

# “Letting Go:” Parent Perspectives on the Outcomes of an Inclusive Postsecondary Education Experience for Students with Developmental Disabilities

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## Abstract

This qualitative study examined the desired and perceived outcomes of inclusive postsecondary education (IPSE) for individuals with intellectual and developmental disabilities (IDD) from the perspective of their parents. Currently, little is known about how individuals with IDD benefit from IPSE. Twenty-three parents of students or graduates of one, four-year certificate program of study, participated in phone interviews, where they were asked about their young adults' college experiences. Data were analyzed using constant comparative methods. Several themes were identified, including desired outcomes (e.g., development of independent living, career, social skills, and inclusion) and perceived outcomes (e.g., increased levels of social involvement, perceptions of self, and independent living skills). Parents witnessed their young adults gaining new capabilities that resulted from the transition to college, which helped them in the process of “letting go.” These findings enhance our understanding of the benefits that are afforded to individuals and families whose lives have been impacted by the “life-changing” experience of IPSE.

*Keywords:* Transition to adulthood, intellectual disability, independent living, skill development, perceptions of self

The opportunity to go to college is a reality for most high school students. Until this decade, inclusive postsecondary education (IPSE) was merely a dream for individuals with intellectual and developmental disabilities (IDD). The authorization of the Higher Education Opportunity Act (PL 110-315) in 2008 allowed for the propagation of programs designed to support individuals with IDD in accessing postsecondary education opportunities. A critical agenda of the Higher Education Opportunity Act was the establishment of high-quality, comprehensive, and inclusive transition and postsecondary education programs (Grigal, Hart, & Weir, 2013). This Act turned dreams into reality for many individuals with IDD and their families.

There is a growing body of literature on IPSE. The majority of early research was limited to program descriptions and evaluations of program components (Thoma et al., 2011). More recently, there has been a shift leading to an emerging body of literature documenting outcomes for students with IDD

(Grigal et al., 2013). Quantitative studies have linked postsecondary education participation for individuals with IDD to improved rates of employment (Butler, Sheppard-Jones, Whaley, Harrison, & Osness, 2016; Migliore & Butterworth, 2008; Miller, DiSandro, Harrington, & Johnson, 2016; Moore & Schelling, 2015; Ross, Marcell, Williams, & Carlson, 2013; Zafft, Hart, & Zimbrich, 2004), independent living (Grigal & Hart, 2013; Miller et al., 2016; Ross et al., 2013), and community participation outcomes (Miller et al., 2016) in comparison to peers with IDD who did not attend postsecondary education. However, authors of each of these studies indicated that results should be viewed with caution due to a multitude of limitations that exist including: (a) the high rate of variance between how IPSE programs are structured (e.g., four-year vs. two-year, residential vs. commuter, inclusive vs. mainstream); (b) the lack of control groups with which to compare IPSE graduates; and (c) the small number of graduates from which programs are based.

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As Henninger and Taylor (2014) noted, there is a "need to consider a wider range of outcomes beyond work, living, and relationships, to give a more complete picture of the transition to adulthood for individuals with IDD" (p. 106). Many of the desired "wider range of outcomes" for IPSE may not be readily measurable through quantitative means. Furthermore, given the complex roles that parents play in the transition process, there is a need to understand parents' perspectives on the desired benefits and perceived outcomes their young adults experience through IPSE.

Although families are communicating a desire for IPSE options for their young adults with IDD (Grigal, & Neubert, 2004; Hart, Grigal, Sax, Martinez, & Will, 2006), many do not expect these opportunities to be realized (Chambers, Hughes, & Carter, 2004; Martinez, Conroy, & Cerreto, 2012). Griffin, McMillan, and Hodapp (2010) surveyed 108 families of transition-age students living in Tennessee and found that parents wanted IPSE opportunities that: (a) focused on employment outcomes, (b) provided structured social activities, (c) allowed for individual choice in curriculum, and (d) utilized inclusive learning environments. Parents' highest rated concerns were for their young adult's safety and ability to function independently.

While little is known about the outcomes parents seek for their young adults with IDD in relation to IPSE, more is known about how they view successful transition to adulthood. Henninger and Taylor (2014) used qualitative analysis of open-ended survey responses to explore the "criteria for success" that parents identified for their young adults with IDD. Occupational and/or functional roles in society were considered top priority by parents, even if these roles were unpaid. Other criteria parents associated with successful transition to adulthood included: moving out of the family home, relationships with peers, skills required for successful daily functioning, independence or interdependence with support, and reciprocal community relationships. The authors concluded that the results:

suggest families' goals for their sons or daughters with IDD reach far beyond conventional criteria of success in adulthood in both depth of criteria and breadth of criteria... In other words, success in adulthood was often described subjectively as the individual reaching his or her full potential. (p. 105)

Moreover, interviews with 30 mothers of transition-age young adults with IDD led to similar results, with the authors noting the need to take a more qual-

itative approach to viewing outcomes of successful transition (McIntyre, Kraemer, Blacher, & Simmerman, 2004). Recreational activities and hobbies were noted as the most important component of quality of life for the young adults of these mothers, followed by their child's basic needs being met, involvement in a social network, and happiness or contentment. The authors also emphasized the disconnect between current federal policy on transition and its overemphasis on employment in comparison to their findings.

Hanely-Maxwell, Whitney-Thomas, and Pogoloff (1995) reported similar results from conducting in-depth interviews with parents regarding the transition process. Parents prioritized their young adult's development of friendships, constructive use of free time, and residential alternatives outside of the home. They desired social relationships outside of the family with unpaid individuals that resulted in happiness and interconnectedness. While parents desired a balance of work and recreation in their young adult's free time, "most also indicated that they would settle for filling free time with leisure and recreation activities and anything else that would keep their child happy, safe, and moving forward in his or her development" (p. 7). Furthermore, residential options outside of the home were perceived by families as essential to their young adult's development of independent living skills and social relationships that extended beyond family members.

Parents may experience a great deal of stress when faced with their young adult's transition period. Research has clearly found this transition period to be one of the most trying times for a family (Hanley-Maxwell et al., 1995). While parent involvement is one of the most commonly cited predictors of successful transition (Foley, Dyke, Girdler, Bourke, & Leonard, 2012), it becomes a balancing act as parents walk the tightrope of not undermining their young adult's self-determination and independence, while being strong advocates and negotiating the complex provider system. Furthermore, parents' concern for the safety of their young adult is acknowledged as a common barrier in the transition process, as parents' "over-protectiveness" often leads to hindered development of social skills and choice-making, often resulting in isolation.

Given the need to better understand IPSE outcomes for students with IDD, and recognizing the important roles that parents play in supporting their young adults throughout this transition period, this study sought to explore: (a) what parents hoped their son or daughter with IDD would gain from an IPSE experience, and (b) what these parents believed were the outcomes of their young adults' IPSE experience.

## Method

To explore parents' perceptions of how their young adult benefited from participation in IPSE, parents of the Integrative Community Studies (ICS) certificate program at the University of North Carolina Greensboro (UNCG) were recruited for enrollment in this qualitative study. The study explored what parents hoped their young adult would gain, as well as the outcomes they had observed in their son or daughter, as a result of the IPSE experience.

### Integrative Community Studies at the University of North Carolina Greensboro

ICS is a four-year certificate program of study offered by the Office of the Provost of UNCG, and coordinated by the Office of Comprehensive Transition and Post-Secondary Education (<http://beyondacademics.uncg.edu/academics/>). ICS was founded in 2007 as a grassroots initiative driven by parents of young adults with IDD. ICS became fully accredited by the U.S. Department of Education as a Comprehensive Transition and Post-Secondary Education program in 2011. ICS has graduated 57 students and currently enrolls 60 students.

ICS encourages students to meet their learning objectives through individualized plans of study that focus on self-determination, career development, and life planning. Student plans include a variety of interdisciplinary courses related to career goals and student interests. Students also complete certificate-based courses that teach them about adjustment to college life, financial literacy, self-advocacy, self-determination, and career development. The career development courses provide students with opportunities to develop their resumes, interview skills, job search strategies, and skills necessary to complete an application. Students also participate in service-learning experiences and internships, which help them further develop these newly acquired skills.

Students receive academic and advising support that supplements university supports and resources. Students work closely with their advisors to explore the principles of strategic life planning, which culminates in a post-graduation portfolio that serves as a summary of the knowledge and skills that have been acquired through the program.

ICS students are fully included in campus life. They have access to academic resources and courses that are consistent with their career and life goals. They have become involved in co-curricular activities such as campus clubs, ministries, activity boards, intramural and club sports, and sororities/fraternities. They also participate in new student orientations and

tours, work out in the recreation center, attend inter-collegiate sporting events, and participate in graduation ceremonies. ICS students are part of the fabric of the campus community.

ICS students live among the general UNCG student body in campus housing or in privately owned apartment complexes for college students that are adjacent to the university. ICS students have randomly assigned roommates from the general student body until they find fellow students with whom they wish to share housing. A combination of paid supports and volunteers assist ICS students in having a comprehensive university experience that prepares them for life following graduation.

### Data Collection

Prior to implementation of the data collection processes, study procedures and materials were submitted and approved by the UNCG Institutional Review Board. Parents of all current and graduated ICS students were emailed an invitation to participate in this study, and interested participants completed the informed consent documents. A telephone interview was scheduled once all potential participants' questions concerning the study had been answered and their consent forms were received. Telephone interviews, guided by a semi-structured interview guide, ranged from 40 to 90 minutes in length. Parents were asked: (a) why they thought it was important for their son/daughter to attend college, (b) what they hoped their young adult would gain from attending college, and (c) what actual gains, benefits, and outcomes they observed in their student/graduate? Telephone interviews were digitally recorded and transcribed verbatim.

Twenty-three parents participated, representing 22 students (two freshmen, two sophomores, five juniors, and eight seniors;  $n = 17$ ) or graduates ( $n = 5$ ) of ICS (see Table 1 for demographics on the participants and their young adults). All but two respondents were mothers. Disabilities represented among students included ID ( $n = 11$ ), autism ( $n = 5$ ), Down syndrome ( $n = 3$ ), ID/autism ( $n = 2$ ), and cerebral palsy/visual impairment ( $n = 1$ ). Student ( $n=17$ ) IQ's ranged from 41 to 69 with a mean of 58.5 ( $SD = 7.84$ ). Sixty-eight percent (68%) of the represented students and graduates were Caucasian, 27% African-American, and 5% Asian. Females comprised 64% of the students/graduates. The demographics of the represented students in the study versus the population from which they were drawn matched closely, except females were somewhat overrepresented in this study.

## Data Analysis

Data were analyzed using constant comparative methods (Patton, 2002), which allowed common phenomena to be identified across interviewees in a descriptive analysis approach. Interview transcripts were read multiple times, independently by the primary author and two research assistants, and were followed up with in-depth discussions to identify key content areas and potential codes. Based on these discussions, a coding system was developed (e.g., cooking, riding the bus). The researcher and assistants conducted independent data coding as an initial data reduction strategy, followed by a coding comparison. When differences in coding were identified, the data and coding system were discussed until consensus was reached. Memos were developed to document how differences were resolved, contributing to the final refinement of codes.

Coded data were reviewed by the primary researcher to identify categories connecting codes (e.g., codes such as riding the bus, riding the train, and using campus transportation, were grouped into the category of "transportation"). Themes (e.g., independent living skills) across categories were then identified. Memos were used to further define the properties and dimensions of the identified themes. Cross-interviewee analysis was conducted to determine whether patterns were consistent across interviews and to ensure the proper fit of thematic relationships.

## Findings

A number of themes emanated from the data. Parents were adamant that it was their young adult's desire to attend college, rather than the parents' preference. Parents desired several outcomes for their young adults that they perceived as only being possible through participation in IPSE, such as: (a) a typical college experience as an opportunity to learn valuable independent living skills, (b) opportunities for inclusion and to learn from peers without IDD, (c) development of social relationships and supports, (d) development of career skills and employment opportunities, and (e) the college experience as a stepping stone to the real world. Themes that arose from the data regarding outcomes that parents perceived included: (a) independent living (i.e., use of public transportation, personal care, handling personal affairs, financial management, use of technology), (b) perceptions of self (i.e., self-esteem and self-confidence, pride, advocacy, increased expectations of self), (c) social life and friendships, (d) campus and community involvement, (e) conversational skills, (f) happiness, (g) employment, and (h) "letting go" as

parents. Additional quotes related to each theme can be found in Table 2.

## Choosing to Go to College

Parents communicated that their young adults made the choice for themselves to attend college in most cases by instigating the search for college opportunities. Oftentimes this was triggered by having a sibling or friend who was planning to attend or was already attending college. Several parents described feelings of "sadness," as they did not want their son/daughter to face the disappointment of not being able to live out their dreams, before realizing IPSE was an option.

## Desired Outcomes

**Independent living.** Parents communicated their belief that the responsibilities associated with the "college experience" would provide valuable opportunities for their young adults to develop essential independent living skills. This included skills necessary for taking care of one's personal care needs, doing the laundry, cooking, housekeeping, financial management, time management, and problem-solving. They believed that this was true of typically developing young adults who attended college, and therefore, should be so for their young adults' development.

Several parents communicated concern that their young adults would be unable to further develop their independent living skills if they remained at home. One mother stated, "It's hard to teach someone independence when they're still living with you and you're doing everything for them" (P16). A few interviewees actually referred to their young adult as having "plateaued" at home regarding skills for independent living. In order to develop independent living skills, several parents believed their son/daughter needed to live on campus, and far enough away from home to avoid being tempted to intervene in their child's development. However, parents were cautious and desired their son/daughter to learn these skills in a "safe" environment with the "necessary supports" available. One parent admitted to being tired, when she opined:

It just took a load off of me to know that he is learning the skills that he needs to survive this world, and there are other caring people out there to assist him. It has just lightened up my life a whole lot because I was stressed out for a long time. (P12)

**Social relationships.** Parents believed the inclusive nature of ICS and the UNCG campus would pro-

vide opportunities for their young adult to develop and maintain social relationships. When addressing inclusiveness, parents identified engagement with peers [matriculating students] in classrooms, campus and community activities, and living arrangements as key components of the college experience. Parents believed that the myriad opportunities to participate in social activities on campus went well beyond the opportunities that were available to their sons and daughters in their home communities. They believed these opportunities provided their young adults with experiences and peer role models that contributed to their social growth.

Parents also believed that their sons/daughters were not the only individuals on campus who learned and benefited from the presence of students with ID. A parent of a freshman declared, "I think the campus community has something to learn from these students. Just because they learn a little differently, they too can succeed and persevere" (P1).

#### **Career skills and employment opportunities.**

Career skills and employment opportunities were almost always listed as desired outcomes by parents, but they were rarely considered to be the highest priority. For many, being able to make a valuable contribution to society was as important as their young adult being able to obtain employment. For example, a father of a senior hoped that "she would be able to live somewhat independently and have some type of job, employment, or just that she could do something to make a valuable contribution to society" (P11).

**College experience as a stepping stone to the real world.** Several parents specifically mentioned or alluded to the perception that the "college experience" represented a vital "stepping stone" to the "real world" for their young adult. One parent described it as an "opportunity to be in the real world with real people. Going to school...You're young, you're going to college. That's absolutely huge" (P5). Many parents described their young adults' secondary schooling as having occurred primarily in segregated settings. Families felt it was important to have the IPSE opportunity as a "stepping stone" between the sheltered world of a segregated high school to living independently in an inclusive community without attempting to make that leap all at once.

#### **Perceived Outcomes Through an IPSE Experience**

Parents identified several perceived outcomes for their sons/daughters through participation in the IPSE. The two most prominent outcome-related themes were independent living and perceptions of self. Within the theme of independent living, there

existed a number of subthemes, including: (a) using public transportation, (b) personal care, (c) handling personal affairs, (d) financial management, and (e) use of technology. Subthemes within perceptions of self included: (a) self-esteem and self-confidence, (b) pride, (c) self-advocacy, and (d) increased expectations of self. Additional outcome-related themes included conversational skills, social relationships, campus and community involvement, happiness, and employment.

**Independent living.** Many parents stated that a desired outcome for their student when entering college was the development of skills in support of independent living. Most parents communicated having some apprehension and doubt when their son/daughter enrolled in the program. They questioned whether it was realistic for their young adult to live on their own following graduation. Nevertheless, families began to believe that independent living was a possibility as they witnessed their young adult begin to successfully negotiate the challenges of adult life during their college years. One parent of a sophomore happily expressed, "We really believe now that she will be able to live on her own and take care of herself" (P3). The mother of a junior shared, "I never dreamt that she would be living in an apartment by herself. And she was there all last summer by herself, not even roommates were there" (P6). Another parent was pleasantly surprised that her female graduate was, "living alone, and we live one and half hours away" (P20). A parent of a senior proudly stated, "I never imagined that we would be buying a house for her to live in on her own, which we are... So it's a dream come true, literally!" (P10).

Parents acknowledged that their young adults would likely need some support (e.g., assistance with finances) to be capable of living in their own residence. However, they also identified several essential independent living skills that their sons/daughters acquired in the program. Acquired skill areas included: use of public transportation, personal care, handling personal affairs, financial management, and use of technology.

*Use of public transportation.* Upon entering the IPSE, a majority of the students had minimal experience with public transportation. Some students lacked basic mobility and pedestrian safety skills upon their arrival. Parents described students currently using local public transportation in addition to the campus transportation system. Several parents were in awe of their young adults not only mastering independent use of public transportation within the city limits, but also across long distances (e.g., trains).

These skills made it possible for individuals to return to their hometowns during university holidays and on an occasional weekend. Parents noted that the development of transportation skills boosted their young adults' participation in community activities.

*Personal care.* Parents spoke of their student's or graduate's increased ability to manage personal care. This area included showering, washing hair, and the use of personal care products. Parents also addressed the acquisition of skills for taking care of their living space, such as doing housework and laundry. They also learned how to make meal plans and grocery lists, as well as buying groceries on a budget. In addition, many students developed basic cooking skills. For some, this included the development of healthy eating habits. Some parents remained concerned that their young adults' eating habits were not quite healthy enough.

*Handling personal affairs.* Parents often identified how their student/graduate became more responsible for their day-to-day affairs. Parents recognized the development of time management skills, being responsible for assignment due dates, and use of personal planners. Handling one's personal affairs also included learning to adhere to one's medication schedule and getting new prescriptions when needed. Parents also described the development of important problem-solving skills (e.g., how to locate an item they had lost).

*Financial management.* Parents described significant progress in their young adult's ability to handle financial responsibilities. One mother of a sophomore described her daughter as being able to "track her spending and her expenses" (P4). A parent of a senior stated, "She is writing checks for bills and getting better at putting notes in a calendar regarding needing to write checks. She writes checks for rent, for GTA [public bus system] passes, etc. on her own now" (P17). Another parent of a senior referred to how her son developed money saving skills, "He knows when he gets paid to go to the bank and have his check cashed and deposit the money that he puts away for savings" (P15). A parent of a graduate indicated that her daughter was still using these skills two and a half years following graduation, stating:

She is really good at managing her weekly money. She understands that if she spends extra money on something, that she doesn't get to go out and have dinner with her friends and things like that... She writes her own apartment rent check. (P20)

While parents were proud of the financial management skills that their sons/daughters developed, none

of the parents believed their young adults would ever become totally independent financially. All parents acknowledged that some level of ongoing support with finance management would be necessary in their child's life.

*Use of technology.* Having the ability to use technology is critical for engagement in society. Parents cited a number of technological skills their young adults developed while in college. They included using a smart phone and applications to assist with time management and independent living, email, social media, and internet research. Parents referred to technology as "opening up new worlds," allowing individuals to remain socially connected and supporting their independent living (e.g., putting reminders in calendars to pay rent). One parent described how she was on the phone with her graduate who was simultaneously using FaceTime on his iPad to show her what was occurring so that they could problem-solve a situation together. Peer companions and staff alike worked together to develop strategies to increase his use of technology which was negligible when entering IPSE. Prior to graduation, he became competent with his cell phone and he currently uses multiple technologies simultaneously.

*Perceptions of self.* Parents often described their student/graduate as having increased self-esteem, self-confidence, and pride as a result of college. Parents described their young adults as becoming "self-advocates." They also described how they had increased expectations of themselves as a result of their college experiences.

*Self-esteem and self-confidence.* As students acquired new skills, developed social connections, and took on greater responsibility for their own affairs, parents noticed their young adult's self-esteem and confidence improving. One parent described this outcome as overcoming "learned helplessness." A parent of a senior indicated that her daughter's increased self-confidence would be connected to fewer support services post-graduation, stating, "She's going to be able to use less formal services because of her greater skills and her self-confidence and her confidence to be alone" (P10).

*Pride.* Parents described a new sense of self-worth being demonstrated by their young adults. For some, it was pride associated with being a student or graduate of college. Others demonstrated confidence in what they were learning in college, as this mother explained, "She says stuff all the time that I'm like, 'Where did you get that,' and that's when she says, 'I'm in college'" (P6). For others, it is pride in the skills they are developing, with the mother of a senior stating, "He is taking more initiative, being proud of

the decisions that he is making as far as his self-care or choices in who he spends his time with.” (P13). A parent of a graduate opined, “It has taught her that she can be her own person. That ‘Yes, I can go to college. I can go to college like everyone else and I can finish college and be an alumni of UNCG’” (P23).

*Self-advocacy.* Parents described their sons/daughters as developing a better understanding of and standing up for their needs and preferences during the college years. Several parents described their young adults as beginning to understand their disability and rights. A few parents provided specific examples of their young adult demonstrating self-advocacy skills such as negotiating with an apartment complex to paint curb cuts bright yellow, challenging service provider agencies for better services, letting family members know when they are going against their wishes, and addressing the city council to have a crosswalk added to a four-lane wide intersection so that he could access work in a safe manner.

*Increased expectations of self.* Parents explained that as their son/daughter developed new skills, their self-perceptions improved. Consequently, their expectations concerning their future also shifted. One mother of a senior linked these concepts by offering, “She is now saying that she wants to live independently. Her having experienced success has opened up her ideas for additional opportunities. She now has her learner’s permit and wants to drive” (P17). Other broadening expectations included being able to live independently, maintain employment, establish intimate relationships, and have children.

**Conversational Skills.** Parents noted that their young adults became more conversational and social. These students/graduates did not simply speak more, but were demonstrating increased reciprocity within their conversations. Students/graduates were also participating in conversations across a broader spectrum of topics, and were demonstrating accompanying social skills (e.g., eye contact and active listening). Parents of students with autism spectrum disorder were most vocal about these improvements in communication. They noticed their students moving beyond rote conversational messages, and gaining intricate nonverbal communication skills such as inflection and improved ability in sequencing the elements of their message. Many parents described changes in their son’s/daughter’s communication and conversational skills soon after starting their college experience with continual progress being made throughout the college years.

**Social life and friendships.** Parents discussed how their young adult became involved in social op-

portunities and developed friendships during college. While many friendships were with other ICS students, several were with matriculating students. Several parents witnessed their young adult developing genuine friendships for the very first time. Parents of students on the autism spectrum were especially surprised by this outcome. Parents of graduates were particularly pleased to observe that many of these social relationships were maintained beyond the college experience. Nevertheless, several parents wished that their son/daughter had developed additional social connections with matriculating students.

**Campus and community involvement.** Parents attributed much of their young adult’s social success to their increased involvement in campus and community activities. Parents identified a variety of campus events (i.e., basketball, baseball, and soccer games), activities (i.e., intramural and club sports, rock climbing at the recreation center), and memberships (i.e., clubs and campus ministries) in which their young adults participated. They described their student’s/graduate’s engagement in community activities such as community groups, volunteering, and church.

**Happiness.** The happiness of their student/graduate was a topic commonly identified by parents. For many, seeing their son/daughter as a “happy person” was priceless. Others in the family’s social network also noticed this increased level of happiness. Several parents expressed the importance of this outcome, not only because it made them, as parents, feel better, but also reflecting on the prevalence of depression among those with IDD.

**Employment.** The desire for their son/daughter to be employed upon graduation from college was met for some parents. A parent of a graduate explained how her daughter participated in Zumba for the first time during the IPSE experience, leading to a newfound passion that also doubles as a source of income, “She is a certified Zumba instructor. She teaches two classes” (P20). The parent of a recent graduate explained that her son had not yet obtained employment, but that he had learned many of the skills necessary to seek and gain employment.

Several parents expressed disappointment in their student not yet finding a job. While some parents may have been unsatisfied with this outcome, it should be noted that research indicates that ICS graduates are outperforming their peers who have not taken part in such an experience. A post-graduation survey noted that 84.6% of the graduates of the program had been employed since graduation from IPSE, and 61.5% were currently employed at the time of the survey (Miller, DiSandro, Harrington, & Johnson, 2016). Findings from the NLTS-2 indicated that

8 years post-high school, only 76.2% of individuals with intellectual disabilities had been employed since graduation, and only 38.8% were employed at the time of the survey (Newman et al., 2011). The significance of this difference is punctuated by the fact that the NLTS-2 data were collected in 2007, before the economic downturn, while all data on ICS were collected post-recession.

### Parents "Letting Go"

Parents expressed that they had also benefitted from their child's choice to attend college. Parent's described a phenomenon that we have labeled "letting go." Parents gained a new perspective of their young adults' capabilities when they witnessed them learning new skills and becoming independent young adults. A mother of a junior reflected, "It has allowed me to see what she can do" (P8). It was a life-changing moment for some parents when they realized their young adult was capable of being more independent, and they often did not find it easy after so many years of providing intensive support. It was recognized that their "letting go" was not only essential for the development of skills necessary to live independently, but also for their own quality of life. As one mother admitted, "I guess I can truly say that ICS saved me from myself...I found myself when I let [student's name] go" (P12). As another parent noted, "Letting go is not easy... However, it is important that parents and the community give our children the opportunity to grow and become productive citizens" (P19).

### Discussion

The purpose of this study was to explore the desired and perceived outcomes of IPSE for individuals with IDD from the perspective of parents and guardians. The findings revealed that the young adults instigated their own college attendance, while their parents were hopeful that the "college experience" would act as a stepping stone to the "real world" by helping their young adults develop essential independent living, career, and social skills. The findings indicated that their young adults learned many new skills, including how to use the public transportation system, personal care, handling personal affairs, financial management, and use of technology. Parents reported that the college experience improved their young adults' conversational skills and social lives, which included relationships developed through campus and community involvement. As a result of their enrollment in IPSE, young adults experienced enhanced self-perceptions and increased levels of happiness.

The findings provide timely insight into what parents value most as a result of their son/daughter's participation in IPSE. Given the important role that parents provide in the lives of these students, and the significant financial and emotional investments they make on their behalf, it would behoove IPSE programs to include these variables in evaluating the success of their programs.

These findings are consistent with the literature on parents' desires for their transition-age children. They fall in line with what Henninger and Taylor (2014) identified as parents' "criteria for success" for transition into adulthood, including moving out of the family home, relationships with peers, skills required for successful daily functioning, independence or independence with support, reciprocal community relationships and occupational or functional roles in society. Furthermore, just as Grigal and Neubert (2004) and Hart et al. (2006) found, parents did not expect these independent living outcomes to actually be realized. Despite having made significant financial and emotional investments on behalf their son's/daughter's college education, parents in this study openly admitted that when their child first enrolled in the program, they were apprehensive as to whether their young adult would ever be able to live independently. It was only when parents witnessed their son/daughter successfully navigating adult life and independent living did they began to believe. Parents were able to raise their expectations as their sons and daughters experienced multiple successes as young adults.

These important outcomes would not be possible, however, without access to matriculating courses with appropriate supports. With this in mind, the *AHEAD White Paper on Students with Disabilities and Campus Disability Services* (Association of Higher Education and Disability, 2010) provided guidance on the role that Disability Services should play in support of students with intellectual disabilities on college campuses. This report stated, "Disability Services professionals have the responsibility to become educated about the changes in the HEOA and the ways in which they can support students with intellectual disabilities within their institutions" (p. 1). While supports for independent and community living may fall beyond the scope of supports to be provided by Disability Services, "a SWID participating in courses or a program on campus, even though not admitted through the usual matriculating process, is eligible (otherwise qualified) to receive accommodations, just as a student with a disability taking a continuing education class would be" (p. 3). It appears that when families, IPSE programs, and Disability Services professionals take on the responsibility of meeting the

learning and living needs of students with IDD, important outcomes evolve.

These results should be viewed with caution. The findings are limited to the experiences of a small number of students/graduates with IDD at one university. Further research is needed to determine whether these findings are consistent with those obtained through other IPSE experiences.

### Conclusion

The Higher Education Opportunity Act (HEOA) of 2008 has provided many individuals with IDD opportunities to reach new heights through postsecondary education. Myriad high quality and comprehensive programs have helped young adults transition to adulthood, and have turned dreams into reality for many nontraditional students and their families. Including parents as integral partners in this process has contributed positively to the delivery of these postsecondary opportunities. Parents, as gatekeepers to these college experiences, working in tandem with IPSE programs and Disability Services professionals, help make continuing education a reality. By sharing their hopes, dreams, and goals for their adult children, inclusive postsecondary education programs have served these students well.

American society has come a long way toward the inclusion of individuals with IDD through increased employment, greater opportunities for independent living, and enhanced participation in the community. That said, it was noted in the current study that it was typically the young adult's desire to attend college, and not due to parents' prompting. Like their college-age peers without disabilities, the comprehensive and inclusive postsecondary experience served as an important "stepping stone" to the adult world. Career skills acquisition, friendship development, appropriate use of leisure, and learning to live independently were among the salient outcomes noted.

Although parents will continue to have significant influences on the overall health and well-being of their young adults, it was learned that a degree of "letting go" proved helpful to all parties. Family members came to the realization that many children's skills and sense of self actually plateau at home, and it may be necessary to instigate and support their young adults continuing their schooling away from home. These "life-changing" experiences become exceptional opportunities for students to transition to adulthood. Also, they often become perspective-changing and eye-opening experiences for parents. Furthermore, accessible and accommodating postsecondary educational opportunities should continue to play a

critical role in ensuring that the larger society benefits from a more broadly educated and prepared populace.

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Table 1

*Participant and Student/Graduate Demographics*

Participant		Student Graduate				
Participant ID Number	Relationship to Student/Graduate	Disability (IQ, if provided)	Age at Time of Interview	Gender	Race	Year in College
P1	Mother	ID (63)	19	Female	Caucasian	Freshman
P2	Mother	Autism (66)	19	Female	Caucasian	Freshman
P3	Mother	ID (57)	22	Female	Caucasian	Sophomore
P4	Mother	Autism (69)	19	Female	African American	Sophomore
P5	Mother	ID (56)	32	Male	Caucasian	Junior
P6	Mother	ID/Autism (64)	22	Female	Caucasian	Junior
P7	Mother	Down syndrome (58)	36	Female	Caucasian	Junior
P8	Mother	ID (61)	22	Female	Caucasian	Junior
P9	Mother	Autism (57)	25	Male	Asian	Junior
P10	Mother	Cerebral palsy/visual impairment	22	Female	Caucasian	Senior
P11	Father	ID	24	Female	Caucasian	Senior
P12	Mother	ID (65)	22	Male	African American	Senior
P13	Mother	Down syndrome (67)	24	Male	Caucasian	Senior
P14	Mother	ID/Autism	22	Male	African American	Senior
P15	Mother	Autism	22	Male	African American	Senior
P16	Mother	Down syndrome	25	Female	Caucasian	Senior
P17	Mother	ID (64)	22	Female	Caucasian	Senior
P18	Mother	ID (61)	26	Male	Caucasian	8-months post-grad
P19	Mother	Down syndrome (48)	32	Female	African American	9-months post-grad
P20	Mother	ID (48)	29	Female	Caucasian	2 ½ years post-grad
P21 & P22	Mother & Father	ID (50)	30	Male	Caucasian	4-years post-grad
P23	Mother	ID (41)	28	Female	African American	4-years post-grad

Table 2

*Supporting Quotes*

Theme/Subtheme	Topic	Quotes
<b>Choosing to Go to College</b>		
		“She really wanted to go to college. She has an older sister who went to college and she wanted to do exactly what her older sister did. And at first it made my husband and I very sad because we thought there’s no way, that can’t be true for her, no matter how hard she works.” (P2)
<b>Desired Outcomes</b>		
Independent living	Types of skills associated with college experience	“...nobody had a kid in college who doesn’t hope on the other end of this that they will be taking care of their finances and taking care of themselves and maybe learning some skills for a job, but skills for life. They can learn not only in the classroom, but in the dorms and in managing your [their] life.” (P7)
	Plateaued at home	“Living independently makes you develop problem-solving skills, time management skills, and life skills in general.” (P17) “I thought it was really important for her to get away from home where we were all sort of in a rut... she was starting to plateau on her ability to be independent, maximally independent. And it just felt like it was a great opportunity to push the envelope to areas in which especially, me as mom found it hard to keep working on.” (P10)
	Away from family’s influence	“If he was here in [home town] then we’d be dropping by all the time. ‘Let’s go check on [student’s name], let’s go make sure he has enough food.’ Your parents love you the most, but I think sometimes they’re your worst enemies because it’s so easy to get back into that ‘well, let me do this for him.’ And now he’s an hour away. If he needs food, he needs to walk to the store and get food. He’s got to figure things out on his own.” (P5)
	But in a safe environment	“I wanted her to have the opportunity to go to a place where she felt valued and had an opportunity to experience what other kids experience in college, but it had to be in a safe environment... Safe environment meaning that she’d have the support that she would need.” (P1)
Social Relationships	Inclusive nature of UNCG and opportunity to learn from peers	“There is greater exposure to peers without disabilities, giving them an opportunity to befriend individuals who may become natural supports... These peers may also be good role models; they also may not, but it’s worth the gamble.” (P20)
		“[If they were not in college] they wouldn’t be around typical college students and typical college social life. The learning from this experience is so broad, it is hard to capture. College life is such a significant growth opportunity for those fortunate enough to have that experience. ICS students live with typical roommates, socialize with UNCG students, and attend UNCG classes... They have the opportunity to make life-long friendships with typical college students.” (P21)

Theme/Subtheme	Topic	Quotes
	Impact on matriculating students	"We've always believed that the world is a better place, and individuals with disabilities can be healthier and happier if everyone's mixed up in a community. So the extent to which people are segregated with disabilities, the world is not going to get to know them, and they're not going to be able to offer their gifts and contributions. And people with or without disabilities have a lot to offer each other and when you segregate them, it's not right, ethically, morally, to me personally, but I also think it's almost impractical. It's not the best way for the world to get the best of everybody's." (P10)
Career Skills and Employment Opportunities	General	"So we hoped that he would gain vo-tech skills of some sort, employability." (P18)  "I don't want to see her kind of down to a very limited income. I think she is capable of being gainfully employed and so I think that that's another thing. Just seeing her maybe being able to utilize a certificate for employment or for self-employment. Just whatever she gains from that part of it academically to be able to benefit her in the workforce." (P4)
	Not the most important outcome	"What I would hope, is that she find a friend or friends to live with...that they can support each other in a good way...and that she's able to have a job that she loves and be happy." (P2)  "...it [employment] is not my greatest priority at all. But I would like to see her more involved in something quasi-employment, whether it's a volunteer job, that's fine. I don't really care about the money as much as the idea that she responsibly get up and go do whatever is on her schedule besides a fun day program or something." (P10)
"College experience as a "stepping stone" to the "real world"	General	"From my perspective what was most important is looking towards living in the real world, living in society, and contributing in whatever way she can when she becomes an adult. I think it would be quite hard to be so separated through most of her life, through special schools, special programs, you know, one-on-one people helping her, and then all of a sudden say, 'okay, now go live in an apartment with a friend and interact with the world in a different way, by yourself.' So this again is sort of the easing in process with the appropriate support that could gradually be withdrawn so she's able to do it." (P2)

### Perceived Outcomes from Participation in an IPSE Experience

#### Independent Living

Use of Public Transportation	Pedestrian safety	"When she was in high school she had a mobility teacher that said she would never learn how to cross the street, which she obviously crosses [major roads] all the time [now]." (P16)
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Theme/Subtheme	Topic	Quotes
	General	<p>“[She] Also learned to navigate the bus system...she rides the Greensboro City bus...Spartan bus [university bus]. And she knows the bus routes and the numbers and she calls and says, ‘Dad I’m going on bus 63 to go so and so or bus 38 back home’ or whatever. She knows how to resolve problems on her own.” (P11)</p> <p>“He has a seizure disorder...So he’s not going to be able to drive. So being able to take the bus. I mean, now he takes the bus from his apartment to the train station downtown in Greensboro and then the train home on Friday nights. You know, it’s fabulous that he can do that.” (P5)</p>
	Impact on community participation	<p>“He is a man about town... He has ultimate confidence in getting anywhere he needs to get when he needs to get... before ICS when he was sitting at home, [he] didn’t know how to get on a bus, didn’t know how to get anywhere.” (P18)</p>
Personal Care	Housekeeping	<p>“Housekeeping. I mean changing the sheets on the bed, and knowing when to do that. And folding his clothes, putting them away. Unloading the dishwasher, mopping the floor in the apartment” (P5)</p>
	Meal planning	<p>“Each week she prepares a meal plan and purchases it accordingly using her debit card to pay...She prepares her own meals...does her laundry...cleans her room and shares the common chores to maintain an orderly residence.” (P11)</p>
	Cooking	<p>“I talked to her over the weekend. She was making eggs. I said, ‘[student’s name] you eat eggs?’ She said, ‘On the weekend I do. There is a lot of protein in eggs. Just on Saturdays or Sundays I eat eggs.’ She never ate eggs at home, no less made them herself. She asked for a George Foreman grill for Christmas.” (P7)</p>
	Healthy Eating	<p>“She’s cooking on the stove and cooking healthy meals...So we are really excited for her for that. Because she was always a bit afraid of the oven or the stove and that kind of stuff so that has been very good for her.” (P3)</p>
Handling Personal Affairs	General	<p>“She has learned to handle her assignments; that was a challenge the first semester. She has learned to check email, which she never did before. Voicemail, which she never did before, she has learned those things. So these kinds of communication, basic communication skills that she never had to do before, she has learned those things. And she has learned about a schedule...now she uses a calendar.” (P2)</p>
	Medications	<p>“...she is usually pretty good at handling that [taking her medications] and getting her prescriptions on time and it used to be [i.e., early college years] we were always reminding her, so I think she’s getting better at those things and wants to do more.” (P7)</p>

Theme/Subtheme	Topic	Quotes
	Problem solving	"For instance, just this week she calls me, she left her bookbag at the Salvation Army when she went there to volunteer. And I said, 'What did you do?' She said, 'I've called them and they have got it stored somewhere, in the closet or behind the desk, and I'll get it Friday morning. Six years ago it would have been, she would have cried and been bent out of shape...she just knows how to deal with a lot of those problems that she could have never dealt with because if she would have been at home, she would have, we have accepted the resolution to those problems for her. We would have just done them ourselves...So she has learned to do that.'" (P11)
Financial Management	General	"She is really good at managing her weekly money. She understands that if she spends extra money on something, that she doesn't get to go out and have dinner with her friends and things like that...She writes her own apartment rent check." (P20)
Use of Technology	General	[referring to student now having a cell phone] "She took off and it opened up a whole world for her as far as communication with people and texting and she talks to cousins and aunts and uncles...I was just floored at how it seemed to open up communication for her." (P3)  "Like working on a computer. She can find anything. That's how she troubleshoots too. She will need something like toothpaste, for example. She will need toothpaste; she will sit down on her iPad or computer and she will research and she will say 'Hey we can go get it at CVS and it's such and such or Walmart has if such and such.'" (P11)
<b>Perceptions of Self</b>		
Self-Esteem and Self-Confidence	Learned helplessness	"[he had learned] this helplessness thing, you know, 'help me, help me.'...But you know college helped him like, 'I don't need that help.'...being able to know that he can handle things. And he does." (P22)
	General	"This program is so important to [student] because it's just a huge boost for his self-esteem." (P5)  "This opportunity allows them to meet new people, learn new things, work on their social skills, learn to navigate a college campus, and take responsibility for their own actions. This is a huge self-esteem booster." (P17)
Pride	Being a college student or graduate	"When we first visited the campus after she'd been there for a little while, she showed us around, gave a description of all the buildings. She's so proud. So she has a great sense of pride and a sense of accomplishment of being there." (P2)

Theme/Subtheme	Topic	Quotes
Self-Advocacy	Have a disability, but have rights	<p>“She loves that class [advocacy]. I think she is learning that she is a little bit different and that there are people that are different and that it doesn’t matter. And that everybody has the right to education and to get a job. I think it has been really good for her.” (P4)</p> <p>“Everybody has noticed that he is much more of an advocate and he is much more comfortable having a disability, and being okay about talking about it...now he feels much more comfortable talking about it and advocating for things that he and others with disabilities should and can’t have.” (P14)</p>
	Being a self-advocate	<p>“She went and negotiated with the [apartment complex name] manager to paint curbs cut bright yellow because she was having trouble seeing, and she explained why. And he did it!...She changed provider agencies from [habilitation provider] to [other habilitation provider] and that was because she wasn’t satisfied with the service. And five years ago she wasn’t even aware of a provider agency as an entity and that you could have a choice and that you had a right to go to another service. And all of those things were things I handled. And now she handles them.” (P10)</p> <p>“For example, if he is in a situation that he doesn’t want do something, he will speak out...If there is a situation where we want him to come home for the weekend, he will say “No, I don’t want to come home for the weekend. I have things to do.” (P15)</p>
Increased Expectations of Self	General	<p>“So he has changed in that he really feels like he can go and do anything.” (P14)</p> <p>“He really didn’t have any expectations on what he could do when he started, and now it’s a job, it’s an apartment, it’s a wife, it’s a circle of friends for dinner parties, it’s volunteering. All those expectations, which he didn’t have any of [before], he just expects those things to be a part of his life [now].” (P18)</p>
		Students with autism
Conversational Skills	General	<p>“Now I’ll never forget the first time she called us and told us a story. I mean, she told the story from start to finish perfectly [emphasized]...because she never really use to have a good conversation. It was more one sided and short answers...She has developed communications skills, eye contact, vocabulary, use of phrases, listening, and questioning techniques.” (P11)</p>
	Students with autism	<p>“So in terms of his verbal ability, what we have seen over the years [while in ICS] is that he is not just saying things that are rote. The timing and the inflection and the volume and the sequence within conversation has matured. It’s not just verbal; it is also that he may be thinking more. The range of words and phrases that he has to choose from has grown. The kind of variety of choices he might draw from for things to say is richer now ...he is picking things that are more socially relevant and he also has more choices and he is verbalizing it in a more natural way.” (P9)</p>

Theme/Subtheme	Topic	Quotes
	Began early and continued to develop	"I noticed immediately after one month in the program that her communication skills and her social skills had improved greatly... she was able to start conversations, ask questions, and do appropriate responses...Once she enrolled at ICS she was coming home initiating conversations. When I say conversations, I mean more functional conversations. She could ask how are you doing, ask about events, she was just more open...I guess the freedom of being at school and to every day be in contact with students and her peers made a difference." (P19)
Social Skills and Friendships	General	"The change within her friendships. I know she is pretty close with [name of another ICS student] and that is something that she had not had prior to ICS; somebody that she would have that would call her. So she would call lots of people [prior to going to college] and she would Facebook lots of people and message lots of people and invite them to parties and all kinds of other things to try to reach out, but she did not have people that reached back and so I see that as a really great change." (P4)
	Matriculating peers	"He calls these people up now and they get together and go out and do things together and that is all I've ever wanted for him is to be social and have friends. And he does." (P12)
		"And it was neat to see the students speaking to [graduate's name]. I was elated when I would be out on the campus with her...and a typical student would say 'Hi' to her and she would say 'Well I know them from X, Y, and Z.' I thought it was neat." (P19)
		"One of [graduate's name]'s best friends was one of his typical college roommates. And they remain best friends...So when [best friend's name] comes down here, they always go out. They go out to eat and have a beer together. And then [best friend's name] said, 'Can [graduate's name] just fly out to D.C. by himself?' And I said 'Why not?' So [graduate's name] flew to D.C. by himself...He's developed some wonderful friendships that have lasted." (P21)
Campus and Community Involvement	General	"He is in a bowling league. He has always bowled with Special Olympics and now he is in a league and he has made friends through that." (P12)
		"Very good community volunteer. [He] Really likes it and that all came through ICS teaching him how to get out in the community, that he could, if he couldn't work, he could volunteer. Loves doing it." (P18)
Happiness	General	"She just seems so happy. Oh, that is another thing that she does now, is that she laughs a lot. Outwardly laughs. It just seems like she kept a lot of that hidden before." (P6)
	Others notice it too	"...she is extremely happy, which is great...her Aunt, especially in the first couple of years would say 'She looks so much happier.' One of our neighbors said last year 'Wow, she just seems so much happier and so much more confident.' So I think it is noticeable...I think she is a happier, fuller person." (P7)

Theme/Subtheme	Topic	Quotes
	Importance for individuals with IDD	“He has been very happy and that is really important. It’s important because so many folks with developmental disabilities have problems with depression...because they feel like they are not a part of life. It’s like sitting by watching life go by. So he has been very, very happy and that means a lot to a parent and you want your child to be happy...he has had the time of his life for four years, so to have him feel that way and be happy for four years where there were many years that he was not because he had some difficulty circumstances in his life, that means everything to a parent.” (P14)
Employment	General	“...actually has a part time job and he wanted to become an auto mechanic and he has a part time job actually working at an auto shop...he helps with oil changes and state inspections, and rotating tires.” (P15)
	Career related skills	“He knows how to apply to a job...all of those things I would say he’s maintaining. He knows what you have to do. He knows sometimes you have to go online, sometimes you go in. He knows the process.” (P18)
<b>Parents “Letting Go”</b>		
	General	<p>“I miss him but I know that I have to let go. I was a protective Mom. I didn’t want anything to happen to him. I wanted his life to be good. I wanted his life to be great and I was overbearing and overpowering him and I had to look at what I was doing. I was doing things because I loved him. I was doing things because I was his Mom and I want to see him succeed. But when I pulled back and I felt secure in the program, he just sprouted.” (P18)</p> <p>“It has helped alleviate the fear of letting go...One of the things parents fear the most is letting go...And I also tell parents that when your child is ready you have to have the confidence to let it happen...You have to have confidence in them and you do feel that confidence once you see them going out without fear.” (P19)</p>