Parent Involvement in the Transition Process of Children With Intellectual Disabilities: The Influence of Inclusion on Parent Desires and Expectations for Postsecondary Education

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Abstract Students with disabilities and their families across the globe are increasingly setting postsecondary education (PSE) as a future goal, a relatively recent phenomenon. To supplement current knowledge on this goal, we studied parents’ means of accessing information and the impact of K-12 inclusive general education experiences on parents’ desires and expectations for PSE. Key findings indicated that parents did not fully understand the transition process and had a low degree of knowledge and access to information about PSE. The data showed that levels of student inclusion related to parental desire and expectation for PSE and to parental involvement in transition planning activities. Implications for theory, measurement, practice, and public policy include a clear need for improved information and dissemination practices regarding PSE as a transition option. The data also imply that teacher education programs would be strengthened by the inclusion of information about PSE options.

Keywords: inclusion, intellectual disability, parent involvement, postsecondary education, transition

INTRODUCTION

That students with intellectual disability (ID)† and their families might set college as a goal is relatively recent and is an increasingly important goal globally when planning for these students (OECD, 2011). This is an exciting goal for students with ID who are less likely than youth with other disabilities to be engaged in school, work, or preparation for work during the early postschool years (Wagner, Newman, Cameto, Garza, & Levine, 2005). For some students, parents’ dreams, desires, and expectations become a dynamic guide for young adults’ successful transition that may include postsecondary education (PSE) as a postschool option (Kausar, Jevne, & Sobsey, 2003). For these dreams and expectations to come to fruition, parents must know about and participate in the transition process.

Federal and state codes address parent involvement in education planning and transition supports and services for young adults with disabilities. Parents in the United States look to federal law for enabling locally provided free and appropriate public education in the least restrictive environment, leading some to high expectations of a successful transition to postsecondary outcomes (as amended, Individuals with Disabilities Education Act (IDEA), 2004). Under IDEA, the federal law, “special education services and supports, including transition services, are entitlements for eligible children and youths with disabilities in compulsory education” (U.S. Department of Education, 2010, p. 11). IDEA states that a youth’s initial transition plan be developed no later than age 16 and be oriented toward the improvement of academic and functional achievement. General and special education legislation in the United States also places an emphasis on parent involvement (IDEA, 2004; U.S. Department of Education, 2003; 2004). The education code in Virginia, the location of our study, stipulates transition planning by age 14 (Virginia Department of Education, 2011). Transition plans, developed in partnership with parents, school district staff, and various community agency representatives, determine the young adult’s special education supports, services, and postschool expectations.

Postschool options for students with ID have expanded from out-of-home make-work weekday activities in segregated congregate settings, to include continued PSE in a college or university setting (Hart, Grigal, & Weir, 2010). Wagner et al. (2005) indicated about one-third of responding parents of young adults’ with ID expected their young adults to pursue PSE after
high school. Yet while parents may desire an outcome for their young adult, professionals offer preselected “realistic” options often placing parents in the dilemma of selecting compromises that differ from their original expectations and desires (Cooney, 2002). Information about the relationship between parents’ desires and actual expectations for PSE as a postschool outcome, their access to information and their involvement in planning for their expectations to be realized, and the relationship between parent involvement in transition to other critical student educational factors is scarce (cf. McNair & Rusch, 1991).

Parent involvement in transition planning includes the means by which parents access information about postsecondary education and available career options for their young adult’s future (Griffin, McMillan, & Hodapp, 2010). Parents may find they must advocate for and initiate that access as part of their involvement in transition planning (Kim, Lee, & Morningstar, 2007). Increased parental involvement in transition planning may be a function of IDEA that encourages active participation by the parents (Kraemer & Blacher, 2001). The literature suggests parents with children included in the general education curriculum develop greater efficacy and skills as involved members of the teaming process (Hanson, 2003). However, inclusion in secondary school is often a challenge, frequently decreasing as the child ages (Hanson, 2003). Thus, further investigation may inform us whether the degree of parental involvement in transition is related to other critical student educational factors such as years of inclusion in the general education curriculum (Kim & Schneider, 2005; Martinez, 2008).

Previous reports indicate parents often lacked awareness of the transition plans, thus reducing their opportunity for direct input (Kraemer & Blacher, 2001). Griffin et al.’s (2010) study indicated only 26% of the parents reported their young adult’s individualized education plans (IEPs) included a transition plan. The study indicated parental report of a lack of general information and guidance about PSE options (73%) and a failure of the school to help them understand (36%). Vaden-Kiernan and McManus (2005, p. 13) question “whether schools that do very well at giving parents information create conditions that lead to greater parent involvement, or whether parents who are more involved at school receive more information about the school and thus are more aware of school practices done well.”

Actions to obtain information and facilitate successful transition often “depend too much on the resources and the resourcefulness of the individuals concerned and their families” (OECD, 2011, p. 10). Parents advise others to be proactive in their transition participation and to seek out other nonschool-related problem-solving networks of families of young adults with ID through electronic mailing lists, advocacy organizations, and disability support groups that provide interconnections to parents and professionals with first-hand experience (Cloth, 2006; Kim, Lee, & Morningstar, 2007).

Materials must be accessible in multiple formats and reflect cultural values (Kim et al., 2007). Desires and expectations of parents for their young adults’ transition into adulthood are value-laden, influenced by their cultural experiences, and affect how they engage with the transition planning team (Smith & Routel, 2010). For instance, Geenen, Powers, and Lopez-Vasquez (2001) reported school staff perceived culturally and linguistically diverse parents as unresponsive and uninvolved, even though the parents reported active involvement in their young adult’s transition outside the realm of school-based planning.

Further research in parent involvement is important to ensure that young adults with disabilities receive the opportunities created by law, benefit from highly knowledgeable professionals, and achieve a quality of postschool life (Griffin et al., 2010). Therefore, we explored parental involvement in transition planning and their desires and expectations for the future goals of their sons and daughters with ID. This critical population of young adults often participates in special education beyond the age of 18, is less likely than youth with other disabilities to earn a regular high school diploma, and is less likely than youth with other disabilities to engage in school, work, or preparation for work during the early postschool years (Newman, 2005). Further research on the degree that parents receive and utilize information distributed by the schools on the wide array of postsecondary options that includes PSE will inform effective transition planning.

**SPECIFIC AIMS**

Our study examined three major questions to supplement the literature on transition planning for PSE and increase our understanding of how other factors relate to that planning:

1. What are the parents’ means of accessing information to achieve their desired and expected postschool goals for their young adults?
2. What is the relationship between (1) parental involvement; (2) access of information regarding the transition process, options, and outcomes for youth with ID; and (3) parents’ desires and expectations for their young adults’ postsecondary outcomes?
3. Is there a relationship between the time a youth has been included in the general education curriculum and the desires and the expectations of parents of young adults with ID in the transition process?

**METHOD**

**Instrument**

This research, conducted in 2007, utilized a census survey developed by the investigators to examine parents’ desires and expectations for PSE as a postschool option, the influence that inclusive K-12 general education experiences had on parents’ desires for PSE, and parents’ means of accessing information in their efforts to achieve desired and expected postschool goals. Items related to transition participation were identified from instruments used previously (Grigal & Neubert, 2004; McNair & Rusch, 1991; Pleet, 2000) and piloted with a small group of parents from a neighboring area who would not be eligible for the final survey. After an additional review by a panel of experts, the survey underwent two field test procedures. The final instru-
ment was designed to be completed within 30 min, and was organized into eight domains: (1) characteristics and general school experience items; (2) participation in school-sponsored planning activities; (3) participation in nonschool-sponsored planning activities; (4) sources of information about PSE options; (5) employment hopes and expectations; (6) PSE hopes and expectations; (7) involvement in advocacy and support organizations; and (8) open-ended comments.

To ensure a high response rate, specific demographic questions were omitted and participants were offered mixed modes of responding, including web-based, mail, or telephone interview. The “within-stage,” “dominant-less dominant design” mixed model (Johnson & Onwuegbuzie, 2004) included quantitative (dominant) and qualitative (less dominant) research questions.

Parents’ expectations have been conceptualized in previous studies as visions (Hanson, 2003), desires (McNair & Rusch, 1991), and hopes (Kim et al., 2007). Our survey distinguished between parental desires and parental expectations. Parents may desire particular outcomes for their young adults, outcomes they hope for that may or may not occur (Kim et al., 2007; McNair & Rusch, 1991). Parents may also expect things for their young adults; outcomes they anticipate actually will happen that may differ from their original desire (Kim et al., 2007; McNair & Rusch, 1991).

In the United States, inclusion is defined as “a commitment to educate each child, to the maximum extent appropriate, in the school and classroom he or she would otherwise attend” if they did not have a disability (U.S. Department of Education, 2008, p. 2). Federal law requires states to indicate the percent of participation time of students in the general education settings as defined in IDEA (20 U.S.C. 1416(a)(3)(A)). As the survey was brief and had to remain simple, it collected only the perceptions of the parents of time their young adults were “included in the general education curriculum” and did not include the categories used by the Virginia Department of Education to ascertain this information. Parents were asked the number of years their young adults were included in the general K-12 education curriculum. Given no specific definition of inclusion, parents were asked for each level of school (elementary, middle, and high school), “Has your child with disabilities been included in the general education curriculum or classroom?” Parents who stated yes to inclusion at any school level were asked the total amount of years their young adults were included in general education. A student’s inclusion level was determined by dividing years in inclusive education by total years of education. Parents were asked if their young adults attended (1) less than 1 h; (2) 1–3 h; (3) 3–6 h; or (4) more than 6 h in a school day. Open-ended questions provided respondents the opportunity to list their nonschool memberships, expand their voice, add their opinions, and share their stories.

Five scales derived from the instrument were constructed using internal consistency measures as guideposts. These scales were utilized and all exceeded .60 on Cronbach’s alpha, with four above .80. Psychometric properties of the five scales are summarized in Table 1. The “school participation scale” included questions about the participation of parents in school-based transition. The “nonschool participation scale” examined the participation of parents in nonschool-sponsored activities. Both scales displayed generally strong properties (see Table 1). Alpha measures for the “received info about PSE scale,” which asked how the parents obtained information about PSE, was low on stability over time (test–retest $r = .498$) and remains troubling. However, the internal consistency for the scale was adequate (.817 pre and .622 post). We found no compelling explanation for these variations. Results based on this scale should, at this point, be interpreted with caution. The fourth scale, “want PSE,” was a measure of the degree to which parents wanted their young adult to consider PSE options. The fifth, “expect PSE,” was intended to reflect realistic expectations about PSE options. Distinguishing items in these last two distinct, independent scales asked parents if they desired and then expected the following options for their young adults: (1) continue course or vocational education on a college campus; (2) enroll as a college student for credit; (3) enroll in a general career or vocational training; (4) take some community continuing or adult education courses; or (5) continue coursework or receive vocational training in a care center for individuals with disabilities. After rigorous scale testing, we omitted an ambiguously worded question from three of the scales, the final

<table>
<thead>
<tr>
<th>Scale</th>
<th>Scale description</th>
<th>Items</th>
<th>Spearman test–retest reliability</th>
<th>Level of significance</th>
<th>Cronbach’s alpha pretest</th>
<th>Cronbach’s alpha posttest</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>School participation</td>
<td>19 to 40</td>
<td>.802</td>
<td>.001</td>
<td>.790</td>
<td>.809</td>
</tr>
<tr>
<td>2</td>
<td>Nonschool participation</td>
<td>41 to 46</td>
<td>.805</td>
<td>.001</td>
<td>.498</td>
<td>.810</td>
</tr>
<tr>
<td>3</td>
<td>Received info about PSE</td>
<td>47 to 54</td>
<td>.497</td>
<td>.084</td>
<td>.817</td>
<td>.622</td>
</tr>
<tr>
<td>4</td>
<td>Want PSE</td>
<td>68 to 72</td>
<td>.939</td>
<td>.000</td>
<td>.618</td>
<td>.876</td>
</tr>
<tr>
<td>5</td>
<td>Expect PSE</td>
<td>73 to 77</td>
<td>.826</td>
<td>.000</td>
<td>.807</td>
<td>.863</td>
</tr>
</tbody>
</table>

*aItems 52 and 53 were omitted based on alpha findings, improving the scale’s reliability.

*bItem 70 was omitted, and 72 reversed because of the negative phrasing.

*cItem 75 was omitted, and 77 was reversed.

PSE, postsecondary education.
scales performed reasonably well by psychometric criteria including the traditional measure of internal consistency reliability, Cronbach’s alpha.

Participants

A sample frame of 136 members of The Arc of Northern Virginia with young adults in transition planning, 14–22 years of age by June 30, was drawn from the 2006 database of 1,600 members. Using sampling theory calculations, including the finite population correction (Kish, 1965), valid responses to the survey (n = 61) resulted in a confidence interval of 90% with a margin of error rate of 9.35%. Excel® spreadsheet (Microsoft, New York, NY, USA) and SPSS® programs (IBM Corporation, Armonk, NY, USA) were used to perform tabulations and statistical calculations. Surveys were coded to preserve the confidentiality of respondents. The nonresponse follow-up protocol, a timed redistribution of the surveys, started with the web, then mail, then the phone as developed by the U.S. Census Bureau (National Research Council, 1994). Survey return rate via web (SurveyMonkey®, n = 25), mail (n = 33), or telephone interview (n = 3) reached 44.9%. Only surveys with responses completed at greater than the 25% level were included (n = 61). Forty-five respondents (12 parents of young adults ages 14–17; 33 parents of young adults ages 18–22) answered the open-ended questions and commented in the survey margins.

Results of parent responses indicated that 52 of 61 (85%) young adults were still in school and 9 (15%) were not, having graduated or ceased attending for other reasons. Ten did not have an IEP, including one student between the age of 14 and 17 years. Twelve were not receiving special education services. Of the 52 young adults still attending school, 44% (n = 23) responding parents reported their young adults had transition plans, 37% (n = 19) did not have a transition plan, and 17% (n = 9) were unsure. Comments by 11 parents suggested their young adults were “low-functioning,” “profoundly retarded,” or required “24/7 care.” One young adult was reported to live in a residential care facility.

Procedures

Quantitative data were analyzed using scales and individual items for descriptive statistical measures and compared for congruencies. Statistical analysis used nonparametric correlations to evaluate associations among the variables. Qualitative data analyses generated meaning from open and a priori coding (Coffey & Atkins, 1996). Comments were examined for logical chains of evidence and supporting statements and organized into matrices for ease of comparison and analysis. Inter-rater reliability was established by two outside researchers familiar with the population. Their consensus estimates of the analyses identified similar themes and were in concordance within the wider framework of the themes (Armstrong, Gosling, Weinman, & Martaue, 1997). Quantitative data analysis was completed simultaneously with the qualitative analysis to triangulate theories advanced in the inquiry (Coffey & Atkins, 1996).

RESULTS

Quantitative Data Analysis

All of the young adults under the age of 17 (n = 18) and nearly one-third of the young adults ages 18–22 (n = 34) were attending public school. Most parents (n = 49, 82%) indicated their young adults had not completed transition from public school. Only parents of young adults between the ages of 18–22 years (n = 6) responded they had completed transition. Slightly more than 8% (n = 5) responded they were unsure of whether their young adult completed transition. Of the 60 parents who responded, nearly an equal number of parents reported having and not having a transition plan (Yes: n = 24, 40%; No: n = 26, 43%), while 10 parents (17%) were unsure. Analysis by cross tabulation of the 52 parents whose young adults still attended school indicated that 37% (n = 19) of these students did not have a transition plan in their IEP; 17% (n = 9) were unsure. Two parents were unsure if their young adults were attending public transition programs.

Parents were asked at each grade level (elementary = preschool–6th, middle = 7th–8th, high school = 9th–12th) whether their child had been included in the general education curriculum or classroom. The brief survey sought only parents’ perceptions of their young adults’ inclusion. Students’ ages and grades were cross-tabulated with this indicator of inclusion. Parents’ responses showed a decrease from 75% (n = 46) inclusion in elementary school to 51% (n = 31) by high school. The reported total years of inclusive education for their young adults was determined by a simple count ranged from none (n = 5) to 14 years (n = 1). When asked the number of hours per day the young adults currently accessed and participated in general education curriculum, 72% (n = 38) stated less than 1 h; 15% (n = 8), 1–3 h; 8% (n = 4), 3–6 h; and 6% (n = 6), more than 6 h (M = 1.47, SD = 0.87).

Parents were asked about their awareness of postschool options for their young adults. Most parents in this study (82%, n = 50) were aware that students with ID between the ages of 18–22 could choose to continue their public school education in PSE sites (e.g., college, adult education, or vocational technical schools) with necessary accommodations and supports. Fewer (70%) were aware that adults with ID older than 22 years might also continue in PSE.

Fifty-four percent of parents (n = 33) responded in the affirmative to the query, “Did your school discuss the importance of high expectations with you?” When asked if parents felt their young adults’ schools had high expectations for their young adults, 47% (n = 28) stated affirmatively their young adults’ schools had high expectations, 38% (n = 23) stated the school did not have high expectations, and 15% (n = 9) reported they were unsure.

Parents were asked to respond yes, no, or unsure for desired and expected PSE options. Frequencies of responses in rank order were as follows: (1) 66% desired segregated coursework or training, 54% expected it; (2) 57% desired general career or vocational preparation and training, 43% expected it; (3) 38% desired coursework or vocational education on a college campus, 20% expected it; (4) 38% desired to attend coursework
on a college campus, 20% expected it; and (5) 23% desired their young adults enroll in college for credit, 11% expected it.

Parents preferred and accessed information through the school and community both formally and informally. Individual meetings, general school meetings, and volunteer work comprised the three most often utilized sources of information. Parents accessed school-sponsored forms of information most frequently (Table 2). Parents accessed nonschool resources of governmental support agencies, disability support agencies, and parent information and training sources (Table 3). The most common sources for information about PSE were family/friends (41%), journals/newsletters (37%), school staff, and disability support organization meetings (35%) each.

The "school participation scale" and "nonschool participation scale" provided a picture of how extensively parents were actively involved in transition planning. The relationship between the total amount of time young adults had been included in the general educational curriculum and the level of parental involvement in transition planning activities was determined for in school-based transition activities ($r_s = .300$, d.f. = 48, $p = .017$) and for nonschool transition activities ($r_s = .256$, d.f. = 48, $p = .037$).

Squaring the correlation coefficients yielded an estimate of the amount of variation in parental participation that can be explained by the student’s level of inclusion. For parent participation in school-based participation in transition activities, $r^2 = .0900$, interpretable as 9% of the variation in inclusion “explaining” or “accounting for” participation in school-based transition activities. The comparable figure for nonschool-based transition activities was $r^2 = .0655$ or about 7%.

We used the scale of parental desires and scale of parental expectations to test the hypothesis that parents whose young adults spent a greater amount of time included in the general education curriculum would be more likely to desire and expect college transition outcomes for their young adults than parents whose young adults spent less time in the general education curriculum. The total years as determined by a simple count that young adults had spent in inclusive situations correlated with both parents’ desires ($r = .269$, $p < .05$) and expectations ($r = .354$, $p < .01$) for college, thus supporting our hypothesis.

**Qualitative Data Analysis**

In open-ended questions, parents listed their memberships in nonschool disability support organizations, including nonprofit disability organizations, church and religion-based youth groups, school, and community and state agencies. Parents were also asked to share any comments regarding their involvement in the transition planning and their desires and expectations for their young adults not addressed in the survey. Many parents wrote extensively along the margins of the survey; another submitted a full page of text. Parents’ unique perspectives gave deeper insight into the complexity and frustrations they felt around their young adults’ transition planning. Using an *a priori* list based on research questions and grounded theory method, six thematic categories emerged (see Table 4).

**Involvement Patterns: Is it Time Yet?**

Parents stated they did not have a transition plan or were unclear of the process, perceiving it as an exit activity to be initiated later rather than as an ongoing planning process started at age 14. Only one parent recommended transition planning to start at age 12, while four parents indicated they were actively engaged in the planning processes. One parent stated, “I don’t

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**TABLE 2**

Frequency of participation in school sponsored activities*

<table>
<thead>
<tr>
<th>School-sponsored activity</th>
<th>Yes, n</th>
<th>Valid %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual transition planning sessions</td>
<td>56</td>
<td>92</td>
</tr>
<tr>
<td>General school meetings (e.g., back-to-school night)</td>
<td>52</td>
<td>87</td>
</tr>
<tr>
<td>Volunteer in school or school-related activities</td>
<td>47</td>
<td>77</td>
</tr>
<tr>
<td>Informal family school/ social events</td>
<td>45</td>
<td>74</td>
</tr>
<tr>
<td>Parent/teacher discussions about good learning habits in school and home</td>
<td>39</td>
<td>65</td>
</tr>
<tr>
<td>Daily home–school communication with staff and teachers</td>
<td>39</td>
<td>64</td>
</tr>
<tr>
<td>Read school newsletters for parents</td>
<td>37</td>
<td>63</td>
</tr>
<tr>
<td>Encourage with school child’s decision making</td>
<td>36</td>
<td>61</td>
</tr>
<tr>
<td>Transition workshops</td>
<td>33</td>
<td>55</td>
</tr>
<tr>
<td>Individual education transition planning</td>
<td>30</td>
<td>49</td>
</tr>
<tr>
<td>Parent workshops</td>
<td>27</td>
<td>45</td>
</tr>
</tbody>
</table>

*Events of student-shared school experiences, school field trips to adult services, volunteering to find community opportunities, school–parent partnerships, and parent helping parent sessions were accessed by less than 15 parents.

**TABLE 3**

Frequency of participation nonschool-sponsored activities

<table>
<thead>
<tr>
<th>Nonschool-sponsored activity</th>
<th>Yes, n</th>
<th>Valid %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governmental adult service agencies (e.g., Community Services Board, work support agencies, or other state or other local developmental disability agencies)</td>
<td>37</td>
<td>61</td>
</tr>
<tr>
<td>Disability support organizations or groups (e.g., The Arc)</td>
<td>35</td>
<td>59</td>
</tr>
<tr>
<td>Parent information and training center (e.g., Virginia’s PEATC)</td>
<td>35</td>
<td>57</td>
</tr>
<tr>
<td>Internet resources not connected to school</td>
<td>27</td>
<td>45</td>
</tr>
<tr>
<td>which contained information on transition options for youth with disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College or university disability student services office</td>
<td>8</td>
<td>13</td>
</tr>
</tbody>
</table>

PEATC, Parent Educational Advocacy Training Center.
want to think about it,” while another made assurances of making the “proper arrangements later on.”

**Level and Adequacy of Information**

Parents indicated they wanted more, readily available information. The information they did receive was inadequate for transition planning. Confusion existed as to their options. Without sufficient guidance or information, they were “floored and scared to death.”

**Adequacy of Service by Schools and Agencies**

Parents’ satisfaction with transition planning was provider specific. A couple of parents appreciated their teachers’ commitment to planning for the young adults’ futures. Many more expressed their dissatisfaction with not only the staff’s level of competence or training, but also the services the school provided with many in disagreement with the recommendations. One parent commented, “Our experience with the school system has been so bad that we now question the sincerity or the meaningful quality of these programs.”

**Partnership between Schools, Agencies, and/or Organizations**

Many had a stronger partnering relationship when communication with the school was good, although they reported information was often not helpful or even correct. Parents felt “pushed” into the schools’ recommendations while having little or no input by them. Some parents reported their advocacy and involvement in other organizations in order to “carry on the good fight!” To resolve the sense of disconnect and lack of information from the failed partnership with the school, one parent turned to The Arc of Northern Virginia to independently access information and was “blown away at the resources available” at their conference.

**Hopes, Expectations, and Concerns for Their Young Adult’s PSE**

Four parents hoped their young adults would continue learning in the postsecondary setting; others desired choice making and continued access to technological supports successfully used in school. Parents who reported their young adults as not severely disabled saw self-advocacy, work, and life in the community in their young adults’ futures and desired as independent and full a life as possible. One parent whose young adult

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**TABLE 4**  
Qualitative analysis of core categories derived from key statements

<table>
<thead>
<tr>
<th>Category and meaning</th>
<th>Representative statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “Involvement Patterns: Is It Time Yet?” reflected parents’ statements on when to begin transition planning.</td>
<td>“I’m not involved with much transition planning because there is no place to go but a sheltered workshop.”</td>
</tr>
<tr>
<td>2. “Level and Adequacy of Information” reflected the parents’ desire for more information.</td>
<td>“I want more information. I don’t want to have to feel like I’m on an archeological, research dig. I want to be included in the planning and decision making process, not just told what my child will do, or where they [sic] will go. I want to talk with other parents who’ve been in my shoes. I don’t want to have to take out a billboard to find them.”</td>
</tr>
<tr>
<td>3. “Adequacy of Services and Information by Schools and Community Agencies” reflected parents’ level of satisfaction with transition services and supports.</td>
<td>[School’s] “Transition” program was a despicable JOKE. The most recent transition section of my son’s IEP listed his career goal as: “Be a Power Ranger.” (Emphasis as written in original response.)</td>
</tr>
<tr>
<td>4. “Partnership between Schools, Community Services, and/or Organizations” reflected parents’ working relationships with agencies.</td>
<td>“Blown away at the resources available,” “Very involved,” “Still carrying on the good fight!”</td>
</tr>
<tr>
<td>5. “Parents’ Hopes and Expectations, for Their Young Adult’s PSE” reflected parents’ aspirations for their children in the area of education.</td>
<td>“Life just like ours,” “Learn life skills,” “A day program for young adults with severe physical and ID on a college campus . . . to continue to develop my child’s life skills and vocational skills in an educational setting.”</td>
</tr>
<tr>
<td>6. “Parents’ Concerns for Their Young Adult’s Well-Being” reflected parents’ concerns or worries for their children’s future well-being.</td>
<td>“24/7 care,” “Other than getting her name on the WAITING LIST—we have done nothing and don’t know what else to do or [what] to think because I don’t think that once she is 21–22 things will be good for her.” (Emphasis as written in original response.)</td>
</tr>
</tbody>
</table>

IEP, individualized education program; PSE, postsecondary education.
Parents’ Hopes, Expectations, and Concerns for Their Young Adults’ Well-Being

Parents were concerned about their young adults’ future well-being given the uncertainty of sustained funding by the adult agencies to ensure their young adults’ goals would be met. This was especially evident for parents of young adults with more significant disabilities requiring medical or 24/7 care. Parents who perceived their young adults to have a low level of functioning expected them to remain at home. One parent expressed a desire for an intermediate care facility for the persons with ID to be closer to her home. Another stated, “We have done nothing and don’t know what else to do or to think because I don’t think that once she is 21–22 things will be good for her.”

Limitations of Study

Data from our small regional study provide preliminary information regarding access to accurate information for transition planning, parent involvement to meet their desires and expectations of PSE, and the relationship of inclusion to parent desires and expectations of PSE. Given several limitations, data should be interpreted with caution.

Respondents were members of The Arc of Northern Virginia, an organization that supports people and families living with someone who have cognitive, intellectual, and developmental disabilities. We expected the sample frame to provide a greater opportunity to securing parents of youth with ID without limiting the etiology of the youth’s disabling conditions. As the survey did not seek respondents to specifically identify their young adults’ disabling condition, it is possible their young adults had other disabilities. Further, the respondents of the English-language survey may not have been representative of the diverse population of northern Virginia. It is possible patterns of engagement in transition planning may have existed due to their specific cultural and linguistic groups’ perspectives of their roles.

The Arc of Northern Virginia’s (a major provider of services) mission of advocacy and training for its membership may have increased parents’ bias, awareness of transition options, and the need for active participation in their young adults’ IEP and transition planning. A PSE program for students with ID located at a nearby university campus may also have influenced the frequency of reported desires for PSE opportunities.

It is possible some parents may have estimated the total time included in general education for their young adults, may have lacked an understanding of their young adults’ IEP document, or may have had young adults who left the public school at the end of their 4 years of high school (usually at age 18 or later). As some parents may not have been able to accurately determine the number of hours their young adult child was included results should be interpreted with caution.

DISCUSSION

As there have been no major changes to federal transition educational policy in recent years, our findings are relevant to effective transition planning. Our research is distinguished from prior work through our examination of parent desires and expectations for their young adult’s PSE goals in relation to the amount of time young adults were included in the general education curriculum. Our results related to transition planning mirrored those of previous research. Examining the means of preferred communication may offer a pathway to improvement parent understanding and participation and planning for the future of their young adults.

Access to Accurate Information for Transition Planning

We found it disconcerting that 60% (n = 36) of the parents reported their young adults did not have a transition plan, were unaware of the transition plan, or, with the school, were deferring the process to the last moment; such results are consistent with studies from over a decade ago (Kraemer & Blacher, 2001). Parents were overwhelmed and confused with the whole process, viewing it as little more than an exit interview often culminating with predetermined outcomes, rather than an ongoing collaborative process. Parents indicated involvement in their young adults’ transition planning often necessitated their accessing information independent of the school (Cloth, 2006; Kim et al., 2007).

Parental reports that students with ID did not have a transition plan or that parents and their young adults were not actively involved in its development, raises questions about the degree of school district compliance with the IDEA. Further, if knowledge transfer between parents and students by the schools were inaccurate or nonexistent, parents and their young adults would be precluded from being effective and knowledgeable partners.

Direct, face-to-face, structured, formalized communication (school meetings, school-related volunteer, or social events) in transition planning processes as preferred by the parents might provide the foundation for relationship building within the processes of transition planning (Pleet, 2000). Negative comments outnumbered accolades for their young adults’ transition planning, implying an erosion of trust in transition agencies when they failed to provide accurate detailed information regarding the transition planning and PSE (Worsham, 2007). Without face-to-face instruction to check for understanding, sustain active participation in the transition process, and clarify parents’ later misunderstandings and misgivings of the transition process, parents may remain unaware of or confused by the transition planning processes. Parents may discover too late that their young adults have reduced opportunities to prepare for meaningful, desired, and expected adult life choices.

Family members were the primary conduits to new information pertinent to the quality of life of their family member with a
disability. Parents concerned for the future well-being of their young adults with severe disabilities and involved in the struggles of their family life transitions may be unaware of new or innovative programs and must rely on others for that information (Kraemer & Blacher, 2001). Many parents, both those whose young adults were included in public school and those not, belonged to county agencies, supervisory and school board committees, and other advocacy-oriented organizations. Parents accessed information often without involvement of school personnel or community agencies. Support organizations (e.g., The Arc) often become “extended members of the family” by virtue of shared experiences. Thus, there were few surprises in our finding that organizations were the second most frequently cited resource after family members as a resource for information about PSE options.

Parent Involvement: Desires and Expectations of PSE

Our investigation examined the relationship between parental involvement, access to information, and parents’ desires and expectations for their young adults’ postsecondary outcomes. Given the main goal for PSE is to secure improved future employment (Grigal & Hart, 2010), it is understandable that quantitative results indicated about one-half of the parents desired PSE with a vocational or employment outcome. Yet many parents commented they did not expect it to be realized. Parent comments indicated high expectations were a strong value for many, especially for those who desired and planned for normalized life for their young adults (Kausar et al., 2003). Unfortunately, nearly a quarter of the respondents felt their young adults’ schools and community agencies did not have the same high expectations for their young adults. These agencies’ failure to embrace similar visions, perceptions of benefit, or provide adequate information for the future of their young adults strained relationships between parents and the transition team as seen in other research (Cooney, 2002; Griffin et al., 2010).

Given our data, we wondered whether parents’ desires and expectations vanish when confronted with insufficient information and seemingly impassable barriers for their young adults’ transitioning into college-level PSE programs. Without access to current and correct information, involvement in transition planning, or awareness of the full continuum of options (including PSE), parents are not able to help their young adults plan for a meaningful or improved quality of life.

Inclusion and Desires and Expectations of PSE

We postulated that a relationship existed between postsecondary outcomes, desires, and expectations for parents of young adults with ID, especially for PSE, for parents whose young adults had been included a greater amount of years. Our findings, synchronous with previous literature (Hanson, 2003), suggested that in Virginia, parents whose young adults spent an overall greater amount of time included in the general educational and curriculum were more likely to desire and expect college transition outcomes for their young adults with ID.

Our quantitative results confirmed that parental involvement in transition planning activities for their young adults with ID positively correlated with the amount of time their young adults were included in the general education curriculum. Many parents in this study, as in prior research, became experienced, efficacious, networked, and involved with the public school systems, especially those whose young adults were included in general education (Hanson, 2003; Keogh, Bernheimer, & Guthrie, 2004).

Parents who perceived their young adults in greater need of medical care and/or supportive services reported they were less likely to be included beyond the primary school years (Hanson, 2003; Minnesota Department of Health, 2004). They were fearful for their young adults’ safety, health, and quality of life. These parents’ dreams and expectations were for a societal infrastructure capable of supporting their young adults’ basic needs and future well-being, although many were unsure how they would be met. Some were ready to advocate for those needs, but others were confused and frustrated. One parent exemplified the paradox of having both greater aspirations and an inescapable reality. She described her 19-year-old daughter as “developmentally 2–4 years old” yet expressed desires “that she continue to develop, grow, and learn like her brothers have in college settings.” Despite her desires, she pragmatically concluded that would not be possible for her daughter with “profound mental retardation.” Parents’ limited aspirations for their young adults’ expected futures appeared to be a simple matter of course based upon the limits perceived because of their disabling conditions.

In contrast were the young adults with severe disabilities who were perceived by their parents as capable students. These parents confronted the same baffling adult agencies and systems, yet they appeared ready to tackle the barriers and perhaps even effect change along the way. These parents’ young adults had been included for many years. They were parents filled with desires for typical lives. Some parents expressed their desires and expectations of their young adults going to college, securing a job, and finding a home with friends in the community.

CONCLUSIONS

Parent responses suggested a varied level of involvement in transition planning and a preference for the direct face-to-face approach. Only a few were satisfied with the supports and information they received from the schools or community agencies, while many were dissatisfied, distrustful, and even angered with the way their young adults’ schools and school personnel failed to provide information. Parents’ desires did not always match their expectations. Many parents desired a normalized life for their young adults; many others were ready to ensure that desires would be actualized. Parents whose young adults spent a greater amount of time included in general education more likely desired and expected college transition outcomes. Parents used processes of advocacy and political action. They became effective change agents armed with goal-directed desires set on a pathway of political action to effect changes so their young adults would have a normal life that included PSE (Wolffensberger, 1972).

The results of our study point to several recommendations toward improvement of the transition process to help parents obtain their desired goals of their young adults with ID:
1. Begin transition planning early so that parents perceive transition as a process and not a culminating event. Parents must be provided accurate information and be included in the planning process to ensure a shared vision for the future that embraces the desires and expectations of the parent and student.

2. Provide preservice and ongoing training for school and nonschool professionals utilizing current knowledge and the skills on parent and community partnerships, instilling in personnel an awareness of the potential that lies within their students with ID, including the potential for life long learning.

3. Distribute information and resources utilizing face-to-face opportunities about PSE to not only parents, but also to mainstream society (family, neighbors, friends in the community, and policymakers).

4. Ensure within the global communities the provision of inclusive education for children and youth with disabilities and identify, showcase, and promote successful innovative projects in the area of PSE for young adults with ID.

Several design components in future investigations will enhance the depth of information. Recommended are: (1) the addition of focus groups; (2) a scale to assess parent frustrations with the transition process; (3) an operational definition of degree of inclusion, and (4) additional demographic questions to better describe disabilities and diversity of the participating families and young adults.

REFERENCES


