



Perspectives on Life after High School for Youth with Intellectual and Developmental Disabilities: Findings of a Statewide Survey of Families

by Nila Benito

INTRODUCTION

In 2010, the Florida Center for Inclusive Communities (FCIC) coordinated a variety of activities to promote inclusive postsecondary education (PSE) for students with intellectual and developmental disabilities (IDD). One activity was bringing together a diverse group to create the Florida College Collaborative. This group included representatives from two-year and four-year colleges, community and state agencies, and K-12 education, as well as students with IDD and their parents. The goal was to develop a sustainable, authentic, and inclusive PSE system to support students with IDD.

The Florida College Collaborative conducted two parallel statewide web surveys, one for professionals who support people with IDD and another for families of youth with IDD. The surveys gathered perspectives about PSE for students with IDD and information on current practices. They asked about students' hopes and dreams and about barriers to their participation in PSE programs.

353 people completed the professional survey, and 553 people completed the family survey. Respondents to the professional survey (see Table 1) were a diverse group that most often included employment specialists and medical professionals in the "Other" category.

While 70% of the respondents to the family survey were parents, family members, and guardians, the remaining respondents identified themselves as friends, mentors, and self-advocates.

Where do I begin? I guess I wish for my daughter to have all the opportunities any human being wishes to have...

Table 1. Roles of Professional Respondents

Professional Role	Percentage
Educator	40%
Other	21%
Support coordinator	11%
College professional	10%
DD medical waiver adult services provider	9%
Vocational rehabilitation staff	6%
Supported employment provider	3%

FINDINGS OF THE WEB SURVEYS

Demographics of Youth

The average age of youth about whom the survey was completed was 19.5 years. Respondents were asked to indicate the condition(s) of the youth they represented (see Table 2). Intellectual disability was the disability most often cited by professionals (78%) and families (38%). Among those who indicated that they represented other disabilities, mental health conditions were most often specified.

Table 2. Conditions of Young People Represented

Condition	Percentage Cited By Families	Percentage Cited By Professionals
Intellectual disability	38%	78%
Autism	35%	57%
Developmental disability	34%	50%
Cerebral palsy	12%	36%
Down syndrome	13%	36%
Asperger's syndrome	14%	33%
Other	27%	24%

High School Educational Setting of Youth

Survey respondents were asked to select *all* the high school educational settings experienced by the youth. As indicated in Table 3, “Segregated special classes” was most often represented, followed by “Some general education classes.” One-third of respondents indicated that students were in a “Fully inclusive” setting. The “Other” category included specialized public schools for students with IDD, private specialized schools, and charter schools.

Table 3. Current High School Educational Setting

High School Setting	Percentage
Segregated special classes	56%
Some general education classes	46%
Fully inclusive	33%
Community-based instruction	28%
Work-based learning site	18%
Other	11%
Home-school	9%
Special residential	7%

Youth Preparedness for Life After High School

The majority of respondents (59% of families, 41% of professionals) stated that the education system had not prepared the youth with IDD for life after high school (see Tables 4 and 5). When asked whether the youth’s Individualized Education Program (IEP) included specific plans for after high school, 57% of families and 20% of professionals responded “No.” A majority of family respondents (61%) said that the student did not understand *all* of the educational opportunities available after high school. One respondent stated that the school that her daughter attended had “failed her by not preparing her for employment.”

Table 4: Family Responses to Preparatory Experiences

	Yes	Not Sure	No
Has your child’s education prepared him or her for life after high school?	16%	25%	59%
Does your child’s IEP include a plan for the time immediately after high school?	32%	11%	57%
Does your child understand all of the educational opportunities that are available after high school?	15%	24%	61%

Table 5: Professional Responses to Preparatory Experiences

	Yes	Not Sure	No
Has the education of the students you serve prepared them for life after high school?	31%	29%	41%
Do the students you serve have IEPs that include individualized plans for the time immediately after high school?	63%	17%	20%
Do you think the students you serve and their families understand all of the educational opportunities that are available after high school?	10%	19%	71%

Importance of Specific PSE Program Factors

The survey asked respondents to rate the importance of specific components of PSE programs. “Curriculum supports/modifications” was cited as the most important component by both parents and professionals. “Social opportunities” and “safety” were also very important to parents; “transportation” and “employment” were also very important to professionals. There was a notable difference in the rating of “transportation” as very important: 56% of family members vs. 85% of professionals. One family member explained this discrepancy: “If you build it, we will make sure we get there.”

Table 6: Importance of PSE Program Factors

	Families: Very Important	Professionals: Very Important
Cost	54%	81%
Curriculum supports/modifications	89%	92%
Behavior supports	60%	64%
Physical health	41%	38%
Safety	77%	72%
Transportation	56%	85%
Certificate/degree	41%	32%
Social opportunities, connections, and friendships	78%	80%
Housing options on campus	31%	28%
Employment during or after completion	70%	81%
Closeness to their home	55%	60%

IMPORTANT COMPONENTS OF POSTSECONDARY PROGRAMS

In an open-ended question, families and professionals were asked to list three of most important components of PSE programs for students with IDD. The majority of respondents cited inclusive, individualized PSE opportunities geared toward students' interests and strengths, with curriculum accommodations and individualized supports. Only a few expressed a need for basic academic and life skills programs.

Survey responses expressed that meaningful college experiences for students with IDD must be geared toward a competitive, customized employment outcome. One parent summed up the thoughts of many: "I don't want my daughter to sit in an adult day training program. I want her to be included in her community with peers without disabilities, to be purposefully employed, and to feel she has a valuable place in society." Respondents overwhelmingly wanted students to receive job training or employment preparation through PSE.

Many families and professionals wanted opportunities for students with IDD to be included in regular college courses and activities and to develop friendships with students without disabilities. Several respondents mentioned the benefits of peer tutors and mentors. Some families stated that they would like to see students living on campus with students without disabilities.

Survey Respondents' Most Important Program Components

- Inclusive
- Individualized
- Geared toward students' interests and strengths
- Curriculum accommodations available
- Individualized supports available

The vast majority of survey respondents expressed the need for instructors and faculty to receive extensive training in curriculum accommodations, instructional strategies, inclusion, and individualized supports.

HOPES AND FEARS FOR THE FUTURE

In an open-ended question, respondents were asked whether they had anything else they wanted to share about their hopes for the lives of youth with IDD after high school. The majority of the 411 individuals who answered this question expressed worries, fear, and unease. One parent wrote, "The opportunities or lack [there]of for my son right [now] is so limiting it is heartbreaking." An educator stated, "When my students graduate and have nothing planned to pursue after high school, they tend to wither away indoors."

There was consensus about the need to provide youth with IDD the same opportunities as their peers. "We need opportunities that don't limit who can attend due to student need for supports (like the student is too impaired)," said one educator. One parent stated, "I want my child to have an enviable life that includes opportunities for a life with friends, social activities, and a good-paying job that will assist my child in living as independently as possible."

My students are all capable of learning, working and contributing to society. We need to have opportunities so that community inclusion becomes a reality, not just a pipe dream.

IMPLICATIONS

This survey indicates a hopefulness and a strong desire for change in the areas of transition planning, PSE, and competitive employment for youth with IDD. "Where do I begin? I guess I wish for my daughter to have all the opportunities any human being wishes to have," one parent reflected. "I pray for her to have the opportunities to be welcomed into the community without prejudice."

In addition, it appears that educators and families are eager to know more about how to engage in innovative, inclusive opportunities and activities. One educator observed: "My students are all capable of learning, working and contributing to society. We need to have opportunities so that community inclusion becomes a reality, not just a pipe dream."

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ABOUT THE AUTHORS

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