"The Most Defining Experience:” Undergraduate University Students’ Experiences Mentoring Students with Intellectual and Developmental Disabilities

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Abstract

In this three-year qualitative study we investigated the experiences and perspectives of university undergraduate students who were peer mentors for students with intellectual and developmental disabilities (ID/DD) in a postsecondary education certificate program at a public university in the northeastern United States. The findings were categorized into three major themes: (a) the roles of these peer mentors; (b) the benefits and challenges related to peer mentoring; and (c) the transformative effect of peer mentoring on these undergraduate students. Findings provide insights into postsecondary education for students with ID/DD and suggest implications for (a) parents of students with ID/DD, (b) transition from high school, and (c) administrators at institutions of higher education.

Keywords: Postsecondary education, intellectual and developmental disabilities, peer mentorship, institutions of higher education, disability support services

Over forty years have passed since the passage of Public Law 94-142, the Education for All Handicapped Children Act of 1975 ([EHA], 1975). Prior to PL 94-142, some children and youth with intellectual and developmental disabilities (ID/DD) did not attend school and stayed at home, others were educated in segregated special education schools and classrooms with other students who were identified as having ID/DD, and still others were relegated to state-operated or private residential (disability-only) institutions across America (U.S. Department of Education [US-DOE], 2010). With the passage of PL 94-142 and its subsequent reauthorizations, including the Individuals with Disability Education Improvement Act ([IDEIA], 2004), public schools in the United States were required to provide free appropriate public education (FAPE) as well as transition services to all students with a disability including if desired, transition services to institutes of higher education.

In addition to the IDEIA (2004) other federal legislation enacted to enhance access and supports to students with disabilities in American education included Section 504 of the Vocational Rehabilitation Act of 1973 (PL 93-112) and the American with Disabilities Amendments Act (ADAAA) of 2008. These pieces of legislation have implications for institutes of higher education as postsecondary options for students with ID/DD begin to take hold across the nation. For example, Section 504 of the Vocational Rehabilitation Act of 1973 prohibits discrimination against individuals with disabilities in programs and services that receive federal funds. The majority of educational entities, including institutes of higher education, receive federal funds and therefore must comply with these regulations.

The ADAAA reinforces and extends the requirements of Section 504 to public programs including higher education, whether they are federally funded or not. The ADAAA requires colleges to provide accommodations including auxiliary aids and services to ensure that students with disabilities have equal access to all educational opportunities (Duffy

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ADAAA provides access, equal opportunity, and nondiscrimination; it does not ensure student success (Duffy & Gugerty, 2005). The Disability Services and Access Offices, located at institutes of higher education, are charged with carrying out the intent of both Section 504 and the ADAAA on their campuses. These offices provide the services that support access, equal opportunity, and nondiscrimination and are often considered to assist students with disabilities to be academically successful.

Inclusion at the college and university levels was facilitated by the federal legislation described above, as well as lessons learned through implementing inclusion at the high school level. Public high schools across the country have facilitated the academic and social inclusion for students with disabilities including students with ID/DD for decades through the use of paraprofessionals and same-age peers (Carter, Cushing, & Kennedy, 2009; Causton-Theoharis & Malmgren, 2005; Downing, Ryndak, & Clark, 2000; Doyle, 2008; Giangreco, Suter, & Doyle, 2010).

Contributions of peers, in supporting the education and inclusion of students with ID/DD in public schools, indicate that peer support provides a focus on educational goals related to communication including: (a) modeling social skills and reinforcing communication attempts (Weiner, 2005); (b) social interactions, such as initiating conversations, making introductions, and discussing shared interests (Hunt, Soto, Maier, & Doering, 2003); (c) classroom participation through sharing materials and teaching self-management (Gilberts, Agran, Hughes, & Wehmeyer, 2001); and (d) academic collaboration, such as completing assignments together, reviewing work, and explaining key concepts (Carter, Sisco, Melekglu, & Kurkowski, 2007). Since the 1980s, students with ID/DD have graduated from high schools with their peers (Getzel & Wehman, 2005; Grigal & Hart, 2010; Wehman, 2013).

Researchers and other proponents of inclusive education have focused on the benefits of using peer mentors in public schools to support students with ID/DD. With transition to institutions of higher education and postsecondary education programs, research related to the benefits and challenges to university peer mentors supporting the educational, social, and employment needs of students with ID/DD is warranted. In an effort to fill a gap in this research, we sought the perspectives of undergraduate university students who were peer mentors for students with ID/DD. In the current qualitative study we examined the experiences and perspectives of university undergraduate mentors as they supported a small number of students with ID/DD enrolled at a public university in the northeastern United States.

Method

Research Design

This descriptive, qualitative study relied on semi-structured interviews, reflective logs, observations, document analysis, and focus group member check interviews to explore the experiences and perspectives of university undergraduate students who served as peer mentors for students with intellectual and developmental disabilities enrolled in a postsecondary education program (PSE).

Participants

The participants were 18 university undergraduate students, three male and 15 female, who served as peer mentors for students with ID/DD in a postsecondary education program during a three-year academic period from 2012 to 2015. The age range of the mentors was 19-22 with a mean age of 20. Participants represented 15 majors, including general and special education, communication sciences, philosophy, social work, neurosciences, English, psychology, biology, Russian, global studies, and mathematics. Mentors on average worked approximately 7.5 hours per week for 30 weeks a year. The mean length of time the mentor functioned in his/her role was 2.5 years. Mentors worked 2,389.75 total hours per semester for 15 weeks. See Table 1 for peer mentor demographic information (e.g., age, gender, academic standing, major). Each mentor underwent a vetting process before serving as a mentor. The vetting process included a formal interview, reference checks, and a criminal background check that was processed through the state’s Department of Public Safety as well as the Criminal Information Center. These background check included conviction records, out of state conviction records and FBI records.

The mentees, who were the students with ID/DD, included four males and 10 females ranging in age from 19 to 30. Mentees had disabilities including autism spectrum disorders, intellectual and cognitive disabilities, and Down syndrome. Table 2 provides basic mentee demographic information.
Setting

The participants were all undergraduate students enrolled at a public university in the northeastern United States. The university undergraduate population is approximately 10,000, the graduate population approximately 1,500. The full- and part-time faculty number approximately 1,500. The university’s land grant mission includes a dedication to the global community, social justice, and a strong commitment to an academic and ethics code of conduct.

Postsecondary Education Certificate Program

All mentees were students enrolled in a postsecondary program from 2012 to 2015. During the term of this study, the postsecondary program was funded by the US Department of Education, Office of Postsecondary Education, through a grant entitled, Transition Program for Students with Intellectual Disabilities ([TPSID]; USDOE, 2010). Major components of the certificate program included that all students (a) had intellectual or developmental disabilities; (b) were nonmatriculated continuing education students enrolled in one of the university’s undergraduate certificate programs; (c) enrolled in and completed 9 to 18 for-credit, undergraduate courses (fully included in the university courses) based upon their career goals identified through a person-centered planning process; and (d) completed a graded internship targeted at obtaining gainful competitive employment upon completion of the certificate program. The mentee completion rate for the program was 100%. The graduation rate for undergraduates serving as mentors, at this point in the project, is 100%. It is within this program context that the undergraduate students fulfilled their roles as peer mentors for the university students with ID/DD (Ryan, 2014).

Data Collection

Data collection included (a) semi-structured interviews, (b) peer mentor notes and reflective logs, (c) documents such as peer mentoring manuals and guidelines, and (d) focus group member check debriefing sessions. The initial interview guide contained open-ended questions such as: (a) describe your role (as a mentor), (b) tell me about the benefits or challenges you experienced within your role as a peer mentor, and (c) describe a typical day. The second or subsequent set of interviews conducted with small focus group of mentors contained the same set of questions, reviews of emerging themes, and questions concerning changes since the previous interview. Interviews were conducted at the university in a quiet office or conference room setting. Interviewees chose the time of the interviews. Interviews lasted 30 to 45 minutes and were audiotaped for later verbatim transcription and coding analysis. Participants who were interviewed more than once during the three years of the study are indicated with an asterisk in Table 1. Pseudonyms are used throughout this article to ensure confidentiality of all participants.

The study also included 20 hours of observation conducted by the lead author. Observations initially focused on the role of the mentor in the academic classroom. Other variables became part of the observation (e.g., interactions between mentor and mentee; activities occurring during free time). During observation in the academic classroom intrusion was minimized. In all cases, the researcher sat quietly in the back of the room and recorded field notes on a laptop computer with no student interaction.

The authors collected and analyzed documents such as peer mentors’ log entries in reflective journals, program newsletters, and other mentor correspondences including entries in Facebook (private page). This article draws from all these data sources but relies most heavily on data collected through the interviews. Over three years we completed 18 interviews with participants, resulting in 1,100 pages of typed, double-spaced interview transcriptions and other documents such as mentor notes and reflections.

Data Analysis

The university institutional review board approved this research. Pseudonyms were used during data collection and analyses to protect confidentiality. All interviews were audiotaped, transcribed verbatim, and then analyzed by the lead author. Transcripts were imported into a qualitative text-sorting program, HyperRESEARCH 3.5.2 (Researchware, Inc., 2013). The lead author established credibility of the data analysis and familiarity with the data by (a) conducting all 18 interviews, (b) listening to all the interview tapes, and (c) reading and rereading all the interview transcripts. Categorical coding was used to analyze the data inductively (Bogdan & Biklen, 2007; Miles, Huberman, & Saldana, 2014). First, each transcript was hand-coded/marked by hand using 161 initial codes (e.g., mentor roles, mentor challenges, mentor benefits, mentor experiences) using words, phrases, or terms descriptive of the text content. Particularly
descriptive passages were highlighted and notes were maintained in a theme notebook related to emerging themes. The interviews were then reread and recategorized or combined into codes (e.g., friendship, frustration with faculty or parents, navigator, difficult situations, transformational experiences). HyperRESEARCH 3.5.2 (Researchware, Inc., 2013) was used to sort the data into 15 code-specific reports. Inductive analysis was applied to the code-specific reports to assist in the identification of themes that overlapped code categories. All interviewees received copies of their interviews and were asked to review them to confirm their intended meaning was communicated accurately. Member checks were conducted with 80% of the interviewees to review content of the interviews, confirm emerging themes, and check the authenticity and credibility of the emerging themes.

Findings

The overarching findings of this study revealed the following: (a) unique roles and responsibilities entailed in being a peer mentor for a student with ID/DD at the university; (b) benefits and challenges of peer mentorship; and (c) the transformational effect mentoring had on the participants (e.g., the undergraduate students without disabilities).

Roles and Responsibilities

Participants described their various roles and responsibilities as peer mentors. Mentors consistently said that there was no typical mentee or typical day. Rather, mentors described students with ID/DD as being unique individuals. Mentors also shared that there was nothing set in stone about being a mentor; each day brought something new and they liked that about being a peer mentor. In fact, participants described their roles as being responsive to each student within each situation. Nonetheless, three consistent roles and responsibilities that emerged as themes throughout the interviews were those of boundary setter, friend facilitator, and academic tutor.

Boundary setter. Mentors talked about the need for them, as mentors, to help set boundaries, particularly in the area of physical touching and physical/personal space:

I’ve been working on establishing boundaries with two mentees. Trying to set boundaries between my role as a professional mentor and tutor and between the friendship role and peer role. For example, Gary really likes to give hugs, and sometimes it is appropriate to do so, and other times I have to say that there have to be limitations to physical contact with him and you know, simple polite verbal reminders of that really work. And also... he might ask me [inappropriate] questions about my personal life that are a little bit irrelevant to what we’re doing, and I’ll um, remind him, “That’s okay that you asked, but, you know, that’s not necessary [for me] to give you that information,” and just reminders like that, so establishing boundaries and I think getting that practice with me is good.

The mentor role of boundary setter, specifically as it relates to supporting mentees to understand physical space, touching, and hugging was a common theme that mentors spoke about. Stephanie reflected:

Back when Lilly was a student, that was my biggest struggle with boundaries because Lilly doesn’t connect very strongly with other people, on that like a friend level, and she and I had a really strong connection and I was really torn between like, encouraging those feelings for other people, and establishing boundaries, because she would put her hands in my hair, constantly hugging and squeezing, and I knew that it was her way of expressing her feelings for me and that we had that bond, but I needed to let her know when it was appropriate and when it was too much. And I think by the end (of her program) she got it.

Other mentors spoke about the need to help students understand, or obtain experience with setting boundaries about what is acceptable to do on campus and what is not. For example, one mentor shared that she tries to help Kelly learn “what is appropriate to do when on campus and what isn’t.” When she is in a university class, this mentor tries to help Kelly understand that “checking shopping websites is not appropriate.”

Friend facilitator. Mentors spoke about issues related to friendship:

There are boundaries that need to be set between...like friendship and work, but I feel like that varies between students so I—like as far as my relationship with Sandy, we have that friendship and can also be professional and she knows when
to turn it on and off whereas a student like Mike doesn’t necessarily understand the boundaries, so you need to reinforce them stronger, or, there’s also the student like Gary who’s sort of here to make friends and understand what friendship is on campus, and is really using us as not only supports in his internships but as gateways into this whole world of collegiate friendship; he has no idea how that even looks, and so in that sense, you really have to be more of a friend, and I feel like the boundaries are definitely more fluid and based on student-to-student, so it’s not like you go into it like a set, rigid, I guess, structure.

Some participants interviewed spoke about the issue of developing genuine friendships with students with ID/DD as a result of being a mentor:

I tend to be on the conservative side when it comes to communication and like work versus personal life, I think, because of the Facebook and social media I’ve backed off a little bit from um, from connecting that way, and I do it partially because of like concerns for like the students. I just think it [developing friendships with mentees] is a very, very sensitive subject.

Academic tutor. All mentors interviewed talked about how they filled the role of an academic tutor in varied ways. Sometimes that came in the form of note taking as described in the interview excerpt below:

A lot of times students need help with note taking so sometimes we’ll both take notes and go over them afterwards. Or a student will listen and I’ll take notes and talk about it afterwards. Sometimes they just need help with remembering when to focus on things and pay attention and not be doing things that aren’t appropriate to do in class. Like using phones and stuff like that.

Another student, Bill, reflected on his role as an academic support person in the following way:

I think that an academic mentor is a large part of what I do, I think helping the students understand their obligations and time restraints, scheduling in terms of their academics is one facet of the mentor job.

Sometimes being an academic mentor comes with challenges:

Being an academic tutor is difficult within a class because you can’t step outside and have a conversation with the student to break down what the assignment is or break down the group work or break down the partner work. So it is a lot more fragile, I think, than one-on-one you can get in an outside environment. A lot of it is prompting. You know: “Don’t you think you should take your iPad out and record this lecture or take notes?” Or “What do you think you should do now?” You don’t know their understanding of the assignment or activity. So, a lot of it is just posing the questions to them and seeing how they respond.

Sometimes it was difficult being an academic tutor outside of one’s subject area as the following mentor described:

Sometimes students are taking classes that you don’t know anything about, like I know when Sandy is taking a film class and the readings are so difficult and she’ll ask me to explain a sentence and I have no idea what it’s talking about. How can I help be a tutor when I don’t understand it?

One mentor shared that her role as an academic support changed naturally throughout the course of the semester as the student’s confidence was built:

I tried to be there to kind of give them some comfort in the beginning, but now they don’t really need that comfort because they’re totally used to everything, but I just try to be as much in the background as possible.

Another mentor talked about her role in the academic class as interpreting what the instructor’s assignment meant. Eileen explained:

Tracy is just struggling a lot this year with her academic work. I think at first I was always just taking their word for it, and sometimes their interpretation of what the professor wants is completely different or they’re missing key requirements or formatting issues or things like that. So my role is like looking over things and getting a good idea of what is expected. With Tracy we normally read
through her articles or readings she needs to do. And what is really helpful (for Tracy) is going through each paragraph by paragraph and switching who reads what paragraph and summarizing after each paragraph to see if she’s comprehending, if she’s understanding. I think sometimes she just tries to push through and just pretend. So I try to reword the instructor’s prompt in a more readable format or more easy to understand format if the students are having difficulty with understanding it.

Benefits and Challenges

It was clear through the interviews that participants perceived their experiences as both beneficial and challenging.

Benefits. The benefits of being a mentor include: (a) gaining personal skills such as patience, compassion, or perspective; (b) receiving internship/work experience beneficial to their chosen career; and (c) seeing how the mentorship benefited the students with ID/DD themselves.

It made me a better person. One mentor described how she gained patience as a result of working with one student with autism spectrum disorders: “I learned a lot about having patience and understanding other people’s challenges that I may not face. Another thing is just seeing them succeed, it’s awesome.”

Mentors also describe being a mentor as the most defining experience of my time at the university. For example, one mentor shared:

Mentoring taught me to be strong and patient when encountering obstacles, and also that life is too wonderful to waste our time getting hung up on our mistakes and insecurities. During my most difficult semesters here, the postsecondary education program was a source of support and comfort.

Other mentors described how it felt to be part of the mentor team: “We were a tight group (e.g., the mentors) and we’d do anything for each other.” At first, she described, “I was very nervous, but immediately all the mentors and mentees are so close, we help each other out no matter what, like if someone needs a cover, immediately within 5 minutes someone will say ‘I can cover for you and it’s such an excellent program.”

It was a resume builder. Several mentors were undergraduate students in special education, general education, or social work. These students shared how being a peer mentor was something they considered to be an experience that would help them in their future careers:

Initially I did it kind of as a resume builder…. But the greatest benefit that I had from being a mentor is just, being in so many situations that I never expected and being able to work through them, it’s awesome; and being able to collaborate with peers. I find that the mentor meeting is really essential to development because I’m just hearing all these [other mentors] have ideas and all these problems that people have and how they’ve dealt with it. I’ve just learned so much. And I think I’m going to gain a lot professionally from it, not just from the resume but also in my workplace in the future.

It was gratifying. One peer mentor reflected on how seeing the success of a student with an ID/DD was gratifying:

One of the first times I worked with June, she got a paper back that she got a B+ on and she was just flying high the whole day. She told everyone that we saw. Other times when like Bev has thanked me so much for helping her and she’s really thankful of all the mentors’ . . . um . . . support with her schoolwork and just hearing that from the students is super gratifying.

Another mentor, Ann, shared:

Barb’s presentation in the participatory action research course was yesterday and she was so proud of her entire project. How she was able to do it without a partner and get it all done. She was very proud of herself. It was wonderful.

There were several mentors who worked the entire three years of this study and therefore were able to speak to the long-term program benefits for students with ID/DD. One such mentor, Bill, was able to witness the growth and success of students with ID/DD over time. He shared one of his most meaningful experiences:
I think seeing the students grow independence. I think a lot of the times we set goals for the students based on what they come in asking to accomplish in their 3 years. And seeing even the smallest goals, like transporting themselves around campus, cleaning out their inboxes, communicating effectively and appropriately with different statuses in society...just the little things that I think a lot of the times their first year you don’t expect them to make those milestones. Seeing where they are at right now and then seeing the progression over two or three years is very, very rewarding. And seeing how you can impact their success is a very rewarding experience.

Leah reflected on hearing a parent describe the benefits of her role as a peer mentor to their adult son with a disability:

I actually met his mom, we had an open house a few months ago and I met his mom and she just went on and on about how he used to hate school, he never wanted to go, and now he just can’t wait to be at school with everyone and that he just like loves it, and she wanted to thank us just so much for everything that we do, like, “you guys don’t know how much of a difference you’ve made.” Just hearing that, oh my God, I started tearing up. It was like so gratifying just knowing that I’m making that much of a difference in someone’s life. It’s something I take for granted just like going to school. It means so much to them and that’s just great!

**Challenges.** Four major categories of challenges emerged from the interviews. These included challenges related to the (a) students with ID/DD themselves; (b) parents of students with ID/DD; (c) other undergraduate students or the university instructor/faculty; and (d) systems, including the university and the sending high school.

*The students themselves.* Mentors experienced challenges related to the students themselves whether that was a student being in a bad mood, not wanting to take responsibility for a homework assignment, or making unhealthy food choices. One mentor shared:

Sometimes some of the students come in with a bad mood, or they’re tired, or they just don’t want to do their work. They don’t want to study right now. So, it is tricky, it is tricky to redirect them and to kind of cheer them up and get them focused. It’s hard.

Another mentor shared her frustration with a situation where a student with ID/DD refused to do homework: “I just remember her flat out saying: “I’m not going to do it. I’m not doing the reading.” The mentor went on to explain that she told the student it was her assignment and her responsibility and the student still refused to work:

I just remember being so shocked and you can’t come into a mentor shift knowing what’s going to happen, you really have to think on your toes. And I’m really growing in that way. And I remember saying how important it was and expressing you’re a college student, this is important. This is your homework, this is your class...she wasn’t hearing it. She just kept on saying, “No, I’m not doing it.” And I remember just being so defeated.

Other mentors, like Emma, explained that there were things that the students with ID/DD did that were embarrassing. She shared:

The way she interacts with certain people is really embarrassing for me. Even though it was nothing to do with me, I’m still a presence there, and not being able to be a role that’s (feels) like “You can’t do that.” We were on the third floor of the student center and it was in between classes and a professor was in a wheelchair and rolled up and was talking to another student and Barb puts her hands on his knees and goes into his face and says “It looks like you’re having a hard time, can I assist you?” and I was standing right there and he got really angry and was really offended and Barb started crying. And it was this huge thing and it was really hard to know how to tell her, you know, teaching the nuances of social interactions like “It’s good to be helpful, it’s bad to be helpful here, and good here.” Those rules are very complicated. But just having to get over being embarrassed sometimes, which is hard for anyone, when you’re in your 20s it’s, it’s embarrassing, everything. So, it was really challenging.

Another mentor shared what she considered to be an inappropriate interaction with a student: “one of the students with ID/DD asked me to marry him. I re-
sponded by telling him that we were just friends and that questions like that made me uncomfortable so I would appreciate if he stopped asking them.”

Several mentors spoke about the challenges they had with facilitating authentic friendships or facilitating friendships in general between students with ID/DD and other nondisabled students: “She was very pushy with wanting to become friends with people, almost to the stalker point. But this semester she’s much better about establishing a relationship first.”

Mentors also spoke about their concerns for the eating habits or weight challenges of the students with ID/DD:

It’s really hard for me to see some of the students trying to control their eating. I don’t think she understands that just because she had a really healthy lunch she can’t go out and have a huge Ben and Jerry’s ice cream.

The parents. Mentors spoke about the challenges they faced with the parents of the students they mentored. Comments ranged from issues related to homework, to having unrealistic expectations, to being overprotective, to reliving their youth through their 20-year-old daughter.

For example, Melissa shared: “There’s been instances where it’s been fairly obvious that a parent has helped with Tracy’s homework. In fact, I asked Tracy, and she said her mother helped her, well, I mean wrote it for her.” Ann, another one of Tracy’s mentors echoed that theme: “Yeah, like we have one of the parents doing the student’s homework. That’s not cool.”

A few mentors talked about other inappropriate or unconventional behaviors depicted by some of the parents. Some acted like “helicopter” mothers, and others wanting too personal relationships with the mentors, talking about boyfriends, clothing, and weekend plans.

The other undergraduate nondisabled students and university faculty instructors. The mentors talked about how some undergraduate students talk down to the students with ID/DD as the following quote reveals:

I think the hardest challenge is seeing that [matriculated students] have that difficulty really adequately communicating with the mentees and seeing that they kind of need to treat them in a different light. I just see how they interact, especial-

ly in Kelly’s hip-hop class, the students without disabilities interact is totally—not totally different but somewhat different—than how some of them interact with her. And, I’m not saying all of them; some of them are great and amazing. But there are those few who just, you know, lower their voice or change their tone and I would go as far as saying that I really do think some of the students see that. To see that they turn and talk with their friends and then turn and talk with [our students] and really change how they interact. So I think that is challenging for me to see and I can imagine it can be challenging for our students to see.

Another student spoke about how other students in the class treated one of the students with ID/DD:

In one student’s public speaking class, they were taking a quiz, and it was a group quiz so they were able to work with other students. And I remember that the other students in her group were not wanting her input.

Several mentors talked about the role, beneficial or detrimental, that UVM faculty/instructors played in the academic life of a student with ID/DD: “[One professor] just sort of said ‘Why is Mike in my class? He doesn’t belong here.’ The mentor went on to say that she felt as if she had to demonstrate to the instructor why the student was in his class.

Another mentor talked about the role they played in connecting the instructor to the student:

That’s the hardest thing to do because I think in a lot of ways, some students or teachers will look towards you to answer the questions or they’ll talk to you as opposed to talking to the student and that’s a huge problem because that’s not what it is, that’s not why we are there. We aren’t there to kind of interpret what the teacher is saying and give it back to the student that we’re mentoring. We aren’t the kind of mirror in between the two. It’s awkward to be there and kind of have to define your role to someone else.

Another mentor talked about having to redirect the instructor to address his/her concerns directly to the student with ID/DD:
It becomes kind of this tricky position of trying to direct the teacher back to the student’s response, you know like, “let’s see what the student thinks,” or “so what do you think of this?” Kind of prompting the teacher to go back to the student so I feel like as mentors we can I feel like it’s kind of like a role where you’re the facilitator between both the student and the professor, to make sure the connection is useful for both parties.

There were times, the mentors shared, that instructors were too lenient with the students with ID/DD. For example, Bill shared:

I can think of two instances where one [instructor] has been extremely lenient and one has been giving way too much time for assignments or way too many redos and way too much facilitation, and others where they’re not sympathetic to their learning needs at all. And those situations are very difficult to, I guess, to mentor because in the first instance where the teacher was much too lenient, I ended up creating my own little deadlines for the student. So sometimes you have to step in and put your own expectations on it. But there are, in terms of the teacher not giving them enough time, or enough attention for what they need in the classroom, that’s something I think you have to turn to the university as opposed to making the instances yourself because those times kind of require the Disability Support Service office or they require the teacher/program manager meetings.

**The “systems.”** As much as there were challenges with the students themselves, the parents, the other nondisabled undergraduate students or faculty, there were also what seemed at times significant or insurmountable challenges with systems. For example, one particularly perceptive mentor seemed to suggest that the sending public high school did not adequately prepare students with ID/DD for the real world after high school, saying, “I don’t understand how high school grading occurred because at least one of my mentees just assumed they would get a good grade even if they did not do the homework.”

Mentors also weighed in on the challenge that the certificate program the students with ID/DD were completing only gave the students nonmatriculated status. This did not allow students to receive specific benefits, such as the ability to live on campus, extended participation in nonacademic activities, and the ability to walk at the university’s Commencement ceremony. One mentor reflected:

I think one challenge is the amount of time the students are on campus because as much as I have friends in my classes, but I don’t necessarily hang out with them outside of classes. I think that’s a hard jump to make because everyone who lives on campus has his or her own base of friends. And the students with disabilities are here for only part of the day. So, if they want to hang out with someone they have to initiate it most likely. Which is hard for anyone to do, especially with past experience in high school and a lot of bullying experiences that our students have. I didn’t understand at first, but the students with ID/DD do not formally graduate, I mean they don’t get to walk on the stage. How sad is that for them and their families.

**Transformational Nature of the Peer Mentorship Experience**

Undergraduate students shared how the experience of being a peer mentor for students with ID/DD at their university caused them to be more collaborative. Some of the undergraduate student mentors spoke about how the experience of being a mentor made them more compassionate, more considerate of others, better students, and happier. One student expressed: “It helped me be a better student. I thought if students with intellectual disabilities could work so hard and accomplish so much, so could I!” Another mentor stated:

Being a mentor has taught me a lot about life skills, interpersonal skills, and navigating campus. It has made me more compassionate, taught acceptance and understanding. It has given me the most diverse group of friends I’ve ever had. Also it has helped me to realize something important about myself and my interests and my ambitions.

The interviews revealed that some mentors changed their majors as a result of their experience as a mentor for a student with an ID/DD. In addition to changing majors, mentors spoke about how their experience had made them change their minds about their chosen careers. One explained:
I didn’t like my major. I hadn’t really gotten my feet on the ground. I was excited about being a mentor. Six semesters later this stands out as one of the best decisions I have made for myself as a college student. I realized that studying psychology and linguistics probably wasn’t the path for me. I changed my major because I decided that I would like to spend the rest of my life working with folks with disabilities.

A small number of undergraduates at this university who served as mentors for students with ID/DD shared that they would have quit college if it were not for their experience of being a mentor:

My first year I did not know about the postsecondary education program or really any clubs or communities where I would fit in. With only two friends and after a year of not finding that niche I was ready to leave, ready to quit. It was not about the academics. I just never felt like I had a place. When I applied [to be a mentor] I wasn’t convinced that I would fit in a seemingly education-related role as I was a neuroscience major. Two years later, I am still part of this mentorship program that kept me from accepting my transfer offers from other institutions. It hasn’t just affected me by helping me choose to stay at this university. I now have a special education minor and am doing my senior thesis on how disability affects learning processes in the brain and how modifying educational practices can stimulate learning in affected students.

Another student explained:

Three years ago, I decided after a miserable first year of college to give this university one more chance. I didn’t like my major, I hadn’t really gotten my feet on the ground and I didn’t have a community. The only thing drawing me back to my sophomore year was this mentorship job. Otherwise, I would have quit.

Discussion

As reported in the findings section, data analysis revealed three themes that represented the mentors’ experiences in supporting the needs of university students with ID/DD. These themes included: (a) mentors functioned in a variety of roles including boundary setter, academic tutor, and friend; (b) mentors revealed the benefits they received and challenges they encountered; and (c) mentors described how being a mentor was transformational. The recurring themes emphasize the benefit and the transformative effect mentorships had for undergraduate students. The themes also suggest implications for public schools, institutes of higher education, and further research.

The effect that the mentorship experience had on the participants in this study was significant, transforming, and career altering. The sense of satisfaction that they gained from being a part of the academic and social successes of students with ID/DD was noteworthy. Our findings are consistent with the work of Penner (2001); mentorship was an experience that fostered concern for “the other”. Being of service to another seemed to provide an enhancing experience for the undergraduate mentors. The mentorship experience resulted in undergraduate students thinking of others and developing an altruistic mindset. One extraordinary finding was that the mentors returned year after year to serve in their role. It was clear that they had found their work to be meaningful and rewarding. Other researchers (Ferrari, 2004; McLean, 2004) report that being a peer mentor can result in positively influencing career choices, their persistence in higher education, and achieving their goals in higher education. The mentors in this current study confirm the results reported in other research students that did not deal with mentorship of students with ID/DD. It would appear that the benefits of mentorship are consistent across various types of mentorship revealing that giving of oneself in service to another is a valuable experience for undergraduates.

In addition to the impact on undergraduate students serving as peer mentors, this study revealed implications for transition from public schools as well as IHEs. PL 94-142 and its amendments require a great deal from public school special education administrators and educators. Through the eyes of the mentors who were interviewed, public schools had failed to foster high expectations, independence, trust and age appropriate social interaction skills. Holding students with disabilities accountable was something the mentors suggested should happen in high school. Ensuring that students with ID/DD complete public school possessing skills such as the ability to work independently, come to class on time and prepared, respect personal boundaries, and submit homework
that represents their work were critical for success in this postsecondary education program according to mentors. In many cases participants in this study wondered if students with ID/DD were given a “free pass” and not held to high expectations by their sending high schools and parents.

Institutes of higher education have standards that include holding college students accountable. This study revealed that students with ID/DD, in some cases, were not held to the same expectations as their nondisabled peers and that they should be. Holding students with ID/DD to high standards was also something that not all students’ parents did. Our study suggests that there is work to be done in this area by public school administrators, educators, and parents working together in order to ensure the success of students with ID/DD in postsecondary education settings.

The role of the parent or parents was a complicated one in this postsecondary education program, according to the mentors interviewed for this study. The concept of helicopter parents is not limited to students with ID/DD. In fact, college administrators, as well as student support service personnel, address the role of parents in higher education. Annually, IHEs address these issues with the incoming freshman class. Issues related to appropriate college academic and social behavior, ownership of homework, high expectations, and building independence away from home are all subjects addressed through orientation, student services, and college advising. We suggest the issue of academic integrity and efficacy of students’ work is a concern that is relevant and applicable to university students of any cognitive ability. In addition to the standard IHE orientation, students with ID/DD would also benefit from the array of supports to students with disabilities provided by IHEs including, but not limited to, student support services, instructional and technology supports, and disability support services. Linking students to disability support services ensures that students receive reasonable accommodations and other supports that will increase college success.

Many IHEs have social justice mission statements. Institutes of higher education also have academic programs where undergraduate students’ future careers will include providing health, education, and social work to people with ID/DD. In other words, children, youth, and adults with ID/DD will be undergraduate students’ colleagues or clients in the future. Therefore, IHEs might consider how their institutions are preparing the next generation to support the needs of our citizens with ID/DD. College and university departments, including schools of nursing, business, medicine, education engineering would benefit from involvement with postsecondary education programs for students with ID/DD. In addition to having their undergraduate students serve as mentors, undergraduate students from various IHE departments may gain experience through involvement in internship or field based experiences in these postsecondary education programs.

Finally, IHEs are facing decreased student recruitment, enrollment, and retention. Some undergraduate students serving as peer mentors interviewed for this study revealed that they would have “quit college” if it were not for their involvement in, and benefit from, being a peer mentor. As IHEs are identifying strategies and focusing resources on increasing recruitment and retention of undergraduate students, they might consider the role that being a peer mentor plays in both the recruitment of incoming freshmen, and the retention of upperclassmen. Undergraduate students interviewed in this study shared that they experienced an increased sense of self-confidence, developed a network of friends, and found a degree program as a result of being a peer mentor. Without these experiences they shared they would not have stayed at the university. The findings from this study shed light on how IHEs might facilitate a sense of community and belonging that may result in increased retention of undergraduate students through implementation of mentorship programs similar to the one described in this article.

Postsecondary education programs for students with ID/DD have experienced a dramatic increase in the last decade due to the passage of the Higher Education Act and the federal funding of the TPSID projects (National Council on Disability, 2011). The findings in this study are applicable beyond TPSID programs and suggest to public school administrators, educators and parents: (a) to set high expectations and hold all students including students with ID/DD accountable, (b) to teach basic socially appropriate behavior such as boundary setting, (c) to build independence, and (d) to link students and faculty to IHE supports such as the disability service offices.
Limitations of Study

The findings are limited in four ways. First, the findings represent the perspectives of only 18 undergraduate peer mentors who attended one specific university in the northeastern United States. Investigating the perspective of other mentors at other university postsecondary education programs might have provided richer data. Second, the participants in this study were mentors in a federally-funded TPSID program. Although the findings from this study are limited to a TPSID project, we believe that the results have implications for other postsecondary education programs. Third, interviews were based on three years of data collected by the lead author. The data represented the perspectives the mentors felt free to share with the lead author. Participants may have been unwilling to share all their most intimate concerns or challenges. A participatory action research approach might yield other valuable data. Fourth, this article focused on the perspective of the mentors themselves and did not compare those perspectives or experiences to those of the students with ID/DD themselves. We decided to focus on the university mentor because we felt that perspective had not been captured by previous research and that the perspective may have important implications for the inclusion of students with ID/DD in institutes of higher education.

Implications for Future Research

There are several potential research questions for future investigations. First, how do mentors contribute to the success of students with ID/DD in higher education? Second, how do university administrators view the involvement of undergraduate students in mentorship programs for students with ID/DD? Can these mentorships be avenues in which undergraduate students find a sense of belonging and meaning in their lives? Third, might peer mentorship serve as a recruitment or retention strategy for IHEs? Institutes of higher education might discover that mentorship experiences are a valuable experience in being of service to others. Fourth, how might university mentors help facilitate the transition of high school students with ID/DD into IHEs? Too often, older adult agency assistants serve as assistants for young adults with ID/DD making inclusion a challenge because of the age difference between the assistant and other potential peers of students with ID/DD. Finally, in what ways does the role of the IHE disability support services benefit students with ID/DD? How have these DS departments evolved since the passage of the Higher Education Opportunities Act of 2008 (HEOA) (PL 110-315) and the increase in IHE access for students with ID/DD across IHEs?

Conclusion

The experiences and perspectives shared by the undergraduate peer mentors in this study are valuable because there have been few other studies to date conducted on peer mentors’ perspectives. The experiences of these peer mentors can inform work in public schools and IHEs to support students with ID/DD in colleges and universities across the United States through the use of undergraduate peer mentors. That data from this study suggests undergraduate students consider being a mentor for a student with intellectual and developmental disabilities one of the most meaningful experiences they have during their time at this university. The opportunities that lie ahead are to: (a) develop successful secondary special education transition programs for students with ID/DD to IHEs, that include the provision of peer mentors; (b) understand the implications of peer mentoring as a potential powerful recruitment and retention strategy for IHEs, (c) support high school special education educators and parents of young adults with ID/DD to set high expectations for children, youth, and adults with ID/DD; and (d) strengthen and utilize IHE disability support services offices in the inclusion of students with ID/DD in colleges and universities.

References


U.S. Department of Education. (2010). *Transition and postsecondary programs for students with intellectual disabilities*.


About the Authors

Susan M. Ryan received her M.Ed. in severe disabilities from the University of Vermont and her Ph.D. degree in special education/early intervention from the University of Oregon. Her experience includes working as an early interventionist and special educator in New York, Delaware, Vermont and Alaska. She was the Director of the Early Intervention Graduate Program at the University of Alaska Anchorage from 1991-2006. She is currently a Professor in the Department of Special Education and the Executive Director of the Center on Disability and Community Inclusion at the University of Vermont (2006-present). Her research interests include early intervention, rural service delivery, fetal alcohol spectrum disorders and postsecondary education. She can be reached by email at: susan.ryan@uvm.edu.

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Table 1

**Peer Mentor Demographics**

<table>
<thead>
<tr>
<th>First Name</th>
<th>Age</th>
<th>Sex</th>
<th>College Level</th>
<th>Major</th>
<th>Average Hours (Weekly)</th>
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<tr>
<td>Bill</td>
<td>19</td>
<td>M</td>
<td>Junior</td>
<td>Secondary Ed., Concentration in English</td>
<td>7</td>
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<tr>
<td>Carol</td>
<td>18</td>
<td>F</td>
<td>Junior</td>
<td>Linguistics: Communication Sciences and Disorders</td>
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<tr>
<td>Emma</td>
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<td>F</td>
<td>Junior</td>
<td>Elementary Education, Concentration in Nutrition and Food Sciences,</td>
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<tr>
<td>Grace</td>
<td>21</td>
<td>F</td>
<td>Junior</td>
<td>Social Work, Spanish Minor</td>
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</tr>
<tr>
<td>Ann</td>
<td>19</td>
<td>F</td>
<td>Sophomore</td>
<td>Philosophy &amp; Psychology, or Social Work</td>
<td>7</td>
</tr>
<tr>
<td>Amber</td>
<td>19</td>
<td>F</td>
<td>Sophomore</td>
<td>Midlevel Education</td>
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<tr>
<td>Sarah</td>
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<td>F</td>
<td>Sophomore</td>
<td>Elementary Ed., Special Ed. Minor</td>
<td>7</td>
</tr>
<tr>
<td>Mary</td>
<td>21</td>
<td>F</td>
<td>Junior</td>
<td>Secondary Education, Philosophy</td>
<td>7</td>
</tr>
<tr>
<td>Margret</td>
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<td>F</td>
<td>Junior</td>
<td>English, Studio Art Minor</td>
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</tr>
<tr>
<td>Mandy</td>
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<td>F</td>
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<td>Elementary Ed.: Special Ed.</td>
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<tr>
<td>Leah</td>
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<td>Junior</td>
<td>Psychology</td>
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<tr>
<td>Melissa</td>
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<td>F</td>
<td>Junior</td>
<td>Biology, Spanish</td>
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<td>Kathleen</td>
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<td>F</td>
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<td>Elementary Ed.</td>
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<tr>
<td>Andrea</td>
<td>19</td>
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<td>Sophomore</td>
<td>Secondary Ed: Special Ed.</td>
<td>6</td>
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<tr>
<td>Eileen</td>
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<td>F</td>
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<td>Neuroscience: Special Ed.</td>
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<tr>
<td>Rob</td>
<td>19</td>
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<tr>
<td>Karly</td>
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<tr>
<td>Liam</td>
<td>19</td>
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<td>Sophomore</td>
<td>Secondary Ed., Concentration in English</td>
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</tbody>
</table>

*Note.* College level refers to year of interview. *a* Mentors who were interviewed more than once.
Table 2

*Mentee Demographics*

<table>
<thead>
<tr>
<th>Name</th>
<th>Disability</th>
<th>Age</th>
<th>Sexual Identity</th>
<th>Focus of University Certificate</th>
<th>Number of Credits</th>
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<tbody>
<tr>
<td>Ann</td>
<td>Intellectual Disability</td>
<td>19</td>
<td>F</td>
<td>American Sign Language</td>
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<tr>
<td>June</td>
<td>Down Syndrome</td>
<td>24</td>
<td>F</td>
<td>Performing Arts</td>
<td>12</td>
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<tr>
<td>Bea</td>
<td>Intellectual Disability</td>
<td>28</td>
<td>F</td>
<td>Early Childhood Education</td>
<td>12</td>
</tr>
<tr>
<td>Ben</td>
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<td>30</td>
<td>T</td>
<td>General Studies</td>
<td>12</td>
</tr>
<tr>
<td>Barb</td>
<td>Intellectual Disability</td>
<td>23</td>
<td>F</td>
<td>Office Administration</td>
<td>18</td>
</tr>
<tr>
<td>Carl</td>
<td>Mowat-Wilson Syndrome</td>
<td>22</td>
<td>M</td>
<td>Campus Recreational</td>
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<tr>
<td>Gary</td>
<td>Intellectual Disability</td>
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<td>M</td>
<td>Radio Media</td>
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<tr>
<td>Jess</td>
<td>Intellectual Disability</td>
<td>19</td>
<td>F</td>
<td>Culinary Arts</td>
<td>12</td>
</tr>
<tr>
<td>Kim</td>
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<td>20</td>
<td>F</td>
<td>General Studies</td>
<td>12</td>
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<tr>
<td>Lily</td>
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<td>Mike</td>
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<td>M</td>
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<td>Kelly</td>
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<td>F</td>
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</table>

*Note.* Sexual Identity: M=male; F=female; T=transgender.