.edu.

- Transition Services for Students Aged 18-21 with Intellectual Disabilities in College and Community Settings: Models and Implications of Success (NCSET Information Brief) (2006). By M. Grigal, A. Dwyre, & H. Davis. Published by the Institute’s National Center on Secondary Education and Transition, this brief provides an overview of some successful models of transition services being implemented in postsecondary settings, describes one such model implemented by the Baltimore City Public School System in three local colleges, and presents some of the implications and strategies for success of this model. Cost: Free online at http://www.ncset.org/publications/viewdesc.asp?id=3395.
You may be wondering why...

...you have received this newsletter. With each issue we mail not only to our regular readers, but also to others whom we believe will find the information useful. If you would like to receive every issue of this publication, or be added to our ICI Updates e-mail list to receive monthly updates on new resources, contact our Publications Office at (612) 624-4512 or icipub@umn.edu. For additional information about our projects and publications, you can also visit our Web site and online catalog at http://ici.umn.edu.

Policy Research Brief on the Web

This and other issues of Policy Research Brief are also published online at http://ici.umn.edu/products/newsletters.html#policy. Available issues include:

- Implementation of Consumer-Directed Services for Persons With Intellectual or Developmental Disabilities: A National Study
- Innovative Models and Best Practices in Case Management and Support Coordination
- A Qualitative Study of the Experiences of Transition-Age Youth With Disabilities in Relation to SSI Redetermination
- The Inclusion of Disability as Grounds for Termination of Parental Rights in State Codes

The opinions expressed in Policy Research Brief are those of the authors and do not necessarily reflect the position of the Center or its funding sources.

Policy Research Brief is available online at http://ici.umn.edu/products/newsletters.html#policy. Additional copies are also available for purchase from:

Publications Office
Institute on Community Integration
University of Minnesota
109 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455
Phone: (612) 624-4512
E-mail: icipub@umn.edu

Policy Research Brief is available in alternative formats; to request an alternative format, contact the Publications Office.

The University of Minnesota is an equal opportunity employer and educator.