

EXPECTATIONS OF FAMILIES WITH YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FOR POSTSECONDARY EDUCATION

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INTRODUCTION

It has long been recognized that high parental expectations lead to high academic achievement by their children. Parental expectations have also been found as a strong predictor of students planning for college (Hossler & Stage, 1992). While that may hold true for students without disabilities, there is limited research about family expectations for the future engagement of transition-aged youth with intellectual and developmental disabilities (I/DD) in postsecondary education (PSE).

The passage in 2008 of the Higher Education Opportunity Act provided increased access for students with I/DD to two and four year college campuses. Even with the recognition that parental expectations for the future help shape the academic engagement of youth with disabilities and the increasing expectations that young people with I/DD can and should be given the choice to participate in some type of college programming, setting college as a goal in special education planning meetings is still relatively recent (Grigal & Hart, 2012). Only a small number of studies have focused specifically on the perspectives of families of students with I/DD (Martinez, Conroy & Cerreto, 2012; Griffin, McMillan & Hodapp, 2012; Wagner, Newman, Cerreto & Levine, 2005; Newman, 2005; Chambers, Hughes & Carter, 2004; Cooney, 2002; Kraemer & Blacher, 2001; and Masino & Hodapp, 1996). While each study examined some facet of transition-aged youth with I/DD, parental expectations, and PSE, none linked all three domains:

Martinez, Conroy, & Cerreto used a pool of Arc membership to examine parents' means of accessing information to achieve their desired and expected post-school goals for their young adults. Two of eight survey domains related directly to PSE, but not necessarily to college (PSE questions also related to vocational preparation and training). A small percentage of their survey respondents (<25%) wanted or expected their child to enroll or participate in college – the majority (>60%) wanted or expected segregated coursework or vocational training for their child.

A study by *Griffin, McMillan & Hodapp* researched family perceptions of transition planning, including barriers families encountered in learning about PSE. Among the many findings from this pool of 108 families of students with ID, inadequate transition planning, a general lack of information and guidance, school and staff

not helping families to understand options, and conflicting advice from agency staff were the most prevalent findings.

Wagner, Newman, Cameto, & Levine culled the National Longitudinal Transition Study for barriers youth with disabilities faced as they made the transition to adulthood. They identified in their findings the importance of PSE for successful adult outcomes and the need for careful transition planning to ensure success.

In an examination of the National Longitudinal Transition Study 2 data for evidence that family expectations for PSE shapes the positive academic engagement and achievement of youth with disabilities, *Newman* found that parents are less confident that their child will attend and graduate college – about three of five youth with disabilities were expected to further their education after high school.

Chambers, Hughes & Carter researched parent perceptions regarding employment, independent living, PSE, social relationships, and recreation as their children prepared to exit high school. Most of the eight families participating in this study thought that their child (even though they thought college was an important post-school outcome) would enter vocational training or not participate in PSE at all rather than go to college.

Research by *Cooney* looked at the transition experience of nine youth with ID and their families during their last year of high school. While parents hoped that their child's abilities would allow them to achieve fulfilling adult lives, the author found that families in this study were most concerned about the unfamiliar transition process and procedures which ultimately impacted the quality of their child's transition plan. PSE was not addressed in this study.

Kraemer & Blacher wanted to know the aspirations parents had for their sons and daughters with ID once they exited the school system. The primary concern expressed by families in this study was determining what their child would do during the day after high school ended. PSE was not included as a survey domain.

Another study, conducted by *Masino & Hodapp*, used the National Education Longitudinal Study data to examine school performance of youth with sensory and orthopedic impairments and parent education levels for possible correlations of predicting parental expectations for college. They only found slightly higher parental expectations for this subgroup of students.

The paucity of research linking families of young adults with ID and parental expectations for PSE was the impetus for a small study to further delve into the personal perspectives of parents of students with I/DD who were accepted into ACE-IT in College; a fully inclusive, supported education transition program at Virginia Commonwealth University (VCU). Specifically, the purpose of this study was to explore how parental expectations for their son or daughter with I/DD grew; what factors contributed to this experience; and what advice these parents would have for educators, community agency personnel, college administrators, and for other parents.

Established at VCU in 2000 to support students with learning disabilities, Academic & Career Exploration: Individualized Techniques (ACE-IT) has successfully used a supported education approach to provide individualized services to students with traumatic brain injury, spinal cord injuries, and other neurological disabilities. In October 2010, ACE-IT was modified (and renamed to add 'in College') for students with I/DD to participate at VCU in a 21 credit, 30 month certificate program. Participants in ACE-IT in College are 18-26 years old; with Intellectual Disabilities, Autism, or Traumatic Brain Injury; and who graduated or are expected to graduate from high school with a Virginia Modified or Special Diploma. Entering VCU as a 'special status student;' the same status for any non-degree seeking student, ACE-IT in College participants are fully included in all academic and social aspects of the university with the support of VCU undergraduate students acting as educational coaches and peer mentors.

METHODOLOGY

This study was conducted in March 2014 utilizing an on-line survey developed by the researchers to examine parental expectations for PSE as a postschool outcome. The survey was designed with open and close ended questions and could be completed in 15 minutes or less. The survey was organized into several domains: PSE influences; PSE expectations; advice for parents, educators, and college administrators; and participant demographics. This survey distinguished expectations as ‘hopes, beliefs, and assumptions.’

The sample included the parents of eighteen young adults aged 19-25 with I/DD who were accepted into ACE-IT in College at VCU between March 2011 and March 2014. The demographics of the student included:

- 68% with ID, 17% diagnosed with Autism, and 15% having other DD;
- 33% are female, 67% male;
- 44.5% are white, 44.5% black/African-American and 11% are Asian; and
- 66% graduated high school with a Special Diploma and 37% with a Modified Standard Diploma.

At the time of this survey, two of the students had completed the 30 month certificate program, five had just been accepted and had not yet started on campus, and the rest were in various stages of program completion.

An on-line survey link was sent to 17 parent email addresses for 15 students (the parents of three ACE-IT in College participants were taken out of the survey pool because no email addresses were available). The survey was open from March 10 - 31, 2014. During that time period, twelve parents (71%) completed the survey representing ten students. Comments were examined for logical themes or patterns and further examined in the Findings section.

PARTICIPANT PROFILES

Twelve (85.7%) parents representing ten (71.43%) students completed the on-line survey.

Age	Percent
30-39	0%
40-49	50%
50-59	41.7%
60+	8.3%
Gender	Percent
Female	83.3%
Male	16.7%

Race & Ethnicity	Percent
Non-Hispanic	100%
Hispanic	0%
White/Caucasian	63.6%
Black/African American	27.3%
Asian	9.1%
Native American	0%
Pacific Islander	0%
Other	0%

Marital Status	Percent
Single	0%
Married	91.7%
Divorced	8.3%
Civil Union	0%

Residence Type	Percent
City/Urban	16.7%
Suburban	58.3%
Rural	25%

Household Income	Percent
\$0-9,999	0%
\$10,000-24,999	0%
\$25,000-49,999	0%
\$50,000-74,999	27.3%
\$75,000 - \$99,999	27.3%
\$100,000 - \$124,999	9.1%
\$125,000+	36.4%

Education Level	Percent
Less than High School (no degree)	0%
High School Degree/GED	16.7%
Some College (no degree)	16.7%
Associate Degree	0%
Bachelor Degree	33.3%
Graduate Degree	33.3%

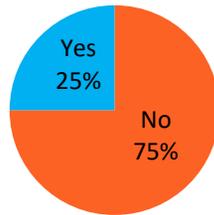
FINDINGS

The aim of this study was to explore the growth in parental expectations for their sons or daughters with I/DD to go to college, what factors contributed to this experience, and what advice these parents would have for educators, community agency personnel, college administrators, and for other parents.

Our research is distinguished from prior research through our examination of parental expectations for college for youth who were accepted to a comprehensive transition program for students with I/DD. With the passage in 2008 of the Higher Education Opportunity Act opening access to college for students with I/DD, our findings are relevant to effective transition planning. Our results yield a number of themes that potentially influence the success of youth with I/DD to go to college and are worthy of further examination.

How did parental expectations to go to college grow? When asked what expectations they had for their child after s/he graduated high school, 50% of the parents in this survey responded that they had specific expectations that their child with I/DD would go to college. Typical answers to the question included having expectations that their child would get a job, go to college, and be as independent as possible. Interestingly, we found that 75% (n=9) of the parents reported that their son or daughter did not have college listed as an IEP goal, yet they still found their way to VCU's ACE-IT in College program.

Did your son/daughter have college listed as an IEP goal?



Per parent report, their child setting the goal for college, a teacher recommending ACE-IT in College, and hearing about VCU's transition program for students with I/DD from a connection they had in the community were the most frequent factors cited when asked *what factors contributed to parental expectations of college?*

What advice is there for parents, educators, community agency personnel, and college administrators? Survey responses provided insight into respondents' perspectives and experiences. Those responses have been categorized into the following three themes:

THE IMPORTANCE OF NOT UNDERESTIMATING ABILITIES

People with I/DD bring a lot to our families, our classrooms, our colleges, and our communities. Parents in this study seemed to have had an innate, positive perspective on their child. They overwhelmingly remarked that parents, educators, and community agency personnel need to not underestimate the ability of youth with I/DD. Regardless of race, culture or income, parents in this study have high aspirations and concerns for their child's success. Encouraging children to have 'can do' attitudes and communicating the expectation that they can continue learning after high school were common responses.

"Don't underestimate the abilities of your child."

"Don't settle for the fact that your child will only be qualified for physical labor"

"Give your child as many opportunities as possible, and watch him/her grow." "Cultivate in them the "you can do it" spirit."

"Your child is capable of more than you think."

"Don't dwell on what you think your child cannot do; focus on what they do."

THE IMPORTANCE OF PARENTS BEING CONNECTED TO THE COMMUNITY

Social networks provide important emotional support and educational opportunities for parents of children with I/DD. Through connections to other families of children with disabilities, parents have someone to talk to about the impact of disability on their family. When connected to a family organization or advocacy group, parents learn about disability services and how to advocate for their child's needs.

Many parents in this study attributed the biggest influences that led to them supporting their child in applying for ACE-IT in College to 1) learning about the program themselves (or from their child's

teacher) through attendance at a presentation in the community, or 2) from hearing about it from another parent they knew in the community.

“XXX spoke at an [Arc] meeting and shared information about ACE-IT in College.” “Stay in touch with situations that could present opportunities such as social clubs, educational activities etc.” “Actively get a presence in special needs organizations.”

THE IMPORTANCE OF THE COLLEGE EXPERIENCE

Looking back on our own college experiences, many of us would say that college is more than just academics; it is about developing interpersonal relationships with peers and professors, meeting new people, and opening our minds to different ideas. Study participants also believe college is good for everyone – they recognized college as a place that helps young people, with and without disabilities, to identify career interests, learn skills to get a job, and to mature and grow personally.

“Putting earning a certificate or diploma aside, a student participating in a college experience will gain in so many other areas: daily living skills, communication, community integration.” “The college experience can be a wonderful opportunity for growth both personally and educationally.” “Many of us do not work in the academic field that we studied in college. But, we all gained value from our college experience. College is about so much more than academic learning, although I do value continued academic learning. College gives the opportunity for your son/daughter to grow in so many other ways -- socially, emotionally, and in just plain old practical ways of living.”

College can be challenging for any student. Those with disabilities can be successful even when there is no K12 special education Individualized Education program (IEP) in college. If the goal is for every student to learn, improving access for everyone is a must. This begins with an understanding that not every student learns in the same way. Parents in this study noted students with disabilities being successful when they had access to 1) technology, 2) appropriate supports, and 3) faculty who have training on teaching to different learning styles; in other words, universal design for learning.

“Find tools to assist each student's style of learning.” “Assistive technology and other accommodations in the college environment will allow access to your child's special area of interest.”

“Students with disabilities may not pass the test, but can still learn the material.”

Many colleges and universities share a belief that diversity in student bodies is important for fulfilling their mission to provide a quality educational experience. We learn from those whose experiences and beliefs are different from our own. The message from parents in this survey is that people with disabilities add to the diversity of their student body – that they are an asset to the college.

“The entire community will gain from the diversity that individuals with disabilities will bring to a college campus.” “People with disabilities are an asset to their school body and

the overall college experience for everyone.” “Students with disabilities are very resilient and can help widen the perspective and outlook of other college students.”

CONCLUSION & RECOMMENDATIONS

Parents in this study want their child to have as ‘normal’ a life as possible. Their responses suggest a strong belief in their child and that they see their child’s abilities first and foremost. They also highly value lifelong learning; in particular PSE.

The lack of college being listed on the IEP for the majority of the participant’s students, as well as parent responses to other survey questions hint that perhaps parental expectations grew less from the federally mandated special education IEP transition process and more from their own experiences having attended college and wanting the same experience for their child, even if the child has I/DD. And, the parents pointed to access to information as a key conduit for growing their parental expectations for PSE; information that came from connections they had in the community with other parents and with family organizations, such as an Arc chapter.

Is the reason for a lack of PSE goals on IEPs attributable to parents and teachers not being knowledgeable about PSE opportunities in their region or in Virginia? Is it because of a concern by IEP teams that if PSE is listed as a goal, they are responsible to ensure it comes to fruition? We don’t know -- further research is needed to answer these questions. But, we do know that it is important get the discussion of PSE back at the IEP table. Parents in this study recommend:

1. Information on PSE programs for students with I/DD is shared by colleges and universities with local school divisions;
2. Teachers, transition specialists, and guidance counselors are trained on PSE opportunities for students with I/DD;
3. Discussions at IEP meetings of the expectation of college as a transition outcomes begin as early as when the child is in elementary school; and
4. Parents are connected to family organizations in the community for emotional, informational and systems navigational support.

LIMITATIONS

Data from this small study provides preliminary information regarding parental expectations for postsecondary education for children with I/DD. The participants in this study are not reflective of the average parent of a college student today. For example, the median household income in the United States is \$49,999 and generally, about 40% of college students come from families in poverty. Of the parent respondents to the survey, 100% had annual household incomes above \$50,000, with 45.5% reporting annual household incomes exceeding \$100,000.

Additionally, the data collected in this study was restricted to those whose son/daughter was accepted to ACE-IT in College, a fully inclusive, supported education model comprehensive transition program for students with I/DD only available in Virginia at VCU. Caution should be exercised to not generalize this data across all postsecondary transition programs supporting students with I/DD.

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