Family Perspectives on Post-Secondary Education for Students with Intellectual Disabilities

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Abstract: This study investigated the issues that families consider when making decisions regarding post-secondary education (PSE) for young adults with intellectual disabilities. Survey respondents were 108 family members of transition-aged students with intellectual disabilities. Although respondents were generally positive about PSE programs, they reported that educators’ attitudes were less supportive. Respondents identified many barriers that prevent their understanding of PSE options, but a lack of information and guidance was the barrier cited by the most respondents. When considering PSE options, respondents were most concerned about student safety, and they considered a focus on employment to be the most important program component. Continued research is needed to investigate the factors critical in developing successful PSE programs for students with intellectual disabilities.

Although recent decades have seen a shift toward providing inclusive, age-appropriate educational opportunities for students with intellectual disabilities (Neubert, Moon, Grigal, & Redd, 2001), prospects after high school remain bleak for these students, many of whom experience segregation and social isolation (Chambers, Hughes, & Carter, 2004). In fact, of all students with disabilities, those with intellectual disabilities are the least likely to be involved in job training, paid employment, or education after high school (Wagner, Newman, Cameto, Garza, & Levine, 2005). As an alternative to such poor post-school outcomes, a movement has arisen to provide these young adults with inclusive post-secondary education (PSE) options. Now numbering over 150 across the United States, PSE programs are located on college campuses and allow students with intellectual disabilities to continue their education alongside typical peers (Consortium for PSE for Individuals with Developmental Disabilities, 2009). In PSE programs, students learn academic material, expand social networks, gain employment skills, and develop independence. Although colleges have historically excluded students with intellectual disabilities, PSE programs offer these students an alternative to traditional college admission and participation (Hart, Grigal, Sax, Martinez, & Will, 2006).

As more PSE programs become available, families are increasingly considering this option (Neubert et al., 2001; Hart et al., 2006). Since families, particularly parents, are instrumental in transition planning, understanding their perspectives can improve the approaches taken by educators and service providers (Chambers et al., 2004; Lehmann, Bassett, & Sands, 1999; Morningstar, Turnbull, & Turnbull, 1995). In prior studies, researchers have focused on general transition outcomes for students with intellectual disabilities compared to typical students (Whitney-Thomas & Hanley-Maxwell, 1996) and to students with other disabilities (Polat, Kalamouka, Boyle, & Nelson, 2001; Wagner et al., 2005). Not surprisingly,
parents of students with intellectual disabilities are among the most pessimistic about transition outcomes, including PSE participation (Wagner et al.).

A smaller literature has focused specifically on the perspectives of parents of students with intellectual disabilities. For example, Kraemer and Blacher (2001) found that the primary concern for these parents is determining what the young adult will do during the day after high school; however, this study did not discuss PSE programs as a transition option. Similarly, Cooney (2002) found that parents were very concerned about the transition process, but also did not address PSE options. In a more recent study of both parent and sibling perspectives, Chambers et al. (2004) found that respondents considered PSE an important outcome, but that their knowledge of programs was limited and they did not think their family member would pursue this option. Although PSE options are increasingly available to students with intellectual disabilities, no studies have investigated the issues that families consider when making decisions regarding PSE participation.

To examine such perspectives, we surveyed families of high school students with intellectual disabilities concerning PSE program participation. We had three goals for this study. First, we wanted to determine family perceptions of transition planning, as well as determine those barriers that families encounter in learning about PSE programs. Second, we wanted to identify those demographic characteristics that might correlate with differential expectations for students after high school. Third, we wanted to examine both the concerns that families have about enrolling students in PSE programs, and the program characteristics that families consider most important. Our goal was to attain an overall sense of families’ knowledge and perceptions of PSE programs.

Method

Participants

Participants included 108 family members of transition-age students with intellectual disabilities in Tennessee. Survey respondents were excluded if they lived in a different state, or if the student was not 14–25 years old.

Family members of students with intellectual disabilities. Of the 108 respondents, 94% were parents or guardians, and 91% were female; in all, 87% of respondents were the student’s mother. The majority of respondents were White (88%); remaining respondents were 8% Black, 1% Hispanic, 1% Asian/Pacific Islander, and 2% other. The majority of respondents were 40 years or older (87%); from urban areas (81%); working part or full time (81%); and had completed college or a higher level of education (76%).

Students with intellectual disabilities. The respondents’ family members with intellectual disabilities were 66% male and 34% female. The respondents reported diagnoses of the students, and in some cases selected more than one category. Their diagnoses were: 35% Mental Retardation; 35% Autism Spectrum Disorders; 29% Developmental Disabilities; 17% Down Syndrome; 10% Cerebral Palsy; and 1% Williams Syndrome. Respondents indicated the academic ability of their family member by estimating the student’s reading level, with 32% indicating that the student reads at a First Grade level or lower; 32% between the Second and Fifth Grade level; and 36% at a Sixth Grade level or higher.

Procedure

This study was performed in collaboration with the Tennessee Task Force for Post-Secondary Education for Students with Intellectual Disabilities, a group that supports the development of PSE programs on Tennessee college campuses. The Task Force is composed of representatives from various stakeholder groups: the Vanderbilt Kennedy Center, the Tennessee Council on Developmental Disabilities; the Tennessee Division of Vocational Rehabilitation Services; community and disability advocacy groups; the public school system; higher education institutions; Tennessee’s Division of Mental Retardation Services; and involved parents and community members.

In conjunction with the Task Force, we created and distributed a survey to learn more about family perspectives toward PSE programs. The survey was designed in both elec-
tronic and print formats; it was formatted electronically using web-based survey software (Survey Gold 8). Respondents who completed the online survey first read a description of the study and an explanation that they could choose to participate or not, withdraw at any point, and skip questions. Next, respondents were directed to the survey; finally, they were asked if they would like to submit their responses. Respondents could only submit answers to the secure website if they answered this question affirmatively. Approximately 94% of participants responded via the web-based survey. The remaining respondents completed and mailed print surveys, which were then manually entered into our database.

Participants were recruited in several ways. The survey was advertised through the Vanderbilt Kennedy Center’s web-based Studyfinder; internal e-mail messages sent through Vanderbilt University Medical Center; and flyers distributed through local newsletters and at community events. In addition, various community agencies that had been involved with the Tennessee Task Force distributed the survey. Because we wanted survey respondents to be as candid as possible, we assured them that all answers would remain anonymous.

Survey Instrument

To develop the survey, we drew on prior research that had addressed post-secondary options for young adults with disabilities (Chambers et al., 2004; Kraemer & Blacher, 2001; Polat et al., 2001; Wagner et al., 2005). Survey development involved collaboration with Task Force members, including researchers, disability advocates, and family members of students with intellectual disabilities. Their feedback informed the final survey, which was composed of 50 items and divided into four sections.

1. Information about primary respondents. The first section of the survey asked 12 questions regarding demographic information about the respondent. Using either multiple-choice or open-ended formats, this section asked about the respondent’s age, gender, ethnicity, relationship to the student, place of residence, level of education, employment status, occupation, marital status, and number of children.

2. Information about the student with intellectual disabilities. Comprised of 22 questions about the student with an intellectual disability, questions in this section asked about the student’s age, gender, ethnicity, place of residence and disability diagnosis. Other questions addressed the student’s health, emotional well-being, and adaptive behavior. Questions also addressed functional abilities: respondents were asked to rate on a 5-point scale (1 = not at all; 5 = very well) how well students perform various activities (e.g. walking, speaking, eating, preparing meals, taking medications, grooming).

This section also included questions about students’ academic history, attitude toward school, and transition plan. Items about academic history concerned the student’s IEP, reading level, most recent school setting, and prospects for graduating with a regular diploma. Other questions asked respondents whether the student seems to like school, and whether the student seems interested in educational opportunities after high school. Finally, questions asked respondents how aware they are of PSE options, how they learned about them, and what barriers they encountered during this process.

3. Perspectives on PSE options. This section asked respondents about post-secondary options, and specifically about characteristics of PSE programs. Items asked respondents what their children would most likely do after high school, and whether they thought that PSE programs were a viable option. A series of questions asked respondents how concerned they were about various factors when considering PSE for their family member. On a 5-point scale (1 = not at all concerned; 5 = very concerned), respondents rated these factors (e.g. the student’s health; cost of the program; the student’s safety; the student’s ability to function without parent; similarity to a typical college experience; focus on employment after program completion; and distance of program from home).

Another series of questions asked about the degree of importance of various program components. On a 5-point scale (1 = not at all important; 5 = very important), respondents rated the degree of importance that they at-
tributed to such PSE program components as residential options; inclusive learning environments; individual choice in curriculum; structured social activities; access to a college campus; certification in a vocational area; and a focus on employment after completion of program.

4. Open-ended questions. The final section was composed of open-ended questions, including: (a) “What would help you make decisions about the options available to your child after high school?” (b) “What advice would you give to parents of younger children with intellectual disabilities to better prepare them for the transition that their children will face after high school?” and (c) “If you could design a program for your child to participate in after high school, what would it look like? What would be the most important aspects of the program?”

Data Analysis

All survey data were transferred for analysis to the Statistical Package for the Social Sciences (SPSS) 16 for Windows. First, we used descriptive analyses to determine demographic information for both the primary respondents and the students with intellectual disabilities. Next, we performed analyses of variance (ANOVAs) to test hypotheses of group differences. Finally, we employed repeated-measures ANOVAs to analyze, within individual respondents, their ratings of relative concern about aspects of PSE participation and of relative importance of different PSE program components.

Results

Parental Perspectives on Transition Planning

Descriptive findings regarding students’ transition plans indicated an inconsistency between parent and teacher perspectives. Compared to parents, who indicated that PSE opportunities would help their child transition to adulthood ($M = 4.0$, $sd = 1.25$), educators were perceived as being less encouraging of these children pursuing PSE ($M = 2.87$, $sd = 1.56$), $t (108) = 6.79$, $p < .0001$. In addition, only 26% of parents affirmed that their child’s IEP included a plan for the time immediately following high school; 53% reported that the IEP did not include this, and 21% were unsure.

Barriers to Parents Understanding PSE Options

Beyond inadequate transition planning, parents also reported many other barriers to understanding PSE options for their children. Most respondents (73%) reported a “lack of general information or guidance,” and the next most-reported barriers were “school and other staff did not help me understand” (56%), and “financial constraints” (56%). Finally, many respondents reported barriers related to services: “different services did not work well together” (30%); “long waiting list for explanation of services” (26%); and “staff from different services gave conflicting advice” (25%). Thirteen percent reported that “written and online materials were difficult to understand;” 9% of all respondents reported that they did not encounter any barriers.

Student Reading Ability as a Correlate to Parent Perspectives

Although as a group parents were generally positive about PSE, parents of students with lower reading levels were less likely to think that PSE would help their children transition to adulthood, $F(2, 104) = 10.73$, $p < .01$. Parents of these students also thought their children were less interested in educational opportunities after high school, $F(2, 104) = 13.47$, $p < .01$; were less often encouraged by school staff to pursue PSE, $F(2, 104) = 10.40$, $p < .01$; and less likely to enroll their child in PSE, $F(2, 104) = 15.44$, $p < .01$. In each of these questions, major differences were found between parents of children at the First Grade reading level or lower compared to parents whose children read at the Second-to-Fifth Grade and Sixth Grade-or-higher levels (see Figure 1).

Parental Concerns and Priorities Regarding PSE Programs

Parents also differed in their concern over various aspects of PSE participation, $F(6,
Among 7 different items, parents were by far the most concerned about their child’s safety; almost 9 in 10 respondents rated this item a “5” on a 5-point scale. Conversely, parents were less interested that the PSE program provided an experience similar to a typical college environment; this item averaged the lowest rating (3.44) and received the lowest proportion of “5” ratings (30.6%; see Table 1). Similarly, as shown in Table 2, respondents reported that the most important PSE program component involved a focus on employment, whereas the two least important program components involved access to a college campus and residential options, $F(6, 642) = 8.48$, $p < .01$.

**Open-ended Questions**

Of the 108 respondents, 94 (87%) answered at least one open-ended question.

**Transition decisions.** The first question asked respondents what would help them make transition decisions. Of the 92 respondents who answered this question, 57% answered that they needed more information to make educated decisions. Respondents noted that such information could come from a variety of sources, including teachers, service providers, PSE program representatives, and other parents. One respondent wrote, “It would be great if the school system had the information to give the parents on the options...”

**TABLE 1**

Mean Scores of the 7 Parental Concern Items, and Percent of the Sample Giving the Highest Rating (5 = Very Concerned)

<table>
<thead>
<tr>
<th>Concern Regarding PSE Programs</th>
<th>Mean</th>
<th>Percent Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your child's safety</td>
<td>4.72 (0.94)</td>
<td>88.0%</td>
</tr>
<tr>
<td>Your child’s ability to function without you</td>
<td>4.34 (1.15)</td>
<td>64.8%</td>
</tr>
<tr>
<td>Focus on employment after completion of program</td>
<td>4.29 (1.35)</td>
<td>67.6%</td>
</tr>
<tr>
<td>Cost of the program</td>
<td>4.06 (1.41)</td>
<td>61.1%</td>
</tr>
<tr>
<td>Distance of the program’s campus away from your home</td>
<td>3.94 (1.26)</td>
<td>47.2%</td>
</tr>
<tr>
<td>Your child’s physical health</td>
<td>3.81 (1.56)</td>
<td>53.7%</td>
</tr>
<tr>
<td>Program similar to a typical college experience</td>
<td>3.44 (1.55)</td>
<td>30.6%</td>
</tr>
</tbody>
</table>
for these children. The school system drops the ball with these children.” Many respondents (37%) also wrote about specific program characteristics (e.g., location, cost, safety, and employment training). Fewer (16%) mentioned student characteristics, and the importance of matching programs to the specific needs of students. Finally, 6% expressed the need for more options; as one respondent wrote, “Options should be offered. Opportunities should be everywhere, just like they are for the general public.”

Advice to other families. Of the 84 respondents that answered this question, 56% advised families to inform themselves about their rights and to plan ahead, for example, by placing the student on waiting lists for adult services early. A subset of this group (17% of respondents) advised parents to work with schools, community organizations, and other families. In contrast, 10% of all respondents advised parents not to rely on others. As one respondent wrote: “Do not wait for your guidance counselor . . . You need to be proactive and persistent in gathering this information.” A final group (15%) emphasized the importance of high expectations and individualized goals for students.

An additional 8% expressed their inability to answer the question at all, stating that they needed advice themselves. One respondent wrote, “There is not a good road map. Things have been pretty clear up to this point. Part of this is likely my own unwillingness to look at a future that feels pretty bleak. Also, I am just tired of advocating and creating opportunities out of whole cloth.”

**Discussion**

As an initial step in determining the viability of PSE programs, our findings extend prior research by investigating the perspectives of families of students with intellectual disabilities. Findings emerged in three major areas: family attitudes toward PSE options; correlates with differential attitudes toward PSE; and families’ priorities and concerns about PSE programs.

First, we found that parents considered PSE opportunities to be beneficial for their transitioning children, but that they did not think that educators encouraged this option. In comparing ratings of parent versus teacher encouragement of PSE options, parents rated themselves more interested than teachers. Most respondents (73%) lacked information and guidance about planning for PSE and, in the open-ended answers, parents wrote that school staff could do much more to facilitate

**TABLE 2**

Mean Scores of the 7 PSE Program Component Items, and Percent Giving the Highest Rating (5 = Very Important)

<table>
<thead>
<tr>
<th>Program Component</th>
<th>Mean</th>
<th>Percent Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on employment after completion of program</td>
<td>4.36 (1.15)</td>
<td>67.6%</td>
</tr>
<tr>
<td>Structured social activities</td>
<td>4.24 (1.09)</td>
<td>56.5%</td>
</tr>
<tr>
<td>Individual choice in curriculum</td>
<td>4.22 (1.12)</td>
<td>57.4%</td>
</tr>
<tr>
<td>Inclusive learning environments</td>
<td>4.08 (1.24)</td>
<td>53.7%</td>
</tr>
<tr>
<td>Opportunity for certification in a vocational area</td>
<td>4.01 (1.29)</td>
<td>50.0%</td>
</tr>
<tr>
<td>Access to a college campus</td>
<td>3.60 (1.43)</td>
<td>39.9%</td>
</tr>
<tr>
<td>Residential options</td>
<td>3.47 (1.45)</td>
<td>47.2%</td>
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</table>
PSE planning. While poor communication has been well-documented as a general barrier to effective transitions to adulthood, our survey addressed this issue specifically within the context of PSE planning. Indeed, while other studies have found that families are generally positive about PSE (Chambers et al., 2004) and have documented poor communication between parents and teachers (Lehmann et al., 1999), this survey is the first to document the barriers to PSE planning and access.

Second, parents of students with lower reading levels were less likely to think that PSE would help their children transition to adulthood. In this study, the break point was between the group of students who read at the First Grade level or lower, compared to students reading at the Second Grade level and higher. This finding mirrors results of the National Longitudinal Transition Study-2 (Wagner et al., 2005), which reported that youth with higher functional cognitive skills were more likely to participate in PSE. However, we also noted that parents of those students with the lowest reading abilities were not wholly negative about the prospect of PSE for their children. Although parents of students with the lowest reading abilities were less positive about this option, some of these parents still considered PSE for their children.

Third, we found that parents harbored both specific fears and specific expectations about PSE programs. Their major fear related to their child’s safety. Indeed, from among 7 potential concerns that we surveyed, parents consistently reported their child’s safety as the highest rated concern. As Table 1 shows, this single concern averaged close to 5 on a 5-point scale, was almost half of a standard deviation above all other concerns, and was rated the highest score by almost 90% of parents.

Although the salience of the students’ safety was somewhat surprising to us, it makes sense that parents would be most concerned about this issue. In addition to parental concerns over their child’s vulnerability (Fisher & Hodapp, 2009; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995), individuals with intellectual disabilities may actually be more likely to be abused and taken advantage of by others. As Fisher, Hodapp, and Dykens (2008) have recently noted, individuals with intellectual disabilities often display personal and familial characteristics that predispose them to abuse and exploitation; recent studies report that such individuals suffer abuse at rates from 2–10 times those noted among non-disabled individuals. Thus, while no research has yet addressed this issue in the context of PSE, concerns over safety will undoubtedly influence parental decisions about their student’s participation. PSE programs, in turn, will need to respond to parental concerns by taking appropriate measures to ensure student safety and by communicating these efforts to families.

Parents also reported a strong preference for certain PSE program characteristics. Compared to other program components, parents want PSE programs to focus on their child’s employment; indeed, post-program employment was rated as a “5” by 68% of all respondents. While other studies have also found that parents consider employment to be a primary outcome (Chambers et al., 2004; Krammer & Blacher, 2001; Whitney-Thomas & Hanley-Maxwell, 1996), none have yet addressed this issue in the context of PSE. Additionally, although many PSE programs currently include employment training, this component takes a variety of forms and is emphasized to varying degrees (Hart et al., 2006). Given our findings, PSE programs should prioritize preparation for employment as the primary outcome for their students.

In contrast, there were also program characteristics that parents did not prioritize. Most noteworthy in this regard were residential options and the program’s similarity to a typical college experience. These views from parents contrast sharply with informal conversations that we have had with potential PSE students themselves. Considering this contrast, we wonder whether parental attitudes align with the priorities of their children, who are ultimately the participants in PSE programs. Given that these students are young adults transitioning to full adulthood, understanding and honoring their perspectives seems especially critical.

Taken together, the results of this study have implications for both families and practitioners. First, parents’ limited knowledge of transition plans and PSE options is a major concern, one that needs to be addressed by high school educators, parent groups, service providers, and PSE programs. Second, given
that educators’ and parents’ post-school expectations for students may not align, there seems to be a need for more effective communication. Third, educators should offer more information about PSE options, even to families of students with lower academic skills.

Although an important first step in understanding parental perceptions of PSE programs, this study also has several limitations. First, responses were based on the reports of family members and not confirmed by school records, student observations, teacher reports, or other sources. Second, responses may reflect priorities that were specific to our sample. Although we are not certain that our respondents were more informed about PSE options than family members of other students with intellectual disabilities, their knowledge of the survey and choice to respond indicates that this may have been the case. Given that we may have surveyed a “connected” sample of parents, our findings regarding limited knowledge of PSE options are even more troubling.

Despite these limitations, this study extends the existing research by identifying barriers that families encounter when trying to understand PSE options, as well as identifying specific parental concerns and priorities regarding PSE programs. Such information has implications for families and professionals, both of whom strongly influence students with intellectual disabilities during the transition to adulthood. Our results can also inform PSE program development, providing much-needed research to guide what has become a growing national movement.

References


Received: 14 May 2009
Initial Acceptance: 18 July 2009
Final Acceptance: 15 September 2009