

“We’ve got to go bigger!”: Relatives of College Students with Intellectual Disabilities’ Perceptions and Experiences

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Abstract

With the inception of the Higher Education Opportunity Act (2008) in the United States, an increased number of inclusive postsecondary education programs have been established for individuals with intellectual disabilities. This study examined the perceptions and experiences of relatives (e.g., parents, siblings, grandparents) of college students with intellectual disabilities who attend an inclusive postsecondary education program. Relatives of currently enrolled students participated in multiple in-depth interviews throughout the program. Transcripts were analyzed using applied thematic analysis, and procedures were implemented to ensure transparency and rigor. The study identified three major themes: The first theme, “evolving goals,” explores the interrelationship between the students’ evolving goals for themselves and the collateral effect on the parents’ own, progressing goals. “Financial, logistical, and communication barriers of a college student” are surveyed in the second theme and focus on experiences from pre-admission through graduation. The third theme, “letting go,” is related to the first theme but further explores the specific transition period and identity shift that participants identified concerning their students’ increased independence. Findings suggest that relatives may require more direct support systems and strategies to navigate these transition experiences successfully. Implications for practice and future research areas are discussed.

Keywords: higher education, inclusion, intellectual disabilities, parents, families

Plain Language Summary

- We aimed to understand the experiences of family members of college students with intellectual disabilities as these students attended college.
 - The college was a Hispanic-Serving Institution (HSI), which means it serves a significant number of Hispanic students.
- **What we did in this study:** We interviewed relatives, including parents, siblings, and grandparents, several times while their students were

enrolled in the program. We then analyzed the interviews to find common themes in their experiences.

- **Findings:** We identified three key theme areas:
 - Evolving goals. As students' goals changed during their time in college, their family members' hopes and plans for the students also evolved.
 - Challenges: Families faced various challenges, including financial and transportation difficulties, as well as communication issues. These challenges started before the students were accepted into college and continued through graduation.
 - Letting go: As students gained independence, family members had to adjust. This was often an emotional process for them.
- **Conclusion:** Relatives of students with intellectual disabilities may need more support to handle these changes and challenges. Colleges could establish more effective support systems to help families navigate these transitions.

Inclusive postsecondary education (IPSE) provides students with intellectual disabilities (ID) opportunities for personal growth, skill development, and access to higher education environments that they have historically been excluded from. Recent legislative advancements, such as the Higher Education Opportunity Act (HEOA; 2008), have catalyzed the expansion of inclusive programs—particularly Transition and Postsecondary Education Programs for Students with ID (TPSID)—in community colleges and universities across the nation. These programs provide critical infrastructure for students with ID to participate in inclusive academics, career development, and campus life, with the ultimate goal of achieving independence, self-determination, and gainful employment (Grigal et al., 2021).

Student outcomes linked to TPSID programs are promising. Many students enrolled in these programs report substantial growth in their employment readiness, social participation, and self-advocacy skills. For example, nearly 90% of students participate in career development activities, and more than half report securing paid employment, often for the first time (Grigal et al., 2021). These indicators suggest that IPSE not only fosters academic inclusion but also directly contributes to the cultivation of independence, social competence, and adult identity development—outcomes central to self-determination theory and life course trajectories for individuals with ID.

Equally important, but less frequently studied, are the dynamic roles of parents and guardians in the lives of students with ID navigating inclusive postsecondary education (IPSE). Families—particularly parents—often serve as advocates, decision-makers, emotional anchors, and logistical supporters as their children enter and persist through college. These roles are not static; instead, they evolve in response to shifting student needs, institutional expectations, and broader life transitions. Parental perceptions, expectations, and changing attitudes can profoundly influence the trajectory of students with ID in higher education settings, shaping not only their academic engagement but also

their developmental progress, including gains in independence, self-determination, and social integration (Francis et al., 2014; Griffin et al., 2010).

This study focuses on these dynamic parental perspectives—how they change over time, how they reflect hope, apprehension, or redefined expectations, and how they interface with students' skill development. As students transition from high school to IPSE, families often face a simultaneous reconfiguration of roles: Parents shift from protectors and primary decision-makers to collaborators in fostering their children's autonomy. This transition, while usually empowering, is also fraught with uncertainty as parents navigate new boundaries around involvement and support (Alqazlan, 2019; Cheak-Zamora et al., 2015).

While prior research has examined the attitudes of service providers and the structural components of inclusive programs (e.g., Gibbons et al., 2015; Raynor et al., 2016; Watts et al., 2023), fewer studies center on the lived experiences of parents or explore how they perceive their children's developmental progress within IPSE. Parents are uniquely positioned to observe subtle changes in self-advocacy, confidence, and social engagement that institutional metrics may not capture. Their insights offer critical perspectives on how student development unfolds outside of classrooms and within broader life contexts (Watts et al., 2025).

Even less attention has been paid to these experiences within culturally diverse educational environments, such as Hispanic-Serving Institutions (HSIs), which introduce unique cultural and structural dynamics that influence family engagement and student outcomes (Aquino & Scott, 2022; Taylor & Burnett, 2021). In these contexts, factors such as collectivist family values, linguistic diversity, and historical underrepresentation in higher education shape both the expectations families bring and the support they require.

By examining the lived experiences of parents whose children are enrolled in IPSE programs, this study aims to illuminate both the supports and tensions that arise during the college transition and attendance process. It also seeks to connect parent perspectives with specific domains of student development—particularly independence, self-advocacy, and social growth—while recognizing that these developmental gains often unfold in tandem with evolving family roles. Ultimately, the study contributes to a deeper understanding of how IPSE impacts not only students with ID but also the family systems that support them, offering insights that may inform more responsive program design, culturally attuned family engagement, and more holistic student success strategies.

Purpose

Parents of students with ID are often close to, and/or directly involved in, their child's educational experiences and decision-making; therefore, they serve as key informants to understanding the strengths and challenges of this population when included in higher education settings (Taylor et al., 2021). The following research questions guided the study: (1) How do family members experience and perceive their student's involvement in an inclusive postsecondary education program?; (2) What challenges and barriers do family members and students encounter throughout the stages

of participation in an inclusive postsecondary education program?; (3) How do relationships and roles within families change as students progress through the inclusive postsecondary education program?

Method

This study implemented in-depth interviews with family members of currently enrolled students within a TPSID program at an HSI. Before implementing the participant recruitment process, the proposed study was reviewed and approved by the university's Institutional Review Board (IRB) as part of their program review data collection procedures. Given the program's ultimate objective of developing effective supports and practices for students with ID in higher education, the present study implemented a qualitative approach to complement emerging research on higher education programming for students with ID. Additionally, a qualitative research design was selected, as it is uniquely suited to enlighten the lived experiences of an under-researched population (Braun & Clarke, 2006; Southam-Gerow & Dorsey, 2014). Due to the participants' diverse cultural backgrounds, it was difficult to predict which factors are most prominent in the lived experiences of families of college students with ID. Therefore, the study purposefully focused on the broad educational and program experiences, and personal observations of the participants (e.g., student outcomes and skill developments) so that any factors relevant to them could be raised and explored.

Setting and Program

The study was conducted at a public four-year university in central Texas. The university was created to provide higher education to a predominantly Hispanic community with historically low levels of educational attainment. The university currently serves approximately 70% Hispanic students, with over 70% identified as first-generation college students, and the university has been officially designated as an HSI. The university's Comprehensive Transition and Postsecondary program (CTP program hereafter) is specifically designed for students with ID to provide a fully inclusive university experience. The CTP program is built on partnerships among the university, local educational agencies, and community organizations, enabling a seamless transition from high school to university while developing foundational life skills. The mission of the CTP program is to provide students with ID access to the same services, programs, and courses as other university students.

The program employs a person-centered approach, which involves individualized planning tailored to each student's unique interests, preferences, and future goals. During their 18 months of study, students participate in both typical university courses (two courses per semester) and specialized training, to develop academic, employment, and independent living skills. The courses and learning experiences focus on developing communication skills, health and well-being knowledge, and practical pre-employment experiences (e.g., internships). Students have broad access to the course catalog, with course selection tailored to their interests and goals.

As part of its inclusive model, the CTP program utilizes natural supports (e.g., peer mentors). These supports assist with academics, social integration, and personal development, and facilitate integration into the broader campus community. Peer mentors play a crucial role in helping students navigate the campus, locate classes, manage their schedules, connect with peers, and adjust to university life. Students in the CTP program have the opportunity to live on campus in the dormitories, which helps them acclimate to university life and develop independent living skills. Upon completion, students receive a certificate, which reflects their achievements in academic, employment, and independent living domains.

Sample and Recruitment

Based on the standards outlined in the literature regarding who might be deemed an expert on a topic, the current study utilized a nonrandom purposive sample of parents of students with ID who had participated in a TPSID program (Hsu & Sandford, 2007). Family members included parents, grandparents, siblings, and former guardians. Although the inclusion criteria did not limit the scope of these relationships, there were no exceptions within the participant pool. After IRB approval, researchers contacted family members via phone and email to inform them of the study's purpose, procedures, eligibility criteria (i.e., based on the student's attendance and involvement in the program), and participation requirements (e.g., the length of interviews). Researchers provided no incentives for participation in the study. Participants were interviewed twice during their students' time in the program: once as an entrance interview and once as an exit interview upon their student's graduation.

Recruitment started before the admitted students' first semester of attendance. The study's duration was just over 2.5 years and included two overlapping cohorts of students. A total of eight families, comprising 18 family members, participated in the interviews, with 15 members participating in both the initial and exit interviews (83.3%). Due to the varying types of family members (grandparents = 2, parents = 14, siblings = 2), the individual participants will be referred to as "relative" in the results section to be inclusive of the diverse family roles. Six of the eight participating families identified as Hispanic (75% of participants), while the other two families identified as Caucasian, which closely resembles the overall demographics of the university's student body.

Procedure

Researchers obtained participant data related to perceptions and experiences via in-depth interviews. Initially, interviews were scheduled to take place on campus within a college of education classroom, but due to COVID-19 restrictions, the initial interviews for the first cohort's family members were pivoted to an online or phone format. The subsequent interviews were conducted in university classrooms and offices, following COVID-19 safety protocols outlined by the university. The interview protocol included open-ended questions that allowed participants to respond in a way relevant and meaningful to their own experiences. Table 1 provides a list of the interview questions at each interview point (i.e., pre- and post-program participation).

Table 1*Interview Questions by Stage*

Interview stage	Questions
Pre-program	Please tell us about your student. What are their interests and strengths? What do you hope your student will gain from this program? What concerns do you have about college? Before enrolling in this program, how did you and your student talk about their hopes or dreams for going to college or life after high school? What are your goals for [student name] as they begin the program? How would you describe [student name]'s own goals for themselves right now (for example, college, work, living on their own)? What do you currently envision as far as a career or future work for [student name]? How would you describe [student name]'s social skills or social/friendship circle at this time? How would you describe [student name]'s independent living skills right now? What are your biggest worries or concerns as your student starts this? How do you currently see your role in supporting [student name]?

Interview stage	Questions
Post-program	How would you describe your overall experience with the program now that your student has completed it? What is the biggest change you have noticed in your student since starting the program? In what ways have [student's name]'s goals for themselves changed over the course of the program? How have your own goals and expectations for your student's future changed since they started and completed the program? What do you now envision as far as a career or future work and life? Can you tell me about any successes you have observed in your student's social skills, social circle, or community participation? Can you tell me about any successes you have observed in your student's independent living skills or ability to do things on their own? Attending this program required changes for both your student and your family. What was the hardest or most challenging part for you as a family? How has your role changed? Looking ahead, what ongoing challenges or barriers do you see for your student and family after the program? How can the program be improved overall to better support students and families?

Note. Follow up questioning was based on responses in order to gain further depth and insights into specific experiences and/or perspectives.

Researchers with backgrounds in special education facilitated all interview sessions in focus groups comprising individual families. Participants were interviewed twice, once at the start of the program and once at the end, resulting in a total of 16 interviews across the participant groups (i.e., families). Interview sessions ranged between 45 to 75 minutes in length. Each interview was recorded and saved to a secure database. The audio files were then assigned a code to ensure participant privacy before being sent to a third-party service for verbatim transcription. The returned transcribed documents were then double-checked for accuracy by the lead researcher before the analysis procedures began.

Data Analysis, Reliability, and Validity

Transcripts from pre- and post-program interviews were analyzed concurrently using thematic analysis (Guest et al., 2012). Although interviews occurred at two timepoints, all transcripts were coded together to allow for comparison of themes across entry and exit. This approach strengthened claims of change by identifying shifts in parental perceptions and roles over time. Pre-program interviews reflected concerns related to safety, uncertainty, and program logistics, while post-program interviews emphasized student growth, independence, and evolving family roles.

First, the lead researcher familiarized themselves with the data through initial, immersive readings of the transcripts (O'Connor & Joffe, 2020) and detailed inductive line coding, as well as the iterative development of categories and superordinate themes. Next, the researcher segmented the transcripts by applying “meaningful conceptual breaks” (Campbell et al., 2013, p. 304). Next, two co-researchers read the transcripts multiple times, making independent notes of emerging themes, and then engaged in critical discussions with the lead researcher to enhance the depth of analysis and transparency. The thematic structure was refined iteratively, with repeated refinement to the themes, subthemes, and related visual charting, which later developed into a visual model based on findings (see Figure 1). Finally, to assess validity, a “member check” was conducted. The research team presented the findings back to the participating families via a follow-up email to evaluate the validity of the results (Lincoln & Guba, 1985). Participants were asked if the identified themes and subthemes resonated with them as members of the target population. The authors also invited revisions to reduce the potential for research bias (Patton, 1999).

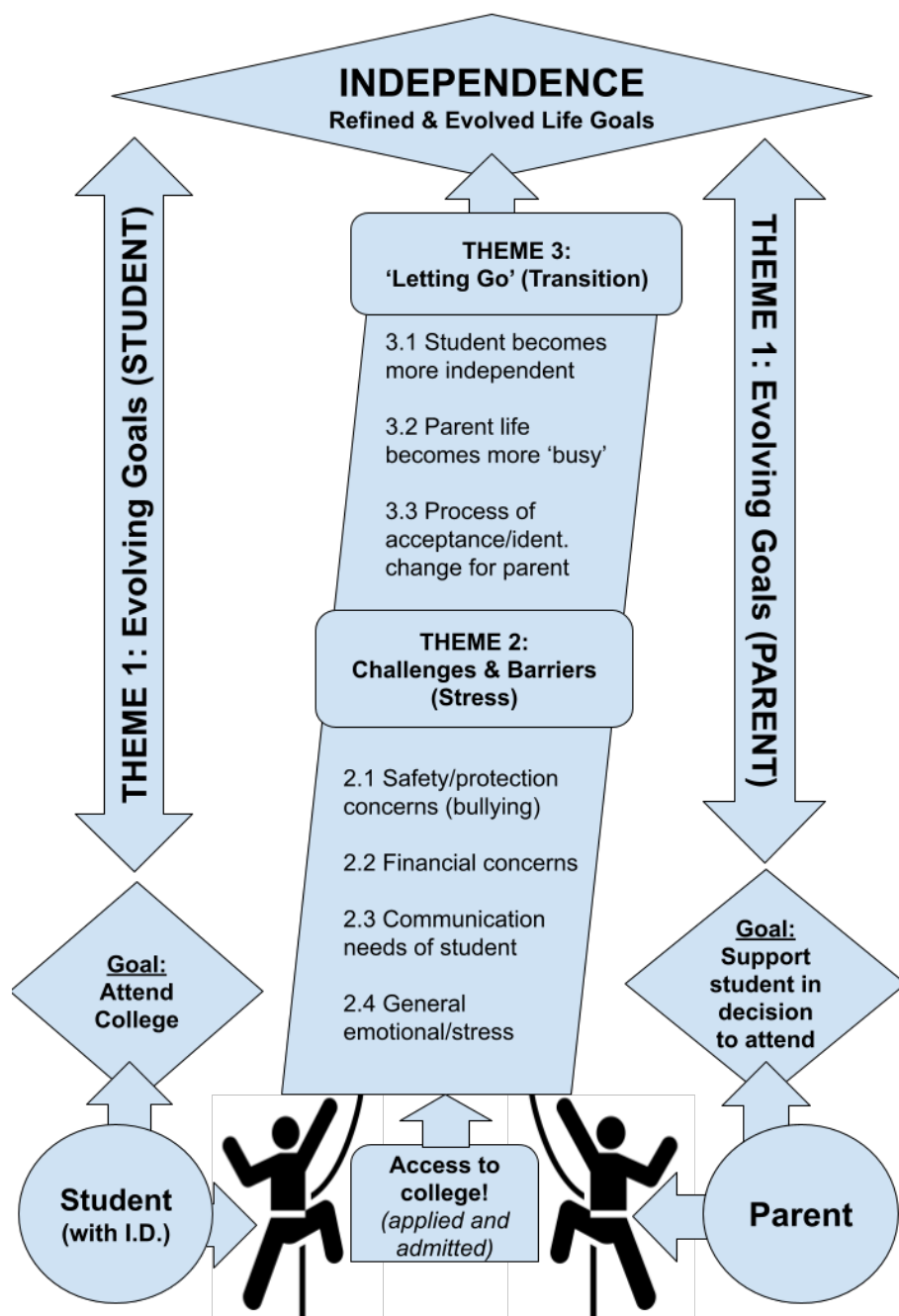
Results

The study identified three major themes from the applied thematic analysis of the data. The first theme, “Evolving goals,” explores the interrelationship between the students’ evolving goals for themselves and the collateral effect on the parents’ own, progressing goals. This theme highlights a shift in parent perspective, from “safety-focused” (i.e., How can I protect my child in a more independent environment?) to more action-oriented (i.e., How can I support my child in obtaining their goal?). Challenges and barriers are surveyed in the second theme and focus on experiences from pre-admission through graduation. The third theme, “letting go,” is related to the first theme, but further explores the specific transition period and identity shift that was found by the

participants about their students' increased independence. A majority of these themes illustrate the transition phases and changes that were perceived by the parents, with their students' evolving independence due to participating in a postsecondary education (PSE) program. Figure 1 provides a visual summary of the themes and subthemes. Relative responses are identified by a code containing the participant's student cohort, family number, and individual respondents within the family.

Figure 1

Thematic Visual: Climbing the PSE Ladder to Independence



Theme 1: Evolving Goals at the Student Level Influences Goals at the Parent Level

Each family group observed developments in their student's own goals and abilities (e.g., independent living, career aspirations, self-determination), which, in turn, changed the family members' own goals and how they supported their student. Thus, as goals evolved at the student level, revisions in goals were required at the parent level at multiple points (i.e., before admittance, while attending, and towards the end, when career goals changed). Before the families had knowledge of the availability of inclusive PSE programs, parents reported struggles in discussing their students' aspirations related to attending college like their family member(s) and/or friend(s). These discussions forced parents into the undesired position of deflecting their students' ambitions and dreams.

We had to so many times, kind of deflect the conversation when she would bring up I want to go to college like, "my friends or I want to go to college like my cousins," and we're like, you know, trying to just figure out a way to navigate through that conversation without discouraging her and making her feel different. So, when she was accepted [to the program], I mean, it was exciting for me. (Relative C2-2A)

After the student was admitted, parents reported additional developments in their perceptions about their child attending a university program. The primary focus was initially on safety concerns, where a pattern was found in participants' anxieties about students' safety on campus, including campus navigation and being manipulated or taken advantage of by other students (e.g., bullying). As the student began attending the program, and family members found themselves observing more self-determination in their student, they began transitioning to a more supportive, student-centered approach.

I told [staff] from day one, the most important thing for me, with my daughter attending a university, is her safety, right? As parents, we just always want to make sure that they're safe, and so they had to constantly tell me, it's going to be okay, you know. [Public transportation] was a struggle and it's still a struggle for me... she is saying "I want to do this, Mom. I want to be able to go here." And I've had to kind of let her shine, right? And let her do her thing. (Relative C2-3A)

And for me, it was like, okay, I'm sending my son. When he was in middle school and in elementary, you know, you would hear the bullying because he couldn't speak or he would stutter. I wasn't sure how it would be as an adult because I told him, you know, people are mean, you know, and even though we are adults there are adults who are mean, but you're in a college environment now. (Relative C2-2A)

As the relatives observed positive developments in their students' self-advocacy and self-determination skills, they also identified a pattern in the expansion or elevation of career goals and ambitions at the student level. Parents perceived this elevation at the student level as also requiring some modifications to parents' visions of the future, as well as their behavior and the way(s) in which they support their student in obtaining these goals.

And now his whole goal, career goal has changed. He's like, no, I want to work at a hospital where before he would be like ... no, no, no, no, I don't want to do that. There was only one [option] that was available at the career place, so I didn't have a choice. But now I see the difference where he's like, "I want to work at a hospital. I don't want to be working at a grocery store." I guess he, kind of like, grew, you know, as far as his career... that changes your whole perspective, your whole mindset, and I see that when he speaks, and I hear that. (Relative C1-2A)

Even today just in her presentation, she's like, "Mom and Dad, this is what I want." And for me, I was like, a little taken aback just because I always thought you know, this is you know, we were in a comfort zone. Like everything that's like he said he was great to be, she got there. But she wants to do other things apparently, you know, volunteering is what she loved. So, she said, "Mom, I want to still volunteer." (Relative C2-2A)

Interestingly, these developments in independence and self-determination frequently increased the time and effort needed from families in supporting their students' increased participation in social, educational, and/or career-related activities and events.

Well, now let's prepare for that because here I thought it was something like maybe just getting to be at home with Mom, right? But that's not her plan. She's like, I want to meet more friends. I want to volunteer. I want to do this. I want to thrive at work and do the best that she can. So that's what's changed for us. So busy, busy life. (Relative C2-3A)

He is more active in his own decisions and outgoing in his decisions. He is doing and involved in more. We are taking him to more activities he chooses. (Relative C1-4A)

Theme 2: Financial, Logistical, and Communication Barriers of a College Student

In addition to the primary concern about safety, family members reported additional concerns related to student abilities and related needs in attending a PSE program. These challenges and barriers were all connected to an outcome of added stress and/or worry about the student as they attended campus, although families reported that added anxieties due to attending the program were worth it, due to the perceived benefits to their student. The first and most common barrier was financial challenges, specifically those related to families' lack of knowledge or experience with higher education (e.g., determining the cost of attendance, procedures for applying for financial aid).

I think a good thing for [the program] is to make more of the university options available to family members. When I had to call in for [student] about his financial aid or anything, I wasn't on his FERPA (Family Educational Rights and Privacy Act) release form so I had to get that signed and sent over. (Relative C1-4C)

I know that they did mention to us living in the dorms, right, and it was just an additional expense. So, for us, it was just doing one week's expense [for summer camp in the dorms], you know, and just letting go, really for me. (Relative C2-3A)

We recognize the need for [financial independence] because we've got some other areas where we're trying to help and we're not really being allowed to help because we don't really understand our [financial aid] program and what we're trying to do here. We're training... but some people learn faster than others. (Relative C1-4B)

Once students were admitted, the logistical concern regarding how the students would get to campus became the primary challenge. Many of the transportation issues were due to parents' or guardians' work schedules or daily routines that were away from the campus location:

I think the hardest for us was the transportation. I'll be honest with you. All the other stuff was manageable. I think for us, it was a transportation figuring it out, trying to get there, because, I mean, as much as you guys are invested in [the student], we were equally invested on our end to make sure she was there and part of it, but it was a little hectic, a lot of travel... And at the end of the day, the transportation was things that we talked about because "it's your turn, or it's my turn," but the reward was immeasurable. (Relative C2-3B)

There is [sic] only challenges with my crazy work schedule. So, I'm trying to get that fixed right now, because it's getting too much for me... I don't like to depend on other people... like taking him to school and things like that. (Relative C1-2A)

Also, related to the first theme, the transportation options were initially limited due to relatives' concerns about safety in using public transportation:

But you see the news and you see how people get treated and it made us so fearful that me and my sister were scared even for him to go on the bus. (Relative C1-4D)

Once the student was on campus, parents' concerns shifted to their students' unique communication needs and how they would be addressed and/or supported in a PSE instructional setting. A pattern in these concerns was found in the initial transition from more parent-led or initiated communication with educational staff, to a campus environment where the communication is student-led. Further, as the student progressed in the program, relatives reported generalization of communication skill development:

I can't depend on him to tell me everything... So that's probably the only thing that we had issues with at the beginning; him talking and expressing or relaying information getting chopped up. (Relative C2-2)

And if we had any questions, you know, I would call [staff], email them, and they're really quick to answer our questions or if I had a concern which I really never did, they were quick about every everything and made me feel very comfortable and always advocated for, you know, for my son. So, it was just special and made us feel good. (Relative C2-1A)

I think [he] is more confident. He was so used to us handling everything. If we go to the restaurant and we sit down and the waiter asks, "what do you guys want to eat?" [He] wouldn't tell the waiter what he wants; he would tell us what he wants and have us order. So now, for him, instead of looking for us to do stuff for him, just being confident; "I can do it without you guys, I can order for myself, or I can say what I want." (Relative C1-4C)

I have really enjoyed the program. I have definitely seen a change in my son. He's definitely more outspoken and willing to be a little bit more independent. (Relative C1-3)

Yeah, he's a lot more, I guess, you could say outgoing with his decisions. He wants to do more things. Get out there. Speak with people. Meet new people. (Relative C2-1)

Theme 3: "Letting Go" (The Transition Period)

The next theme that evolved from the interviews was the notion of "letting go." As discussed by the participants, this theme highlighted the process and discussion of their student becoming self-sufficient as a result of the skills learned within the program and the related learning experiences on campus (e.g., involvement in study groups, clubs, student organizations). Some outcomes of the autonomy described further resulted in family life becoming more hectic and the progression of parents' acknowledgement of their students' development of independence and identity. Family members shared their observations of student successes as they progressed through the program and showed more self-determination skills. Relatives reported the experience of having to relinquish the "familial hold" they had upon the students' functioning since early childhood, and throughout the educational experience up until this point, branched into multiple, related sub-themes, based on their observations of increased student independence, the effect of this independence on their personal lives (i.e., more busy lifestyles), and the process of acceptance and identity change or shift for parents.

Participants reported, in some instances unexpectedly, seeing their students becoming more self-reliant in daily activities. Additionally, when entering a new environment/situation, such as a university or campus-organized event or program, they were more independent and required less support than they had in the past. Family members indicated that for the first time, they considered that their child could live autonomously, not being dependent on parents/family in their day-to-day functioning. Furthermore, opportunities, such as joining student organizations on campus, were opening up for their child.

We realized though once he got to college that even though it doesn't look like he's thriving he, kind of, is and he's a little more confident. We thought maybe we babied him too much that we hindered him and that's on us... also it's just giving us the time to let him actually be an adult, not let us coddle him as much. (Relative C1-4C)

We did coddle him a lot growing up so knowing he goes to class now by himself... for us, these are big things. When he was first born and we realized that [student] was a little different, we were like is this possible or is this going to happen? For us, it was a dream come true honestly. (Relative C1-4A)

I guess, you know, when you have a student with special need[s], it's hard to let them go. You're always worried about every single thing that could possibly happen. That was the hardest part. But you know, once he started going and telling me about all the things he was doing, I felt a lot better about it. And he just started getting to all these different clubs and opening up his horizons, you know, and it was just a complete blessing. (Relative C3-1A)

As the students became more self-sufficient and independent, parents indicated that they would underestimate their student, particularly in being involved in self-determining pursuits. Parents further reported that everyday living became hectic for them, as their student became more involved in working towards their ambitions, in activities, and in their interpersonal relationships. In addition, it was indicated that their students' interests grew through their becoming engaged in the university academic and social experiences:

I guess being there on time, always looking forward to being there. Be prepared and waking up. He is the first one getting up in the morning and waking everybody up to be there on time. He's trying his best to reach his goals. I see that way, I don't know, and want it more and more every day as he is going in his journey. (Relative C1-1A)

She just really amazes me sometimes because here I'm thinking, sometimes I think small, but she will be like: "No, mom we got to go bigger, like, I can do more." And that's what's changed for me is that I've realized that sometimes it's okay to dream big, right? Like she can. If she tells me that that's what she wants to do now, it's okay, now let's prepare for that. (Relative C2-3A)

The third subtheme revealed parents' acknowledgement of their focus on being the primary, or in some cases the sole source of support for their student in obtaining their educational goals. Further, a majority of participants assumed that this arrangement would be consistent throughout their child's entire life. The recognition of independence and identity development emerging in the student was shared in observed behaviors. Participants described the process they went through in allowing their student to become independent and acknowledging they were able to accept the transition they and their student were experiencing, furthering the goal of self-determination:

I would speak with [student], she would say that, okay, but we will be trying to initiate for her to advocate for herself, not through the parents anymore, you got to take a step back. Once she explained that to me, I was okay, I need to step back, right. It's hard being the mama bear. So, I know for Dad, he'll probably share a completely different experience because I was the one that was just trying to hang

on to being more involved with her and I've learned to step back and that's a good thing for her. (Relative C2-3A)

I'm through and through, and I had to kind of let go of the reins. And that was a big, big change for me. But I mean, with these women here, they helped me to kind of understand, hey, you're not always going to be there. And we want for [student] to be independent, and for her to be able to advocate for herself, and so I mean, with this program, I just, you know, with their partnership, that helped us realize [student] was her own independent person, right, that she needed to do things. There was [sic] things that I didn't even know she liked, because I was always the one making that decision for her, and so it was nice to see her come to her own. (Relative C2-3A)

Discussion

The findings of this study shed light on the complex and evolving experiences of relatives of college students with ID. Three major themes emerged from the analysis, providing valuable insights into the challenges, transitions, and transformations experienced by relatives throughout their student's college journey. Figure 1 provides a basic visual model based on the themes discussed by the families of students with ID participating in an inclusive PSE program. The model illustrates the navigation of the family members (i.e., both individually and collaboratively) through the various developments, challenges, and overall positive outcomes related to attending the program. The key developments in students' abilities and subsequent revisions in their personal goals had a direct effect on their family members' perspectives of supportive behavior(s) and future goals. The interconnectedness of the themes was apparent and aligns with previous findings related to parents' and families' experiences with PSE programs for students with ID (Shurr et al., 2021).

These relatives' experiences both mirror and extend prior research on families of students enrolled in inclusive postsecondary education programs. Parents and guardians in previous studies have similarly emphasized safety, campus navigation, and vulnerability when youth with intellectual disability enter college, along with persistent concerns about transportation and financial strain (e.g., Griffin et al., 2010; Francis et al., 2016; Smith Hill et al., 2024). Their descriptions of unfamiliarity with college procedures, financial-aid processes, and role expectations are consistent with research showing that families, especially those who are first-generation college-goers, must acquire new knowledge and skills to support students' access and persistence (Alqazlan et al., 2019; Cheak-Zamora et al., 2015). At the same time, relatives in this study highlighted how these challenges unfolded within a Hispanic-serving institution and among predominantly Hispanic families, underscoring the added salience of collectivist family values, first-generation college-going experiences, and culturally responsive communication, dimensions that remain underrepresented in the broader IPSE literature on families (Garcia et al., 2019; Taylor et al., 2021).

Participants' accounts of "evolving goals" and "letting go" also align with prior work describing parents' gradual shift from protective decision-makers to collaborators in their

adult children's self-determination, as youth with intellectual disability assume more agency in postsecondary and community settings (Cheak-Zamora et al., 2015; Miller et al., 2018; Shurr et al., 2021; Watts et al., 2025). Similar to earlier studies, relatives reported surprise and pride as students' aspirations expanded beyond families' initial expectations, yet they further described how this growth increased families' own workload and forced a re-negotiation of parent identity, family routines, and long-held assumptions about lifelong dependence and barriers to postsecondary education (Plotner & Marshall, 2015; Watts et al., 2025). These findings suggest that, while the core trajectory of increasing student independence and parental role redefinition is common across IPSE contexts, families in this program experienced these changes within a particularly complex intersection of cultural, institutional, and socioeconomic factors that warrant more explicit attention in future research on relatives of college students with intellectual disability (Garcia et al., 2019).

The first theme, "evolving goals," underscores the dynamic nature of both the students' and parents' aspirations. As students progress through their college experience, their goals evolve from initial safety-focused concerns to more action-oriented pursuits. This shift not only reflects the students' growing independence and self-determination but also impacts parents' own goals and perspectives. Parents navigate a transition from a protective stance to one of empowering their students to pursue their ambitions, fostering a collaborative approach to goal setting and achievement.

Building upon this, the theme of "letting go" delves deeper into the emotional and psychological transition experienced by parents as their students assert greater independence. This process was prompted by observable shifts in student behavior, including participation in study groups, joining campus organizations, and navigating daily routines with increased self-direction. As students became more self-sufficient, parents described feelings of pride and surprise, but also a reckoning with the need to step back from roles they had long occupied. "Letting go" was not simply an emotional release; it represented a fundamental redefinition of parenting, wherein support shifted from control to encouragement (Miller et al., 2018). As students pursued goals and social opportunities independently, families experienced their own parallel transformation, adjusting to more hectic daily lives and newly emerging relational dynamics. This shift led many families to see, for the first time, the possibility of their students living autonomously—an idea once considered unreachable.

This transformation was particularly evident in moments when students displayed previously unseen levels of self-advocacy, organization, and forward thinking. For some families, the realization came when the student expressed goals that exceeded parental expectations, prompting a reevaluation of what was possible. Many participants spoke of learning to "step back" and allow their students to make decisions, acknowledging how their students' identities were being shaped through these new experiences. Parents described the emotional work of releasing their long-standing roles as sole advocates and decision-makers and instead becoming partners in their child's self-determination journey. This emotional and relational evolution deepened the program's developmental impact, fostering growth not only in the student but also in the family unit as a whole.

The second theme, "challenges and barriers," highlights the multifaceted obstacles faced by parents and students from pre-admission to graduation. Financial constraints, transportation issues, communication gaps, and career uncertainties are common and significant hurdles experienced by parents of college students with and without disabilities (Watts et al., 2022). Parents often find themselves grappling with systemic barriers and limited resources, which necessitate familial resilience and creativity in finding solutions to support their students' academic and social integration needs. These common challenges exhibit an area of need for proactive approaches for interventions and PSE support systems that deter or limit barriers to accessibility and student success.

A central insight from this study is that all three themes, "evolving goals," "letting go," and "challenges and barriers," share a foundational root in the developmental transformations that students undergo as a direct result of participating in an Inclusive Postsecondary Education (IPSE) program. While the themes were identified as distinct during the coding process, their interconnected nature became increasingly evident when viewed through the lens of program-influenced student growth. As students acquired new skills in self-determination, problem-solving, and independent living, they became better equipped to navigate complex college environments. These skill gains were not isolated outcomes; instead, they acted as catalysts for shifting parent perspectives. Parents, in turn, recalibrated their roles, expectations, and emotional attachments, reflecting a system-wide evolution in how support, autonomy, and success were understood within the family unit.

The theme of evolving goals is deeply intertwined with these program-induced changes in student behavior. Early goals often centered on student safety, support, and basic access; however, as students developed competence and confidence, parents reported a shift in their hopes toward independence, self-advocacy, and future employment. This transformation required parents to both recognize and respond to their children's emerging capabilities. Likewise, the theme of "letting go" was not simply a process of emotional release; it was triggered and sustained by repeated observations of student competence in meeting environmental and academic demands. When students succeeded—by navigating public transportation, handling coursework, or managing time—parents' anxieties gave way to trust. In this way, student development served as both a cause and a feedback loop, empowering parental shifts that further encouraged student agency.

The challenges parents and students faced were not disconnected from this process, but instead were the crucibles in which growth occurred. Many of the barriers—such as difficulties with transportation, lack of inclusive campus infrastructure, or bureaucratic hurdles—initially tested families' capacities. However, these obstacles also revealed student strengths as they learned to adapt, advocate, and problem-solve. In overcoming challenges, students demonstrated real-time development that transformed abstract parental hopes into lived, observable realities. Parents, witnessing this adaptive resilience, adjusted their definitions of what constituted a "challenge" and redefined their roles from guardians to supporters of adult learners. This mutual adaptation underlines the interwoven nature of the three themes: Program participation fosters student development, which in turn reshapes parental expectations, reframes challenges, and

reconfigures relationships. The IPSE experience, then, is not simply an academic pathway, but a dynamic, reciprocal journey of growth for both students and their families.

Recommendations and Implications for Practice

The implications for practice derived from these findings are multifaceted. They can inform various aspects of development and planning for support services, interventions, and policies aimed at enhancing the college experiences of students with disabilities and their families. First, practitioners working with college students with ID and their families should recognize the evolving nature of their aspirations and goals throughout the college journey. Emphasizing student-centered planning and goal-setting processes can empower students to articulate their ambitions and develop action-oriented plans for achieving them. Collaborative goal-setting approaches that involve both students and parents can facilitate alignment of expectations and foster a sense of ownership and accountability (Smith et al., 2018).

Practitioners should be proactive in identifying and addressing the multifaceted challenges and barriers faced by students with disabilities and their families. This may involve providing information and assistance in navigating financial aid options, transportation services, communication platforms, and career development resources. Developing partnerships with community organizations, disability service providers, and financial aid offices can also expand access to support services and resources for families facing systemic barriers. It is essential to note the increased use and effectiveness of these resources with direct instruction and/or training of families in accessing these services (Stinnett et al., 2023).

One specific example of programming and support considerations for families is to provide financial literacy training and support during the admissions process. Financial literacy training can equip families with the necessary knowledge and skills to navigate the complexities of college expenses, scholarships, grants, and other financial aid options. By offering guidance and resources early in the admissions process, families can make informed decisions and better plan for their student's educational journey. Another example of support, outside of the higher education environment, is the development of family networking and social groups.

Family network groups offer a supportive community for parents and families of students with disabilities. These groups serve as platforms for connecting with others who share similar experiences, challenges, and triumphs. Whether through in-person meetings or online forums, these networks provide opportunities for mutual support, shared resources, and collective problem-solving. By fostering a sense of camaraderie and solidarity, these groups empower families to navigate the college landscape more effectively and advocate for their students' needs with confidence.

Related to the findings in family identity developments, supporting parents and families in navigating the process of identity change throughout their student's postsecondary education journey is essential. Providing an awareness and understanding of concepts such as worldview and identity development can be beneficial,

particularly during orientation sessions and ongoing discussions throughout the program (Sue et al., 2019; Vázquez, 1997). By introducing parents and families to models and stages of self, practitioners can help them better understand and support their students' journey toward autonomy and self-actualization (Rodriquez et al., 2023). Rodriquez et al. (2023) introduced a progressive outcome in their investigation of the view of self, from individuals with disabilities, "through prosocial engagement in the school and community, reciprocal helping, and relationship building" (p. 761). This constructive approach aligns with the experiences reported by parents of program participants, emphasizing the importance of proactive support and ongoing dialogue to promote positive outcomes for students with disabilities and their families.

These study findings fill the space Taylor and Burnett (2021) refer to in supporting students with disabilities who attend HSIs. Furthermore, the results validate the need to foster culturally responsive praxes at HSIs (Aquino & Scott, 2022). For example, as described above, this opens an opportunity for programs to be more responsive to the needs of families and students at various stages of identity development, by determining their needs and meeting them where they are, and responding in the most effective and receptive way to provide support.

Limitations and Future Research

The recognition of limitations within a study catalyzes avenues for future research. In this study, a nonrandom purposive sampling method was employed to select parents of students with ID who had participated in a TPSID program. While acknowledging the validity of their experiences, it is conceded that alternative sampling methods or a different sample of parents may have yielded varied results (Hsu & Sandford, 2007). The modest sample size of 12 participants was a consequence of the program's novelty and the specificity of the population, which may present a challenge to the generalizability of the findings and the social validity. Additionally, the composition of focus groups, which predominantly consists of families from the same ethnic background, may limit the broader applicability of the findings. However, it offers rich insights within familial contexts. Furthermore, it is essential to note that the perceptions and experiences collected in this study were from the relatives' point of view, rather than the students themselves. This is both a limitation and a necessary future area of study in determining the effectiveness and outcomes of TPSID programs for college students with ID.

While this study provides valuable insights into a singular TPSID program within a university setting, its findings are constrained in their generalizability. Nevertheless, the study highlights specific programmatic elements and areas that warrant enhancement or development to bolster effectiveness, particularly within programs at minority-serving institutions. Although comparisons have been drawn with prior research on different TPSID programs, it is recommended that future investigations aim for larger and more diverse samples to bolster the reliability and robustness of findings.

Future research should explore the specific information and resource needs of parents, including their preferences for delivery methods, content, and sources of support. Existing research highlights the importance of access to accurate and comprehensive

information for parents navigating the college transition process for their children with disabilities. Although there is a wealth of resources and tools available to parents of students with ID, direct delivery and hands-on training on the use of this information may be required for parents to feel more empowered (Stinnett et al., 2023). Research indicates the value of peer support and networks for parents of college students with disabilities in navigating challenges, sharing experiences, and accessing resources. Future studies could investigate the role of peer support groups, online forums, and community networks in providing emotional support, practical advice, and advocacy strategies for parents. Exploring the characteristics and dynamics of effective peer support networks can inform the development of peer-led interventions and support programs (Watts & McKenna, 2022). Understanding how parents seek, interpret, and utilize information can inform the development of tailored resources and support services. Additionally, related to the current study's method, we suggest that future research implement mixed focus groups comprised of participants across families, as this may support the identification of different perspectives and experiences, and possibly lead to the collection of more salient data. Finally, moving forward, the researchers acknowledge that the recent qualitative literature base consists primarily of data from parents and siblings of students with ID rather than the students' perceptions and experiences, or even their service providers, who are often underrepresented in participant populations (Belperio et al., 2024).

Conclusion

Overall, these thematic findings underscore the intricate interplay between students' evolving goals, the challenges and barriers they experience along the college journey, and the emotional transition parents undergo as they observe their student's increased independence. As the number of these programs increases, recognizing and addressing these themes is essential for informing the development of supportive policies, practices, and services that empower parents and students alike in navigating the college landscape for individuals with ID (Think College, 2020). By fostering collaborative partnerships between parents, educators, and policymakers, we can work towards creating inclusive and supportive environments that enable all students to thrive academically, socially, and personally. This model should continue to be developed and refined by future research lines to assist existing and subsequent programs/systems, as well as potentially expand to address the needs of a broader population of students with disabilities in higher education more effectively.

Declarations

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