INTERACTIONS WITH AND BETWEEN FAMILIES AND PROFESSIONALS IN
COLLEGE: PERSPECTIVES OF YOUNG ADULTS WITH INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES

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Abstract

Postsecondary education programs (PSEs) are becoming increasingly available for young adults with intellectual and developmental disabilities across the United States. Positive interactions between young adults and their families and professionals, and collaborative family-professional interactions can enhance transition outcomes for individuals with disabilities, including successful transition into and out of PSEs. However, there is limited research on the perspectives of the young adults who attend PSEs regarding these topics. The purpose of this qualitative study was to examine the retrospective perceptions of 10 PSE graduates regarding (a) interactions with their families, (b) interactions with PSE professionals, and (c) interactions between their families and PSE professionals. Participants reported negative and positive interactions with their families and PSE professionals, described how their families and PSE professionals interacted, and also provided recommendations for families and professionals to support young adults with disabilities. Implications and future research are discussed.

Keywords: transition, disability, college, collaboration, student, parent

Interactions with and Between Families and Professionals in College: Perspectives of Young

Adults with Intellectual and Developmental Disabilities

Postsecondary education programs (PSEs) are higher education programs designed to

increase social, academic, and employment-related skills among young adults with intellectual

and developmental disabilities (IDD; Griffin, McMillan, & Hodapp, 2010). Although PSEs offer

many of the same experiences and opportunities as typical college programs (e.g., college

courses, internships, involvement in student groups and organizations), students are not required

to meet standard admission requirements such as a high school diploma or SAT/ ACT minimum

scores. Further, although the nature of PSEs vary widely (e.g., length of program, on-campus

living options, program requirements, number of college courses taken; Grigal, Hart, & Weir,

2012), students who attend PSEs receive a certificate of completion from the college, not an

official college diploma.

PSEs are becoming increasingly available to young adults with disabilities across the

United States (Plotner & Marshall, 2016). In fact, according to the Think College website, there

are over 260 PSEs operating in 49 U.S. states as of early 2019 (Think College, n.d.). PSEs are

found to result in numerous positive outcomes for individuals with disabilities, including

individual growth and development, greater independence, social satisfaction, and increased

rates of employment (Grigal, Hart, Smith, Papay, Domin, 2018). Given greater access and

research documenting the positive outcomes of PSEs, it is likely that PSEs are an increasingly

desirable goal for many students with IDD preparing to transition out of high school.

Better transition outcomes occur when educators provide students guidance, information,

and encouragement to learn about a range of post-school options and set goals to achieve those

goals (Byndloss, Coven, Kusayeva, & Johnston, 2015). However, transition from high school to

college is challenging for many young adults, as they experience difficulty making decisions

related to college programs and may experience financial strain as well as heightened levels of

stress and difficulty adjusting to college life (Arnold, Lu, & Armstrong, 2012). Further, the

transition to college can prove especially challenging for students with disabilities, who are more

likely to experience a lack of preparation for college in high school (e.g., appropriate social

skills, coursework; Francis, Regester, & Reed, 2018), compared to their peers without

disabilities. Moreover, transition barriers are exacerbated for students with IDD seeking to attend

PSEs (U.S. Department of Education, Office of Special Education and Rehabilitative Services,

2017). For example, students with IDD are more likely than their peers with and without

disabilities to experience: (a) a lack of involvement in transition meetings in high school

(Shogren & Plotner, 2012), (b) student and family difficulty navigating changing roles and

responsibilities (Francis, Fuchs, Johnson, Gordon, & Grant, 2016), (c) a lack of special educator

knowledge of available resources and services outside of high school (U. S. Department of

Education, National Center for Education Statistics, 2017), and (d) low expectations from

families and professionals (Francis, Gross, Turnbull, & Turnbull, 2014). However, positive

interactions between young adults with IDD and their families and professionals, and

collaborative family-professional interactions can enhance successful transition into and out of

PSEs (Francis et al., 2018).

　　　Positive family interactions with their young adults with disabilities (e.g., interactions

that occur between families and young adults that result in successful young adult outcomes) are

crucial during transition planning, as young adults often turn to their families for on-going

guidance and support into adulthood (Francis et al., 2018; Lindstrom, Doren, & Miesch, 2011),

including guidance on postsecondary education, residential opportunities, and employment

options (Boehm, Carter, & Taylor, 2015; Timmons, Hall, Bose, Wolfe, & Winsor, 2011; Yarbrough, Getzel, & Kester, 2014). Positive professional interactions (e.g., interactions that occur between professionals and young adults that result in successful young adult outcomes) also influence positive student outcomes by teaching key skills and providing important information and support as students age (Timmons et al., 2011; Wehman et al., 2015). In addition, research indicates that collaborative family-professional interactions (e.g., families and professionals collaborating to achieve shared goals related to positive young adult outcomes) result in benefits for all stakeholders, including students (e.g., enhanced academic achievement and positive behavior; Hoy, 2012), families (e.g., reduced levels of stress; Burke & Hodapp, 2014), and professionals (e.g., enhanced instructional efficacy; Lawson, 2003).

Despite research indicating positive outcomes associated with positive family and professional interactions and collaborative family-professional interactions as young adults age into adulthood, limited research exists on the perspectives of young adults with IDD on these constructs (DePape & Lindsay, 2016). For example, while some research has captured perspectives of college-age young adults with disabilities (Ankeny & Lehman, 2011; Cawthon & Cole, 2010; Dallas, Ramisch, & McGowan, 2015; Getzel & Thoma, 2008; Kubiak, 2017; Paiewonsky, 2011; Sayman, 2015), these studies (a) include small numbers of participants (e.g., case studies) from a single school or program; (b) do not investigate the perspectives of students who graduated from PSEs; and (c) do not investigate how students, families, and higher education professionals can interact to enhance student outcomes.

In addition to a general paucity of research exploring the perspectives of young adults with IDD without the aid of proxies (Francis et al., 2014), and despite the demonstrated importance of positive family and professional interactions with young adults during transition,

there is a gap in understanding of how young adults with IDD perceive interactions with and between families and professionals. An exploration of young adult perspectives regarding these important topics may have the potential to inform policy and practice related to young adult interactions with families and professionals, and family-professional interactions aimed at supporting young adults to achieve positive outcomes following graduation from educational systems. Therefore, the purpose of this study was to explore the retrospective perspectives of PSE graduates regarding their interactions with families and PSE professionals, as well as interactions between their families and PSE professionals. Specifically, three research questions guided this study: (a) what are the perceptions and experiences of PSE graduates regarding their interactions with their families while in college (e.g., ways in which families and PSE graduates communicated, ways in which families were directly involved in the lives of PSE graduates), (b) what are the perceptions and experiences of PSE graduates regarding their interactions with PSE professionals (e.g., ways in which PSE graduates and PSE professionals communicated, ways in which PSE professionals were directly involved in the lives of PSE graduates), and (c) what are the perceptions and experiences of PSE graduates regarding the interactions between their families and PSE professionals while they were in college (e.g., ways in which families and PSE professionals communicated and collaborated). Although positive interactions are important, this study was intended to report emergent data from the interview questions related to participants' retrospective perspectives, rather than focusing on the participant perspectives of the direction of interactions (e.g., positive and/or negative interactions).

Methods

The researchers employed a phenomenology approach for this study, as they sought to understand a lived human experience- in this case, the experiences of PSE graduates in relation

to interactions with and between their families and PSE professionals while in college (Patton, 2002). We elected to interview PSE graduates for two reasons. First, we sought to explore the retrospective perspectives of individuals with lived experiences attending and graduating from a PSE. Second, we rationalized that participants may feel less pressure to answer questions about their PSE experiences "correctly" or acquiesce if they were no longer attending the program. Although purposeful sampling is ideal for phenomenological research to ensure that participants have direct experience with the phenomena under study, we employed a three-step convenience sampling procedure to recruit participants for this research (Maxwell, 2005). We engaged in convenience sampling due our inability to gain access to PSE graduate contact information from PSEs (in compliance with FERPA regulations).

The first step to recruit PSE graduates for this study involved the principal investigator emailing nine PSE directors and staff who expressed interest in family-professional collaboration during conference presentations. This introductory email described the investigator's interest in learning more about family-professional collaboration in PSEs and requested that PSE directors distribute a recruitment email to parents (e.g., biological or adoptive mothers, fathers, legal guardians) of young adults who graduated from the PSE within the last three years. A total of five directors from PSEs located in differing U.S. regions (i.e., West, Midwest, Northeast, Eastern, and South) agreed to distribute the recruitment email (Author, 2017).

Second, parents completed an online demographic questionnaire embedded within the recruitment email. This brief questionnaire included demographic questions (e.g., race/ethnicity of parents and young adults, age and disability of PSE graduates, guardianship status) and provided parents an opportunity to provide contact information to participate in an interview or

focus group. In total, 22 mothers and four fathers participated in interviews with the principal

investigator (Author, 2018).

Third, the principal investigator invited parents to extend the opportunity to participate in

an interview to their young adults who graduated from a PSE for the current study. The principal

investigator communicated with interested PSE graduates in one of three ways: (a) emails

initiated by parents that included both the PSE graduate and principal investigator, (b) emails

initiated by PSE graduates sent to the principal investigator- some of which also included their

parents, or (c) emails initiated by the principal investigator sent to PSE graduates via email

addresses provided by parents. The principal investigator included legal guardians on emails sent

to PSE graduates, as appropriate.

Participants

In total, the principal contacted 14 PSE graduates. Of these, 10 participants who

graduated from one of four PSEs located in the Midwestern (*n*= 4), Eastern (*n*= 2), Southern (*n*=

3), and Western (*n*= 1) regions of the U.S. responded and agreed to participate in an interview.

The programs from which PSEs participants attended varied. The Midwestern PSE was two-year

residential program with approximately 30 students enrolled that, according the Think College

website, focused on providing inclusive academic, social, residential, and vocational

opportunities for students. The Eastern PSE was a four-year program with approximately 50

students enrolled. This PSE had an option for program participants to live on campus, if dorms

were available. According to the Think College website, this program focused on providing

academic supports and vocational opportunities. The Southern PSE was a four-year residential

program with approximately 60 students enrolled, that according to the Think College website,

focused on enhancing self-determination, long-term planning, and vocational skills. Finally, the

Western PSE was two-year residential program with approximately 40 students enrolled that,

according the Think College website, focused on teaching independent living, vocational, and

self-advocacy skills. With the exception of the Midwestern PSE, all programs were

Comprehensive Transition Program (CTP) Certified at the time the interviews took place.

According to the Higher Education Opportunity Act of 2008, CTP certification ensures that,

among other things, PSE students attend university courses and experience

employment/internship opportunities among individuals without disabilities at least 50% of the

time. CTP certification also ensures that students enrolled in PSEs are able to use federal

financial aid for tuition (e.g., Pell Grants), thus enabling greater access to PSEs for economically

diverse students.

Table 1 provides information related to participant demographics, including disability

diagnoses and basic family demographics. PSE graduate demographic data was derived from a

questionnaire completed by participants' parents (described in the previous section), but the

principal investigator corroborated questionnaire information during interviews with PSE

graduates. At the time of the interviews, Gabriel, Finn, Christian, and Lennon lived with their

parents. Mae, Quinn, Zach, and Wren lived in community settings with roommates who also had

disabilities. These participants received paid drop-in support from a disability service agency.

Sean lived in a group home for individuals with disabilities with 24-hour support provided by a

disability service agency. Cooper lived in an intentional community designed for individuals

with disabilities with 24-hour support provided by unpaid individuals without disabilities also

living the in community, in addition to paid one-on-one support from a disability service agency.

All participants qualified for Social Security disability-related benefits and received support from

vocational rehabilitation and other disability support services (e.g., Medicaid Waivers, paratransit).

Interviews

The principal investigator obtained written consent from participants via an IRB-approved modified consent form that included simplified sentences, enlarged print, and interview questions. When applicable, the principal investigator also obtained consent from legal guardians prior to conducting interviews. The principal investigator communicated with all participants to determine their preferences regarding (a) the degree to which they wanted their family member(s) or another trusted individual involved in the interview process (e.g., if they would like a parent to be present during all or part of the interview), (b) how they would like to be interviewed (e.g., in-person, over the phone, via Facetime), and (c) where and when they would like to be interviewed. In addition to securing written consent, the principal investigator also obtained verbal assent prior to conducting all interviews by reviewing the purpose of the study, affirming participant comfort participating in the study, inviting questions about the study, and reminding participants that they could skip questions or stop talking at any time.

Interviews lasted between 32 and 92 minutes, averaging 67 minutes in length. All participants preferred to participate in interviews without their families present. However, Gabriel and Christian preferred to participate in an interview together. A total of six interviews took place remotely; three via phone and three via Facetime or Skype. Young adults who participated remotely were interviewed in their homes, with the principal investigator situated in a private university office. The principal investigator placed a noise-cancelling machine outside of the closed office door to encourage participant privacy**.** Interviews with the four remaining participants took place in local restaurants of the participants' choice.

The principal investigator used a semi-structured interview protocol to facilitate interviews. The protocol was developed based on findings from interviews with parents of PSE graduates about their experiences collaborating with PSE professionals and supporting their PSE graduates into adulthood (e.g., Francis et al., 2018; Francis & Reed, 2019) and previous research on barriers and strategies related to student-centered transition practices and family-professional collaboration (e.g., Hetherington et al., 2010). The protocol included questions and probes related to (a) transition experiences in high school (e.g., "Tell me about high school," "Tell me about the best/worst part of high school."); (b) experiences in PSEs (e.g., "Talk to me about when you started [College]." "Tell me about the most difficult/your favorite part of college." "If you could go back to [College], what would you change?"); (c) experiences with their families while in high school and college (e.g., "Did your relationship change at all when you went to college with your parents or with your siblings?" "Pretend you're in college and you see your family calling. What do you think they are calling about?" "Pretend you're in college and you need to call your family. Why are you calling them?"); and (d) advice for students, families, and teachers in high school and university settings (e.g., "Pretend that I am going to teach parents what to do when their children go to college. What should I teach them?" "Pretend that I am going to teach professors and [PSE] staff how to support students in college. What should I teach them?" "Pretend you're in front of a group of new [PSE] students. What advice do you have for students going to college for the first time?").

Analysis

Our analysis team was comprised of the principal investigator and a graduate research assistant from a public university. Both researchers had experience teaching high school students with IDD. The principal investigator was a faculty member in the department of special

education, the former director of a PSE, and the sibling of a brother with multiple disabilities.

The graduate research assistant was a doctoral student in the department of special education and

also previously taught courses for students in a PSE. These experiences provided the researchers

important contextual background for understanding the nature of different PSEs, PSE students,

and interactions among students, families, and professionals.

For the first step in the analysis, a professional transcriptionist transcribed all recorded

data. Second, the principal investigator read transcripts while listening to audio recordings to (a)

de-identify the transcripts, (b) get a general sense of the data, and (c) ensure transcription

accuracy (Creswell, 2009). Third, the researchers engaged in data reduction and interpretation by

open coding the data, or making meaning of the data by coding it for primary categories of

information. They began the open coding process by independently reading a single transcript

line-by-line to determine keywords and descriptive categories represented in the data. Next, they

debriefed to identify similarities and differences among the open codes and developed an initial

codebook based on this discussion (Creswell, 2009). Given the nature of the protocol questions,

many of the codes reflected the interactions and relationships participants had with their families

and PSE professionals. However, the researchers did not use the interview or research questions

to guide the open coding process. The researchers then used the initial codebook as a guide to

independently read and hand-code another transcript, before meeting again to discuss codes,

identify unique or irrelevant topics, develop descriptions of each code, and place codes into

categories (e.g., "relationships with families"). This process resulted three versions of the

codebook before consensus was reached (both researchers agreed on all codes for a transcript)

for a finalized codebook. The principal investigator imported the finalized codebook (which

consisted of 28 codes related to all interview topics and data provided by participants) into

NVivo, a software package designed specifically for the analysis of qualitative data (QSR

International, 2019). Using this software, the principal investigator organized all data into the

codes in the finalized codebook. During this time, the researchers continued to meet weekly until

all data were entered into NVivo to ensure consensus regarding all codes and categories. No new

codes or categories emerged during this time.

Trustworthiness

The researchers employed several measures to ensure the credibility of data collection

and analysis procedures, including considering the potential for communication breakdowns,

misunderstandings, and participant acquiescence, or responding to questions with answers

participants believed the principal investigator desired (Finlay & Lyons, 2002). Initial

trustworthiness procedures occurred prior to interviews, as the principal investigator provided

participants with the interview protocol for them to review and reflect on without the principal

investigator present. The questions were also written in a simplified and direct manner and in

enlarged font to help promote accessibility and understanding. During interviews, the principal

investigator employed additional procedures, including (a) encouraging participants to command

the discussion through the use of open-ended questions and prompts; (b) re-wording and re-

phrasing questions, as necessary, to ensure that participants clearly understood questions; (c)

using visualizations to accompany interview questions to help participants frame the questions in

light of their own life experiences (e.g., "Pretend you're in college and you need to call your

family. Why are you calling them?"); (d) summarizing participant information and asking

confirmatory questions (e.g., "So you are saying that professionals should or should not contact

parents about missing class?"); and (e) asking counter questions to check for acquiescence (e.g.,

participant indicates that parents and PSE professionals should not communicate: "So do you

think parents and professionals should speak daily?"; Wolcott, 1990). Further, with participant

consent, the principal investigator recorded interviews to gather precise information and wrote

memos immediately after data collection (Wolcott, 1990). These memos were used during

transcription checks and discussed during the coding process to ensure the codebook accurately

represented the context of participant information and intent. The principal investigator also used

field notes to conduct member checks (i.e., reviewing key points regarding each protocol

question) with participants at the end of each interview and invited participants to correct or

expand on information (Brantlinger, Jimenez, Klinger, Pugach, & Richarson, 2005).

The researchers then engaged in four additional trustworthiness procedures during data

analysis, including (a) comparing written transcripts to original interview recordings to ensure

accuracy, (b) reviewing transcripts for potentially leading questions that may have influenced

participant responses and eliminating them from analysis, (c) using a team approach to transcript

analysis, and (d) meeting weekly to review and discuss interpretations of data and discuss

potential researcher bias in the analysis (Wolcott, 1990).

Results

From the 28 codes entered into Nvivo, we report on those related to our three research

questions: "relationship with family," "relationship with professionals," and "family-professional

interactions." Four primary themes emerged from these codes: (a) challenging interactions with

families and PSE professionals, (b) positive interactions with families and PSE professionals, (c)

interactions between families and PSE professionals, and (d) recommendations for families and

professionals to best support young adults attending and graduating from PSEs.

Challenging Interactions with Families and PSE Professionals

Participants described challenging interactions with both their families and PSE professionals.

Challenging family interactions. Participants such as Christian indicated that "it's really hard for people with disabilities to go to [PSEs]" because "some parents are worried about certain situations" and, as a result, do not allow their children to attend college. Gabriel observed that parents who "control" young adult decisions resulted in young adults losing "the initiative to go out on their own." Negative interactions related to decision-making with families emerged as a challenge among many participants. For example, participants including Finn, Cooper, Christian, and Quinn indicated that they didn't decide many aspects of their lives, including where they lived, because their parents decided for them. In some instances, participants avoided sharing housing, relationship, or employment preferences with their families because, as Wren put it, they did not "know how [parents] would react" and did not want to risk rejection or a negative response.

Challenging PSE professional interactions. Participants including Sean, Mae, and Zach described instances in which they believed that PSE professionals "cross[ed] the line" (Sean) by "questioning" (Zach) PSE student decisions or otherwise involving themselves in participant "personal love business" (Sean), friend/classmate conflicts, or roommate disputes. Gabriel believed that PSE professionals "did not realize" how intervening in young adult relationship issues "hurt" students by diminishing their autonomy, privacy, and dignity. Likewise, Finn thought that PSE professionals should model their interactions with PSE students based on other university faculty who "act very professional" by not getting involved in the personal lives of college students without disabilities. Further, participants including Finn, Gabriel, and Zach also described feeling undignified when PSE professionals determined that, as Zach noted, they

"were not ready" to take on certain responsibilities (e.g., independently taking medication, getting up on time, cooking), enroll in specific classes, or engage in activities such as taking public transportation or getting together "with a couple of friends" off campus, even though participants such as Zach "felt ready" to engage in those activities.

Positive Interactions with Families and PSE Professionals

Although participants shared challenging experiences, they also described positive interactions with their families and PSE professionals.

Positive family interactions. All participants generally described close relationships with their families. Participants such as Mae, Lennon, and Cooper noted that they "would call [their] parents every night just to say goodnight" (Mae) or call daily to "catch-up" (Lennon) about classes or share how the "day is going" (Cooper). Participants also indicated that their families maintained high expectations for their success and provided them encouragement and opportunities to accomplish goals. For example, participants described their parents encouraging them to set goals and helping them locate college, employment, and/or residential opportunities. Further, Sean indicated that his parents "paid a little more" money for him to receive specialized services needed to attend a PSE and live outside of the family home while attending a PSE. Similarly, Finn described how his "family gathered up what they had and put that into [his PSE] tuition… tak[ing] out their pension and everything."

Gabriel's statement that "parents want what's best for their kids" reflected the sentiments of many participants, which influenced participant willingness to accept advice and support. Participants such as Sean appreciated when parents avoided giving directives (e.g., "Don't do this") and, instead, offered suggestions. For example, Quinn stated "It's nice having parents that are like, 'You can have something that's bad, but you need to have something that's good for a

meal' or 'You need to decide what night you do this and what night you do this.'" Mae also

described the positive impact of her parents maintaining guardianship on her wellbeing and

ability to stay informed about her own healthcare needs:

> My parents are guardians of me so they have lots of rights…like when yesterday I went
> to the dentist and I had no idea what the dentist person was saying, so they're going to
> send a letter to my house addressed to me, but I'm going to let my parents open it and
> they're gonna tell me all what the letter will say and tell me in words more for me.

Participants, including Mae, Quinn, Christian, Wren, and Gabriel, who lived outside of

their family home while attending a PSE and/or after graduating from a PSE, often spoke about

how "nice" (Gabriel) it was "having parents who come help" (Mae) them with household tasks

(e.g., minor repairs, furniture assembly, modeling how to cook) or to drop off food or other

needed items. Quinn explained how she called on her family for support: "If I need something…I

will be like, 'Hey, if you're going to Costco will you pick something up?'" Quinn also

appreciated when her and her roommates' parents helped them develop roommate "chore lists,"

"meal plans," or made living spaces more accessible (e.g., adding specialized grip handles,

widening hallways, making living spaces "a little more walkable").

Mae also described the positive influence of "wanting to be just like" her sibling on her

own motivation to achieve goals: "I watched my sister grow up and I just wanted to have the

steps of a normal life… like her." Siblings served as a source of social support for some

participants by inviting them "on outings" (in Quinn's case) and providing advice about

friendships, roommates, romantic relationships, and getting along with coworkers.

Positive PSE professional interactions. Participants also reported positive interactions

with PSE professionals, including the ways in which they provided meaningful support. For

example, Christian described the importance of PSE support to obtain employment and "set

goals of what [he] wanted to achieve" during "person-centered plan meeting[s]." Lennon also

noted the positive impact of a PSE professional who "helped [him] figure out how to plan a resume, how to do an interview, and how to start the process of interviewing." In addition, PSE professionals provided emotional support to Mae, Gabriel, Zach, Cooper, and Finn by checking to see if they were "feeling stress" (Mae), "help[ing] with anxiety" (Gabriel), or connecting them with professional resources such as counselors. Moreover, participants described positive experiences when PSE professionals supported them to take university courses or join university clubs or activities. For example, Cooper described the impact of taking a university class with support from PSE professionals: "I had my presentation [on] person-first language. And boy that was my favorite class…And then after I graduated, [University Professor] asked me to come back and speak- which I did …And he knew my *name*." Cooper went on to reiterate this story several times during his interview and describe how proud he felt participating in a university class and being asked back without the support of PSE staff.

Interactions Between Families and PSE Professionals

Participants described the nature of interactions between their families and PSE professionals, as well as their perceptions of these interactions.

  Nature of family-PSE interactions. Participants indicated that their families and PSE professionals interacted in numerous ways, including emailing and meeting in-person. In general, participants agreed that their parents most often interacted with professionals to advocate for them. For example, Zach described his parents contacting PSE professionals to advocate for him to receive an extended curfew on campus, which helped PSE staff become "more flexible" with their rules, including curfew expectations. Similarly, Lennon described email interactions between his mother and PSE professionals: "I know my mom would send emails to staff if she had any questions…[and PSE professionals] would send…a report on the different domains that

I've done …[and they] might meet up and she might ask questions about it." However, many participants indicated that they were unsure about what their families and PSE professional discussed during meetings (e.g., Sean: "I'm not even in those meetings.").

Perceptions of family-PSE interactions. Participants also shared their perceptions of family-PSE professional interactions. Participants reported that while they felt comfortable with their families interacting with PSE professionals when they needed help (e.g., emotional support, support finding a job), they indicated that students should be the primary point of contact between the two stakeholders. More specifically, Mae, Zach, Finn, Gabriel, Christian regretted that there were not more frequent person-centered plan meetings or meetings where students are present. Participants also noted that professionals sharing information with parents such as class attendance, grades, bedtimes, and food choices was, Gabriel indicated, "a bit nosy" and intrusive. Further, Finn indicated that extensive family-professional interactions "would be holding back on [students] pushing toward independence."

Recommendations for Families and PSE Professionals

In addition to discussing challenging and positive interactions experienced with both families and PSE professionals, as well as their experiences with family-PSE professional interactions, participants also provided recommendations for families and professionals to effectively support individuals with disabilities aging into adulthood.

Recommendations for families. Participants including Zach and Mae suggested that families "try not to be overly protective" (Zach) of young adults or "smother them too much" (Mae) because, as Gabriel indicated, "the main reason for the [PSE] is for us to be more independent." Christian elaborated, "Mom and dad call[ing] five times a week or whatever to check up and see how you're doing and say what you need to be doing- that's not

independence." Finn recommended that parents "back off and let their kid live his own life… [and] think about your child, how they feel about your overprotectiveness." Sean, Lennon, and Zach also suggested that families "keep their child's worth in mind" (Sean), "put trust in your child" (Lennon), and give young adults "a chance to prove themselves" (Zach). Further, Quinn recommended that parents "talk with your children and let them make their own decisions and be confident that they can make good ones."

Although participants uniformly desired "parents to just…trust" (Zach) and support them to make decisions about their lives, participants such as Lennon and Christian recognized the "worry [and] stress" (Lennon) that parents experience as their children "leave the nest" (Christian). Christian compared parents needing to balance "let[ting] kids be a lot more independent, but also…hav[ing] [their] back, just in case" to being a coach: "Like how in sports, coaches on the field guide you. They don't actually do the work for you, they guide you." As a result, several participants, including Gabriel, Quinn, Finn, Christian, and Mae suggested that parents develop coping strategies to deal with their own stress and anxiety to provide young adults more independence.

Recommendations for professionals. In many ways, participant recommendations for PSE professionals mirrored those they suggested for families, including affording young adults dignity and trust. For example, participants suggested that PSE professionals enforce "fewer rules" (Gabriel) related to curfews, bedtimes, travel restrictions, activity requirements, food constraints. In particular, Zach believed that overbearing rules such as students "checking in and out of the dorms" prevented students from "stay[ing] more independent." Similarly, Quinn recommended that PSE professionals "know…that [young adults] are independent" and trust that they "know what to do." Further, Gabriel, Finn, Zach, Wren, and Lennon indicated that

professionals "should be able to handle when they are under stress" (Gabriel), "learn how to have patience" (Finn), and "try not to get annoyed at the student- it's not the student's fault" (Lennon). Participants provided additional suggestions related to PSE professionals "keeping cool" (Wren) under stress; recommending that professionals try not be "so blunt and harsh" (Gabriel) when "students get upset with the staff" (Finn) or threaten to "call parents" (Zach) to resolve young adult issues or conflict. Instead, Finn suggested that professionals focus on "keeping their resilience to different types of students," especially those who have "a little attitude" or who have "common sensory issues" or "behavioral problems."

Participants also provided suggestions for PSE professionals to better support young adults in college, such as Lennon's suggestion that PSE professionals engage in "more communication" with residential life staff so that those staff members "know how to help" PSE students living in residence halls without family or PSE involvement. In addition, participants provided recommendations for university faculty to effectively accommodate and support young adults, including (a) professionals spending "*moooooore* one-on-one time" with students (Cooper); (b) incorporating "more actual, hands-on activities in lessons" (Christian); (c) inviting guest speakers to courses; and (d) faculty communicating with students "through technology, books, the media, different workshops, activity books, [and] through workbooks" (Mae). Quinn also recommended that university professionals "need to realize that some students *are* capable" to take university courses, but that they may need to "adapt" lessons and activities with university faculty to meet student needs. Likewise, Zach suggested that PSE staff "look on a teaching website" or "go to different kind of conferences" to get information or resources on how to be more supportive of PSE students in university courses.

Other instructional recommendations for PSE professionals included modeling and practicing functional life skills that make young adults "a little uncomfortable" (Christian), such as getting lost on public transportation or, as Cooper suggested, teaching students how to cope with "people coming up and asking me for money." Zach indicated that application activities in the community would help young adults learn their "surroundings" and Wren expressed that such experiences would help her "actually know what to do when situations happen" in the community.

Most participants also noted that young adults would benefit from instruction on "how to venture out with new people" (Christian) in college. Participants offered several suggestions that PSE professionals can use to enhance social outcomes, including encouraging students to take public transportation instead of relying on their parents and developing a social networking group. Finn also suggested courses that include a "combination [of] people with disabilities and people without disabilities" in PSE-specific courses. Finn also suggested PSE professionals create a PSE course to "basically teach interactions, maybe what to do or what not to do… like for example, don't say this or don't do that in social settings."

Recommendations for family-professional interactions. Participants provided recommendations for family-professional interactions, including recommendations for the frequency in which families and PSE professionals should communicate- ranging from "once a month" (Lennon) to "more frequent meetings… if that's okay with the student" (Sean). In addition, participants provided recommendations for why families and PSE professionals should interact, such as Gabriel's recommendation of "a once-a-month meeting for the parents to come up and have a face-to-face meeting with the staff and the student [to discuss] what are the kid's goals… [and provide] a little bit of closure for the parents" as students prepare for graduation.

        Participants also provided recommendations for information that families and

professionals should share during their interactions. Participants suggested that families and PSE

professionals should share information about (a) young adult "medical issues" (Mae), (b) "drama

that is extreme that needs to be solved" (Quinn) such as extensive roommate arguments and

discrimination on campus, (c) "resources" that young adults "have on campus" (Zach), (d) "what

[PSE] classes entail" (Christian), (e) "upcoming changes to the [PSE]" (Finn), and (f) "more

information about [community] housing" (Lennon). On the other hand, participants such as Sean,

Finn, Zach, and Gabriel recommended topics that families and professional *not* discuss,

including "a lot of the personal info" (Zach) such as young adult social activities, class

attendance, grades, job performance, purchases, and nutritional choices. Many participants,

including Sean, particularly emphasized that families and professionals should not discuss young

adult "personal love business." Similarly, Finn stated that "if it's someone's sex life, other

people should stay out of it…because they're over 18 [and] in college now. If they want to have

sex, they can. That's the thing- our bodies, we do what we want with them." In general,

participants expressed that, as Quinn noted, "there should be a fine line when parents step in" to

intervene in young adult personal issues in college. Instead, participants such as Gabriel

recommended that PSE professionals should first "to try to mediate" young adult issues "without

any parental interference" and "check in with the students" before reaching out to families to

resolve issues or concerns. Further, several participants recommended that all family-

professional interactions should, as Gabriel put it, "be directed to the students" and that "the

student [should] also be there" during conversations between families and PSE professionals to

provide their input or "jump in and defend themselves," if needed.

Discussion

The purpose of this study was to examine the following research questions: (a) what are the perceptions and experiences of PSE graduates regarding their interactions with their families in college, (b) what are the perceptions and experiences of PSE graduates regarding their interactions with PSE professionals, and (c) what are the perceptions and experiences of PSE graduates regarding interactions between their families and professionals while they were in college. Participants reported negative and positive interactions with their families and PSE professionals, described how their families and PSE professionals interacted, and also provided recommendations for families and PSE professionals. These findings contribute to the scant literature that focuses on the perspectives of young adults with disabilities (DePape & Lindsay, 2016). Our findings suggest that PSE staff may not be prepared to teach students functional skills required to fully participate in the community such as travel training, although research indicates that students with IDD often receive functional life skills training in high school (Chiang, Ni, & Lee, 2017). Our findings also reinforce the notion of family interdependence (Oswald et al., 2017), as all participants desired independence, as well as some degree of family and professional support, including families and PSE professionals interacting to help them achieve their goals and provide emotional support.

Although these findings add information to the literature on PSEs and young adults with disabilities aging out of school-systems, reported preferences and recommendations support research documenting the importance of interagency collaboration (Riesen, Schultz, Morgan, & Kupferman., 2014), on-going family support (Francis et al., 2018; Lindstrom et al. 2011), person-centered planning (Wells & Sheehey, 2012), and parent-professional collaboration (Bryan & Henry, 2012). Further, participants confirmed the need for families to develop strategies to cope with stress and worry (Francis et al., 2016) and the need for comprehensive

professional training to provide students meaningful life skills (Blalock et al., 2003). Our

participants also emphasized a need for professionals to learn coping strategies to "keep cool"

when frustrated with PSE students, consistent with literature related to stress experienced by

special education teachers and the need for coping strategies (Ansley, Houchins, & Varjas, 2016;

Cancio et al., 2018).

This study also provides unique findings to the literature, including describing methods

for ensuring conducting trustworthy qualitative research with participants with IDD. This study

also contributes to the understanding of the perspectives of PSE graduates with IDD, including

their preference for PSE professionals to afford them privacy, especially with regard to romantic

relationships. Study participants also described displeasure with overbearing PSE rules (e.g.,

curfew) that were not expected of other university students. Similarly, participants did not like

when professionals questioned student decisions and abilities, including if they were "ready" to

take on responsibilities and risks (taking public transportation). These findings are consistent

with professionals maintaining low expectations for students with IDD in other contexts,

including high school and work settings (Francis et al., 2014) and is troubling, as the

expectations of professionals, including those related to students engaging in decision-making

and risk-taking profoundly influence student outcomes (Timmons et al., 2011; Wehman et al.,

2015).

This study also adds to the literature on family-professional collaboration by

investigating such interactions during college and providing the unique view of PSE graduates

and their preferences, including families and professionals trusting their judgement and

preferring that interactions between families and PSE professionals be more student-centered and

initiated by students when they need support. Participants also recommended age-appropriate

parameters for parent-professional interactions (e.g., professionals not reporting student

behavior, professionals collaborating with residential life staff to systematically support young

adults with disabilities in college).

Limitations

There are five primary limitations of this study. First, although the generalization of

findings is not the intent of qualitative research (Bogdan & Biklen, 2007), the relatively small

and heterogeneous sample of 10 participants is one limitation of this study. A larger number of

participants and purposeful sampling techniques would enhance researcher ability to engage in a

deeper analysis of how various factors, including the characteristics of young adults (e.g., nature

of disability and support needs), families (e.g., social capital and financial means), and PSEs

(e.g., nature of inclusive practices) influence participant experiences. Second, participant

characteristics, such as disability diagnoses, were not confirmed via official documentation

provided by the university or other sources. Third, although conducting research directly with

PSE graduates adds to the literature, cognitive, social, memory, and communication challenges

can make it difficult to obtain robust and genuine information from this population (Bylov,

2013). For example, in this study participants frequently answered interview questions using

single words, brief phrases, or with off-topic responses, requiring the principal investigator to ask

probing questions. These probing questions may have influenced participant responses.

Therefore, the principal investigator took several measures to ensure that participants had

opportunities to expand or correct information throughout interviews (e.g., asking the same

question in different ways). However, extensive piloting of the protocol with individuals with

IDD would have enhanced the trustworthiness of the study by potentially identifying leading

questions. In addition, follow-up interviews and the inclusion of more than one interviewer may

have aided in better capturing and confirming participant perspectives. Fourth, six of the 10

interviews took place remotely. However, three remote interviews took place via Facetime or

Skype, thus enabling the principal investigator to read participant body language, gestures, and

lips when verbal communication was challenging to understand. Conducting interviews in-

person or via Facetime or Skype also helped the principal investigator build rapport and redirect

participants, as necessary, through gesturing and other visual cues. These advantages were not

apparent in the three phone interviews, especially during Cooper's phone interview, as he spoke

quickly, had a speech impairment, and was challenging to redirect from topics of interest or

childhood memories unrelated to the interview questions. As a result, these differences in

collection procedures may have influenced the data. Finally, we did not investigate the potential

influence of social capital on interactions between PSE staff and families.

Implications

Despite noted limitations, the findings of this study hold numerous implications for

young adults, families, and high school and PSE professionals. First, transition teams in high

school should collaborate with families and young adults to prepare for PSEs by implementing

person-centered meetings to review key issues discussed by participants, including (a)

developing goals for college that are meaningful to young adults (e.g., learning how to make

friends), (b) identifying and discussing college expectations for all stakeholders (e.g., nature of

interactions), and (c) identifying key skills that families and young adults will need to maximize

the college experience (e.g., families developing emotional coping skills). These meetings could

also serve as an opportunity to engage in greater degrees of interagency collaboration while

young adults are still in high school by bringing together young adults, families, high school

professionals, PSE professionals, other university professionals (e.g., residential staff), and

community agencies that may support young adults while in college.

Findings from this study also reinforce the need for PSEs to establish clear expectations

for family interactions and family-professional communication (e.g., ensure that communication

is student-centered), and conduct meetings that address student-family interdependence, while

maintaining student-centric focus. Findings also indicate a need for more intensive person-

centered planning meetings with key stakeholders (e.g., families, community service providers,

community employers) as students prepare to graduate from PSEs to help them achieve their

employment, recreation, and housing goals. PSEs should also consider participant

recommendations regarding less oversight, fewer rules, and student desire for trust. For example,

PSEs may include the concepts of dignity of risk (Lenehan et al., 2004; Wolpert, 1980) and

presumed competence (Biklen & Burke, 2006; Jorgensen, 2005) in their mission statements and

development of expectations and practices for family-professional interactions. Moreover,

according to this study, PSEs should collaborate with university faculty and staff to increase

inclusive experiences, opportunities for socialization, and student independence. PSEs may use

instructional recommendations provided by participants (e.g., technology, books, the media), as

well as evidence-based practices found to support skill acquisition and generalization for

students with a variety of needs (including students with significant support needs) such as direct

instruction and community-based instruction (Wehman, 2011) to achieve these important

outcomes.

Study findings may also enhance future training and professional development programs.

For example, our findings indicate a need for in-service professional development and pre-

service teaching programs to prepare high school professionals to teach young adults how to

effectively problem-solve emotional and logistical conflicts in college. Similarly, PSE

professionals could use the findings from this study to develop program expectations or

guidelines that focus on social and problem-solving skill development, person-centered planning

procedures, student-centered communication, and family-professional interactions that are

initiated and guided by young adults. In addition, high school, university, and community-based

organizations (e.g., Parent Training and Information Centers) may collaborate to develop training

and other forms of support for parents to "let go" to promote young adult self-advocacy and self-

determination, as well as for PSE professionals to calmly and appropriately address PSE student

issues, even when frustrated.

Future Research

Future researchers should address the limitations of this study by (a) recruiting greater

numbers of participants; (b) conducting interviews in-person or via Facetime, Skype or another

mode that allows both parties to see each other (Opdenakker, 2006); and (c) employing

additional methods to expand or confirm information provided by participants, such as

conducting follow-up interviews. However, researchers can use interview procedures described

in this study, including lessons learned (e.g., the need to extensively pilot interview protocols) to

enhance their own practice for interviewing individuals with IDD.

Future researchers should consider interviewing young adults at different points in time

(i.e., after graduating high school, mid-way through PSEs, following PSE graduation), as well as

interviewing individuals who dropped out of PSEs to gather more robust and diverse

perspectives of transition and college experiences for individuals with IDD. Relatedly, future

research should recruit larger groups of participants with similar characteristics (e.g., participants

who moved back home after the PSE, participants who are not their own guardians, participants

who attended 4-year programs) to determine if interactions are influenced by specific

circumstances or characteristics. Moreover, more research should explore how PSE professionals

and families collaborate and communicate regarding students' exit from the program to inform

effective and meaningful practices that result in positive school outcomes. This is especially

important for young adults with significant support needs, as they are more likely to experience

unemployment and a lack of community living and participation into adulthood (Lipscomb et al.,

2017).

Future researchers should continue to investigate PSE variables that influence young

adult outcomes during and after graduating from PSEs, such as relationships, employment, place

of residence, stakeholder expectations, and transition strategies to inform PSE policies and

practices. Furthermore, future researchers should use purposeful sampling techniques to

investigate the experiences of young adults with more significant disabilities, as they may differ

from PSE graduates with fewer support needs. Finally, although the perspectives of young adults

with disabilities are underrepresented in the literature, investigating the perspectives of PSE

professionals and families of PSE students may help create a more holistic picture of family-

professional partnerships in PSEs and establish opportunities for policymakers and PSEs to

develop programs that consider the needs and strengths of all invested stakeholders.

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Table 1

Participant Demographic Information

Pseudonym	Age	Gender	Disability	Own Guardian	PSE program attended	Current residence	Annual family income	Highest degree earned in family
Mae	20	Female	Deaf-blindness	No	2-year residential	Apartment	$95,000 or higher	Graduate degree
Christian	25	Male	TBI and intellectual disability	Yes	2-year residential	Family home	$95,000 or higher	Graduate degree
Gabriel	22	Male	Specific learning disability	No	2-year residential	Family home	$95,000 or higher	Graduate degree
Finn	20	Male	Autism and Bi-polar disorder	Yes	2-year residential	Family home	$55,000 - $64,999	4-year college degree
Quinn	24	Female	Physical Impairment and intellectual disability	Yes	4-year residential option (did not live on campus)	Rented home	No response	No response
Zach	25	Male	Intellectual disability	Yes	4-year residential option (did not live on campus)	Rented home	$95,000 or higher	Graduate degree
Sean	25	Male	Intellectual disability	No	4-year residential	Group home	below $15,000	4-year college degree
Cooper	25	Male	Autism and AD/HD	No	4-year residential	Intentional community	$95,000 or higher	Graduate degree
Wren	24	Female	Visual	Yes	4-year	Apartment	$95,000 or	4-year

			impairment and Freeman-Sheldon Syndrome		Residential option (lived on campus 2 years)		higher	college degree
Lennon	19	Male	Autism	Yes	2-year residential	Family home	$95,000 or higher	Graduate degree

Note. Information provided by parents of participants via a demographic questionnaire and confirmed with participants during interviews. Participants grouped by PSE attended. All participants were white and spoke English as their first language.