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Social Lives at College: Experiences of Students with Intellectual and Developmental Disability

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Abstract

This dissertation qualitatively studied the social interactions students with IDD had in Inclusive Postsecondary Education (IPSE) programs. Through a DSE lens, I analyzed the experiences of 15 current and former IPSE students to determine the phenomena of social interaction while at IPSE. Methods included focus groups, participant observations, and interviews with the participants. Adaptations of social circle diagrams and photovoice were also utilized. Findings illustrated the presence of ableism surrounding the lives of individuals with IDD. This ableism was apparent within many aspects of the participants lives and experiences during IPSE. Ableism across larger systems was impacting access to higher education spaces as well as social opportunities and personal relationships. Additionally, I discuss findings that implicate how to ensure future research with individuals with IDD is done inclusively and accessibly. Implications are given for higher education and k-12 policy and practice, as well as for research. Future directions for IPSE research are also discussed.

Keywords: **intellectual disability, developmental disability, inclusive postsecondary education (IPSE), social interaction**

Social Lives at College:
Experiences of Students with Intellectual and Developmental Disability

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Chapter 1: Introduction

"Mom, don't worry. I'll be fine. I got this!" ~Poppy

Over the years, my understanding of inclusion has shifted in ways I never expected. I thought I saw *inclusion* during my undergraduate work at an inclusive postsecondary education (IPSE)[1] program. I thought I saw *inclusion* when I was in the community with my friend and former student who has Down syndrome, eating turkey legs at the Lilac Festival, going swimming together at the YMCA, and even giving lectures together to graduate literacy students. I thought I saw *inclusion* when students in that IPSE program I had worked for came to my apartment during Springfest my senior year for hot cocoa because it was freezing in April, and we could not stay outside anymore. In some ways, I even thought I saw *inclusion* when I was working at a camp for kids and adults with disabilities for ten years. I thought I saw *inclusion* again when I ran into another friend and former student with autism working at Wegmans, and he introduced me to his coworkers.

Before my undergraduate work, I did not have the language to discuss *inclusion*. I had gone to school with a few people with disabilities[2] and sang with them in the chorus. I had some disabled relatives and grew up playing barbies with them. I have worked with autistic students and students with muscular dystrophy in segregated school and camp environments. Thinking about whether those environments were inclusive did not cross my mind for many years. I enjoyed seeing and working with these individuals, but I did not question why I did not see them more often and in more spaces. I also did not question why their presence made some people

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[1] Appendix A is a list of common terms and acronyms from this dissertation.
[2] Regarding language choice related to disability, I understand there is contention between using identity-first and person-first language. I recognize the importance of this tension and difference in opinion between disabled individuals by using both forms of language throughout this work. I use individual preferences when I am aware of them.

uncomfortable. This is the truth of my life and is also true for many people. Many of us, especially at young ages, are unaware of the social constructions surrounding us concerning identity. Growing up, I knew who I spent time with. I did not often think about those I did not spend time with. I did not have identities that forced me to recognize the impact of social construction earlier. For many people, it is difficult to understand what is missing in our life until we are reminded or taught to do so. We do not question the way that things are.

Thinking back on those previous experiences, I wonder if I was experiencing inclusion. What is inclusion, and how is it defined? Can I ever describe what I saw as inclusive since I am not from a marginalized group that is either excluded or intentionally included?

One experience in the Fall of 2021 had me asking these questions. At the institution where I have done my graduate work, an IPSE program supports students with an intellectual and developmental disability (IDD) to live and learn on campus. This was new to me. As mentioned, my previous college also had an IPSE program but did not yet give their students the opportunity for residential living. For a short period, I worked as a mentor in the program with residential options. That role allowed me to attend social and sports events with the students and visit the students' dorm rooms. Once, I walked into a dorm with the student I was working with. The other IPSE student who lives there and their Residential Mentor were cleaning the bathroom and jamming out to music. While I was there, a few friends of the students came over, and they ultimately ended up playing a card game. In the brief 20 minutes of being in that space, I was overjoyed with what I saw. *This* felt like inclusion. *This* was different from those moments I had seen before. I was the guest. Those students, a mix of students with and without IDD, lived in that space. They were joking about boys, the speeches they would one day give at each other's

weddings, and other typical things college students talk about in their dorm rooms. This must be *inclusion*, right?

I have decided to investigate the experiences of students with IDD who are in IPSE programs to understand the meaning these students make from their social interactions on college campuses. I hoped to witness their social interactions, similar to or different from the moment I had with those students in their dorm room. Knowing the experiences of disabled students in college is essential, especially as the IPSE field is growing quickly. The only way to know if we see inclusion is by listening to the students who are being *included*. Do they feel included? Would they use a different term instead of inclusion? Is feeling included the goal IPSEs should be striving for? Is something more needed? The social situations or interactions IPSE students encounter throughout their time on campus will likely impact how they would answer those questions. Through this work, I aim to answer these questions in a way that acknowledges the competence and knowledge of students in IPSE programs.

Purpose

While designing any new research study, it is crucial to focus on an area of interest that is a problem or concern. This is an essential step in any research because "the way in which the problem is framed, while it will keep changing, determines much of what follows" (Schratz, 1996, p. 55). Some questions to consider in determining the main research question are: "What is happening already? What is the rationale for this? What am I trying to change?... Who is affected? With whom must I negotiate?" (Winter, 1996, p. 11). After considering these thoughts and questions about the IPSE field, I have come to one main research question.

In what ways do students with intellectual and developmental disability experience social interaction during their time in an inclusive postsecondary education program?

This research was designed considering previous studies on engaging disabled people in research and engaging students as active participants through inclusive methods[3]. Overall, this research aims to be an inclusive research design, meaning I strived to involve adults with IDD as much as possible throughout the study. While there is a need for further quantitative action research with individuals with disabilities (Stack & McDonald, 2014), there is still a need for inclusive qualitative research with individuals with disabilities. The insights gained in qualitative work are essential in pursuing social justice-based research. It has been said that with qualitative research, "your role is to try to capture how people define their world or construct their reality" (Taylor & Bogdan, 1998, p. 53). Qualitative methods allow researchers to gather thick and rich descriptions of "actions, behaviors, and words of people, including processes, intentions, and feelings [that involve] a portrayal of individuals and groups in their settings and cultural context" (Holloway & Brown, 2012, p. 20). Although useful, data points from quantitative surveys cannot fully produce this level of knowledge about individual experience.

Problem and Significance

Understanding students' experiences with IDD at institutions of higher education (IHE) is essential. Students with IDD have only recently begun to be accepted into these higher education spaces (Baker et al., 2018). It should be noted that program acceptance is variable depending on the specific location and institution (Think College, 2022). With this increase in students with IDD entering IPSE programs, there is a need to determine how to ensure they are not feeling like a "squatter" or "poster child" at the institution. These feelings of being an outsider or on display because of one's disability often surround movements toward inclusion (Kliewer, 1998). Although the number of IPSE programs and the increase in students attending

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[3] Chapters 3 and 6 discuss inclusive methods used in this work and their basis in research.

them has been moving in a positive direction, there persist many barriers to participation for individuals with IDD at different times throughout their postsecondary transition. In this research, I examine how these barriers may impact the social experiences of students with IDD in IPSE programs.

At the root of many barriers in the lives of people with disabilities is the concept of ableism. This term, rooted in the disability rights movement, "question[s] and highlight[s] the sentiment that perceives species-typical bodily abilities as essential…" (Wolbring, 2012, p. 151). Ableism highlights the idea that specific abilities are necessary or coveted by society and privileges those abilities. With that privilege for some people comes a disadvantage for others. Which abilities are privileged and seen as essential in society depends on the culture of that particular space. The terminology of ableism was initially termed 'handicapism' (Ashby, 2011; Bogdan & Biklen, 1977; Hehir, 2002). Ashby (2011) states that ableism implies that "individuals who fall outside the range of dominant norms of bodily appearance or normative performance face exclusion and oppression" (Ashby, 2011, p. 346). Considering that IDD is a disability label given to individuals categorized within the definition of those impacted by ableism, this understanding is essential to this work. It is also necessary to understand that ableism impacts each individual differently, often depending on their other intersectional identities and how discrimination impacts them simultaneously.

The participants in this work all identify as people with IDD. In looking at their social interactions while in an IPSE program, I anticipated that there would be examples of ableism and other forms of discrimination in the data. I knew the participants would understand those discrete moments of discrimination in varying ways. By determining how participants

understood those experiences, I could better determine barriers to successful social interaction and inclusion at an IHE, which is important for the IPSE field.

There is a need to determine strong practices for facilitating inclusion in IPSEs and IHEs at an individual, organizational, and institutional level. Literature has begun to determine model practices regarding improving transition outcomes for students with IDD. Much of this research has investigated practices that lead to competitive paid employment success as an outcome of postsecondary education (Grigal et al., 2019; Papay, 2018; Qian et al., 2018). Although employment is often upheld as necessary to the societal norms of a capitalist country, other outcomes are also essential to investigate how they impact the quality of life for an individual with IDD[4]. These other outcomes include independent or interdependent living, community involvement, academic achievement, and overall happiness or contentment.

FutureLIFE, the IPSE program where this research was completed, includes supports specifically for students enrolled in the program. These supports were created to facilitate inclusion and success at IHEs in academics, residential living, social life, and employment. Student support assistants, an academic coordinator, and peer mentors are paid supports who assist with facilitating academic success by going to class with students, working with them on homework assignments, and helping with academic organization. A residential coordinator and residential mentors are paid staff who assist FutureLIFE students with residential-related aspects of college, such as peer mediation, independent living tasks, and self-care exploration. Paid peer trainers, a graduate assistant, and volunteer peer partners attend social events with FutureLIFE students, helping to facilitate positive social interactions with disabled and non-disabled peers. An internship coordinator and paid job coaches assist FutureLIFE students with

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[4] Chapter 2 discusses the history of IPSE and current outcomes research in more depth.

their internship experiences. Each FutureLIFE student also has an advisor who can help them with all aspects of college life. Many IPSE programs across the country include similar support structures.

Social experiences and interactions are often associated with definitions of inclusive practices and what creates a non-exclusive experience (Rimmerman, 2013). These social and possibly inclusive experiences may impact various outcomes, such as employment, independent or community living, and overall happiness after graduation from an IPSE program (Jones et al., 2015; Qian et al., 2018).

There are many ways the systems surrounding a student with IDD can impact their success in the future. Barriers exist which impede success for many individuals with IDD throughout the US as they transition into life after high school. Although society has come a long way in terms of disability inclusion, there is still a long way to go. The variance in how IPSE programs are run has caused an issue in research, as most findings could be more generalizable to other programs. After analyzing the barriers that impede student success throughout and after IPSE programs, a few significant areas for additional research are necessary to further the field and improve programs and student outcomes. Some of these barriers include issues related to social interaction and friendship. This study will examine how IPSE students experience those barriers within the various systems they are in daily. The IPSE research field will grow in its understanding of inclusion because of the experiences and findings I discuss in this work.

Positionality

Choosing to do this research was intentional. My position is one of not just allyship but one of accomplice. As Bourke (2020) discusses, "Because of the passivity of allyship, allies can

be seen as taking a position without taking risks. On the other hand, an accomplice is in the thick of things, actively participating, assuming risks" (Bourke, 2020, p. 190). I have and continue to interrogate oppressive systems, especially towards disabled folks, facilitating change through action with those who are marginalized. This is not just something I talk about, write about, and research literature. Daily I can be found in communities with disabled people, learning about their lives and discussing everyday trials and tribulations. In the classroom, I teach about ableism and explain the impacts of societal constructs on disabled people, utilizing first-person accounts of marginalized individuals as often as possible. As an accomplice to people with disabilities, I have researched IPSE program experiences and helped advocate for change within IPSE programs and beyond, along with other allies and accomplices. This has included advocacy work in the U.S. and NYS Capitols. In this specific research work, I advocated on my participants' behalf by always keeping their preferences at the forefront and pursuing work to then disseminate to educate others about the oppression IPSE students face. Although my experiences did help with rapport-building, they also caused some tensions in determining my role throughout this work. This is a risk I took on as a researcher doing this type of research. I believe each person is the expert on their own experience, and I cannot be an insider on someone else's life. I discuss my role in this work more in Chapter 6.

An important initial aspect of becoming an accomplice is recognizing my own privilege (Bourke, 2020). Awareness of researcher positionality is vital in qualitative research, especially in how positionality relates to power and the dynamics of working with participants. The issue of positionality is often discussed along with the idea of insider/outsider status that a researcher takes concerning the research subjects. Benefits have been discussed related to the researcher's insider and outsider status (Mason-Bish, 2019). For this research, I was an outsider. I am a

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researcher who has no identified disabilities. Even though I have worked extensively with people with disabilities in various contexts, I cannot fully understand the experience of a disabled person. The experiences I have had helped me build rapport quickly with individuals with IDD in many different contexts and prepared me well for work with the participants in this study, but they did not make me an insider. I position myself as an outsider and a respectful observer and learner. Even so, I chose to pursue this work with disabled people because I have witnessed firsthand the impact IPSE programs can have. I have heard from parents and guardians of disabled children when they first realize their five-year-old child can have the same opportunity to go to college as their non-disabled sibling. I have experienced the change that comes from becoming friends with IPSE students. I have listened to disabled college students present and advocate for their desires in front of conference rooms full of disabled and non-disabled individuals. I recognize the immense potential that IPSE programs, and the stakeholders within them, have to change disability stigma in society. Additionally, I have felt and owned the discomfort that is inherent in evaluating and reflecting my own implicit biases as they relate to marginalized identities like ability and race. These aspects of reflection and action are essential in being an accomplice (Bourke, 2020).

Although as a researcher I take on risk in this work, I have been strategic with when participants are named[5] and not to minimize risk of the participants. Many of these participants knew each other and were together during observations or events discussed in interviews. Statements that may be more controversial or could cause social harm if connected to the individual have been entirely anonymized by being written without any pseudonym. Institutional

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[5] All names of people, places, and organizations have been changed to facilitate confidentiality.

Review Board (IRB) precautions were kept in terms of confidentiality, but I used this additional strategy to ensure participant safety doubly.

Organization of this Dissertation

This dissertation consists of the following sections: (1) Introduction, (2) Literature Review and Theoretical Framework, (3) Methodology and Methods, (4) Findings about Systemic Barriers, (5) Findings about Relational Barriers, (6) Findings about Methods, (7) Discussion, Implications, and Conclusion. Within the introduction are the personal connections I have made to this research topic and how those experiences brought me to the question this study addresses. Hearing from students about their social interactions and whether students in IPSE programs understand their experience as inclusive during college is explained as the focus of this research in Chapter 1. Chapter 2 gives background information surrounding IPSE programs and their recent national increase. In addition, the literature review addresses social interaction theories and understandings of IDD and inclusion. Chapter 2 also discusses how the theoretical framework of disability studies in education framed this study. Chapter 3 gives rationale to the methods choices of participant observation, semi-structured interviewing, focus groups, and background on inclusive research methodologies framed by phenomenology. I discuss the social circle diagram technique I have transformed for this study. The timeline of this research and the methods of analysis are also explained. Chapters 4, 5, and 6 delineate three main findings from the data collection. Chapter 7 further explains the analysis and discussion of these findings and concludes the work with an overview of limitations and suggested implications for future work. Additional appendices with more specific methodological techniques for this research are compiled at the end of this manuscript.

Chapter 2: Literature Review and Theoretical Framework

"I think some people are different. Some people have situations and want to be with the University. Some people like to talk; some people don't. But that's what they choose to do. And that's what I have to say about that." ~ Naranj

Three significant and intersecting fields of literature have been utilized to inform this research. These are IPSE[6], IDD, and Social Interaction. Although literature in these fields intersects, there are gaps among them, and this work specifically addresses the gap in how IPSE students experience college socially.

Inclusive Postsecondary Education

Individuals with disabilities have historically been excluded from the public and faced ridicule and even banishment through measures that included sterilization, institutionalization, and even death (Kliewer & Drake, 1998; Longmore & Umansky, 2001). Due to the engrained nature of ableism, or the oppression of disabled people in society, and the pathologizing of disability, there are still many aspects of daily life for individuals with disabilities that are made more difficult because of the barriers brought on by the environment (Francis et al., 2019; Moore et al., 2011; Thomson, 1997; Watts & Erevelles, 2004).

Educational systems in the United States historically disregarded children with disabilities, often not permitting them to attend public schools (DeMatthews et al., 2020; Dukes & Berlingo, 2020; Lemay, 2009). Instead of public schooling, children with disabilities were often kept in institutions for the entirety of their childhood years and sometimes their entire lives. When these institutions began to close, and individuals with disabilities were more present

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[6] The term "inclusive" within Inclusive Postsecondary Education is not clearly defined in the literature. There is also a possibility that some programs called IPSEs are not "inclusive" based on particular definitions. The terminology of IPSE will be used as a marker for all postsecondary education programming for individuals with IDD at an Institution of Higher Education discussed in this dissertation.

in public spaces, students with disabilities (SWD) were instead sent to segregated schools without the possibility of interacting with the general education students from the same school district (Ferri & Connor, 2005). There have been numerous legal acts implemented to try to reduce the segregation of SWD in K-12 schools[7], such as Section 504 of the Rehabilitation Act, the Education for All Handicapped Children Act (EAHCA) and its subsequent revisions and updates: the Individuals with Disabilities Education Act (IDEA), and the Individuals with Disabilities Education Improvement Act (IDEIA) (EAHCA, 1975; IDEA, 1990; IDEIA, 2004; Section 504, 1974). These acts implemented federal guidelines, giving students with disabilities more rights to be educated in inclusive settings through secondary school. In addition to these acts, there has been legislation passed to help SWD with their transition after high school, including the Americans with Disabilities Act (ADA) and the Higher Education Opportunity Act (HEOA) (ADA, 1990; HEOA, 2008). Titles II and III of the ADA of 1990 have jurisdiction within IHEs, prohibiting discrimination based on disability in both public and private institutions (ADA, 1990). The expansion of the definition of disability in the 2008 reauthorization of the Americans with Disabilities Act Amendment Act (ADAAA, 2008) gave disabled students greater access to reasonable accommodations in higher education (Grigal et al., 2019).

Initially, the Higher Education Act of 1965 (HEA) created a stronger relationship between the federal government and IHEs for the general public than had ever been made prior, which began to make higher education more accessible, especially in terms of finances (Madaus et al., 2012). HEA has been reauthorized eight times, most recently creating the HEOA of 2008. Another reauthorization has been in progress since it was scheduled in 2013. HEOA was the

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[7] A more detailed discussion of how schools understood "inclusion" during these different movements is given later in this chapter.

first piece of federal legislation to give specific guidelines that would give individuals with IDD access to higher education. In totality, the HEOA contained seven Titles. Specifically related to IDD, the HEOA gave these students access to "federal work-study funds, Pell Grants, and Supplemental Educational Opportunity Grants" (Madaus et al., 2012, p. 36) if the program qualifies as a Comprehensive Transition Program (CTP). Being a CTP signifies a certain level of inclusion of students with IDD in coursework with students without IDD (Grigal et al., 2019). Another specific area of the legislation that significantly increased IDD student access to IHE was the language within Part B of the ID definition, i.e., including current and former eligible individuals of a Free and Appropriate Public Education under the IDEA. There were multiple amendments related to disability engagement in higher education, specific to; pedagogy, accessibility of materials, allowance of pell grant funding during summer terms, etc. With the establishment of the HEOA, there were more opportunities for IPSE programs to be created and thrive on college campuses (Smith Lee et al., 2019).

The earliest iteration of IPSE is said to have been in the late 1970s but was highly segregated and only focused on independent living and employment (Grigal et al., 2019; Neubert et al., 2004). From what is known, early in the 2000s, there were community-based transition programs for students ages 18-21 that were often connected with local school districts, but many of them did not include access to higher education (Gaumer et al., 2004; Grigal et al., 2022). There is evidence of at least 25 programs in 2004 (Grigal et al., 2019; Hart et al., 2004). In 2008, prior to the enactment of HEOA, there were only 49 IPSE transition programs (Baker et al., 2018). In 2011, there were reportedly 160 IPSE programs (Madaus et al., 2012). According to Think College, there currently are 312 college programs for students with IDD (Think College, 2022). With this increase in programs, there have been more opportunities for

young adults with disabilities, especially those with IDD, to participate in IHE after high school meaningfully.

Demographic data related to IPSE students is minimal. However, white students are often in a place of privilege to be able to attend IPSE programs when compared to other racial demographics (Grigal et al., 2022). A few demographic reports have been on a subset of postsecondary education programs called Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID). These programs were created through the HEOA when they established the National Coordinating Center (Madaus et al., 2012). Up until this point, there have been three 5-year cohorts of TPSID programs funded by the National Coordinating Center TPSID grants. "TPSID grants were awarded by the U.S. Department of Education (USDOE) Office of Postsecondary Education (OPE), and grantees were charged with establishing or expanding model postsecondary programs focused on academic enrichment, socialization, independent living skills, and integrated work experiences leading to gainful employment" (Grigal et al., 2022, p. 5).

Among the 58 most recent TPSID programs whose data was compiled in 2019, 60% of students in those TPSID programs were white, 25% were Black or African American, 12% were Hispanic, 6% were Asian, 1.5% were American Indian or Alaska Native, and 1% were Native Hawaiian or other Pacific Islander (Grigal et al., 2019). As shown with the TPSID program demographics, there is a much smaller percentage of students attending who identify as a racial and ethnic minority. This was also true among the students within the focus program (FutureLIFE) in this study. A study was done by Carter et al. (2019) with five campuses that house IPSE programs. Of those five programs, four were TPSIDs. The race and ethnicity makeup of students across all five programs focused on in that study was consistent with the

Grigal et al. (2019) work, albeit more diverse, showing a breakdown of 55% of students who identified as white, 43% African American, and 3% characterized as other races and ethnicities. According to the Office of Special Education Programs (OSEP; 2021), the demographic breakdown of students ages 5-21 with an intellectual disability is as follows; 38.67% white, 26.17% Black, 27.54% Hispanic, 2.59% Asian, .39% Native Hawaiian or Other, 1.3% American Indian/ Alaska Native, and 3.34% two or more races (OSEP, 2021). The racial and ethnic makeup of these IPSE transition programs is not mirroring the makeup of public schools. TPSID programs are a small subset of all transition programs but often have more financial resources than other transition programs at IHEs because they are grant funded. Due to this discrepancy in funds, non-TPSID programs are even less likely to have resources that would enable them to better assist multiply marginalized students to attend IPSE. That said, there has yet to be any substantial demographic data concerning the many other non-TPSID programs and their outcomes. This is of concern because even though there is an overrepresentation of marginalized students placed in special education settings, many of these students are not ending up in IPSE programs (Grigal et al., 2019; OSEP, 2021; Watts & Erevelles, 2004). As will be discussed in Chapter 3, I purposefully recruited from a large program to ensure diversity in my participant pool. I will discuss the impacts of that demographic diversity in later chapters.

TPSID programs offer a variety of living situations to their students. In recent TPSID data, approximately 67% of students lived with their parents, while 23% lived in IHE housing (Grigal et al., 2019). The IHE residential options vary widely among the different TPSIDs, and other IPSE programs not funded through TPSID grants. Some options include living in dorms, on-campus or off-campus apartments through the college or university, or off-campus housing, not through the IHE (Think College, 2022). Participants in this study lived on-campus in

residence halls and at home with their parents. Across the entire FutureLIFE program, approximately 70% of students commute and 30% live residentially.

For many students, in IPSE programs and not, college is their first time living away from parents and guardians, which can cause stress (Marron & Kayson, 1984). This transition to being more independent can initially seem very scary. For students in IPSE programs living in IHE housing, there are sometimes options for housing staff, such as on-call staff, residential mentors, or roommates tasked with supporting the student (Grigal et al., 2019). One of the most significant difficulties with determining best practices for IPSE programs and researching their success is that there is not one standard type of program. It is not easy to obtain generalizable data regarding all the programs in the country due to this immense variance in programs.

Inclusion itself in IPSE programs is something that varies widely from program to program. According to Hart et al. (2006), there are three major types of postsecondary education programs for people with IDD. These include *separate, hybrid,* and *inclusive* programs, all varying in the level of inclusion they provide for students (Hart et al., 2006; Madaus et al., 2012).

Programs created with an inherently *separate* model are segregated and have students in their program only participating in activities with other students in their program who also have disabilities. There is less of an influence on and from the campus community, and the program is its own separate entity on the campus, not interacting with the rest of the students by design (Hart et al., 2006). *Inclusive* programs or IPSE programs give students individualized attention while allowing them to be fully included with the college campus and other students. The student's personal goals drive their program, including the courses they take and the activities they participate in (Hart et al., 2006). The middle ground among IPSE programs is considered

hybrid. These programs often give students opportunities to engage with students without disabilities but also mandate IPSE students to spend time with only other students in their program. Often, these specialized times are for classes about employment preparation and independent living (Hart et al., 2006). A student's success after completing their program may depend on the type of program they were a part of. The more inclusive an IPSE experience is for a student, the more likely they are to find competitive employment (Grigal et al., 2019; Papay, 2018; Qian et al., 2018; Rooney-Kron et al., 2022). Despite a lack of exhaustive research on the impact of levels of inclusion in higher education, there has been a push for IPSE programs to become more like the inclusive model (Jones et al., 2015). When creating a more inclusive campus, it is essential to remember that, as Uditsky and Hughson (2012) mention, just having students present is not inclusion. The theoretical understandings of inclusion are a focus within this work because they connect heavily with social interactions happening on campus.

Theoretical Background of Inclusion

What inclusivity means on college campuses and how to create and adapt systems and structures within higher education to make more inclusive spaces is something that many IPSE programs have been wrestling with (Baker et al., 2018; Hart et al., 2006; Jones et al., 2015; Myers et al., 2019). The FutureLIFE program, the focus program in this study, has undoubtedly been impacted by the variance in theoretical understandings of inclusion throughout history. The FutureLIFE program, similarly to other IPSE programs, has practically pursued inclusion based on its current understanding while continuously being impacted by the persistent ableism within IHEs and society.

Historical Roots of Inclusion

IHEs are exclusionary by design (Dolmage, 2017). Only the most privileged in society, in ways related to identities such as race, ethnicity, class, and ability, were historically able to attend IHEs. Individuals with marginalized or multiply marginalized[8] identities were not often allowed to attend IHEs and historically were denied access. This work focuses on the identity of IDD and the participants' identities that intersect with a disabled identity. Although perceptions of identity are social constructions, research must be done to understand these constructs' implications and material consequences. Major structures have led to disparate opportunities and outcomes for students with IDD. It is crucial to understand inclusion and its transformation over time to reduce these disparities. In many ways, the structure and growth of IPSE programs have mirrored the ways inclusion as an idea has shifted over time.

Some think of inclusion as a means to bring students with disabilities into general education classrooms (Ferguson, 1995). This traditional view of inclusion has shifted in many settings recently. This view began as "mainstreaming," which is common terminology in the US, and "integration," which is common in other countries (Farrell, 2000) and consisted of two separate programs, one for students with disabilities and one for students without. The students with disabilities could be "mainstreamed" into the traditional or general education classroom, but they were distinctly different in structure. Models then shifted away from this idea of multiple systems into a more combined program, termed "inclusive" (Artiles et al., 2006; Gartner & Lipsky, 1987; Stainback & Stainback, 1984; Will, 1986; Zollers et al., 1999). Some may consider this an abolishment of "general and special education," being replaced by services among a combined education system of students with and without disabilities (Gartner &

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[8] An individual with multiple intersectional identities is marginalized by their society, such as a person who is disabled and Black.

Lipsky, 1987). Qvortrup & Qvortrup (2018) mention this evolution, saying, "inclusive education has evolved from a story about children with special needs to a story about inclusive schools and inclusive learning environments for children with all kinds of physical, cognitive and social backgrounds" (p. 804). These shifts in inclusive models have not been without great contention (Fuchs & Fuchs, 1994; Taylor, 1994).

Uditsky (1993) has given an overview of inclusive education and its defining traits when shifting from a more integrated model [in Canada].

In the inclusive classroom, the student with a significant disability, regardless of the degree or nature of that disability, is a welcomed and valued member. The student is: taught by the regular classroom teacher (who is supported as needed); follows the regular curriculum (with modification and adaptation); makes friends; and contributes to the learning of the entire class. (Uditsky, 1993, p.82)

The push for inclusion has gained support because research has shown that students with disabilities have had improved success after being included with their non-disabled peers (Cole, 2006; Cole & Meyer, 1991; Cole et al., 2004; Lipsky & Gartner, 1996; Lyons et al., 2016; Manset & Semmel, 1997; McDonnell et al., 2000, 2003; Vaughn et al., 1996).

As inclusion has been implemented in different educational spaces, there have been further changes in how it is understood and implemented. Qvortrup and Qvortrup (2018) argue that:

Inclusive education includes not only the physical and social dimension of educational practice, but also the psychological dimension (the experience of being included), and that inclusive education covers not only the classroom, but also a lot of different communities in and related to the school. (Qvortrup & Qvortrup, 2018, p.807)

This expands the idea of inclusion to not only be about academic success but also include elements of interaction in any space because of the social and physical aspects of the various systems individuals are within.

A key piece to their (Qvortrup & Qvortrup, 2018) understanding is that there is no inclusion without exclusion. Inherent in creating a system that includes specific individuals, there will be individuals who are not allowed into that space, even if the intention is for all to be included. This is an issue that needs to be considered in any inclusion initiative. As explained by Lipsky and Gartner, the plight of the disability and inclusion movement has shadowed that of other social justice movements. With the disproportionality among race, language, and gender at work within unique education systems and how ableism is engrained within society, this furthers the necessity to treat this fight as one of social justice (Artiles et al., 2006; Lipsky & Gartner, 1996).

Inclusion Implementation

Numerous studies have been done and policies put in place in previous decades explaining the practical nature of inclusion and how it can be implemented in schools, mainly focused on K-12 settings. In terms of organizational and institutional implementation, several frameworks have been used to support inclusion in k-12 settings, one of which is *communities of practice (CoP).* The premise of CoPs is collaborative groups of teachers interested in enhancing their pedagogy, often related to a specific concern or passion (inclusion, hands-on learning, social-emotional learning, etc.) (Patton & Parker, 2017). CoPs typically are developed with the elements of the domain (a shared interest among the group), community (an element of consistent interaction with group members), and practice (group members are practitioners of a specific field) (Wenger-Trayner & Wenger-Trayner, 2015). Within the idea of communities of practice among teachers and administrators, it is argued: "the development of inclusive practices

requires processes of social learning within particular organizational contexts" (Ainscow & Sandill, 2010, p. 404). In higher education, potential CoPs could help pursue inclusion initiatives, specifically related to the pedagogy of faculty and IPSE program involvement on campus.

Ainscow and Sandill (2010) also discuss the importance of problem-solving coinciding with collaboration in school cultures. They explain, "the implication of all of this is that becoming more inclusive is a matter of thinking and talking, reviewing and refining practice, and making attempts to develop a more inclusive culture" (Ainscow & Sandill, 2010, p.407). This is seconded by Zollers et al. (1999) when they discuss the importance of school organizational culture in creating an inclusive school culture. Having conversations about the experiences of inclusion students have had through collaborative means is essential.

Loreman (2007) agrees with this idea the importance of inclusive school culture and created *seven pillars of support for inclusive education*. These pillars are not ways to implement inclusion in schools; they create settings that wholeheartedly welcome inclusive strategies. These pillars include: "Developing positive attitudes, supportive policy and leadership, school and classroom process grounded in research-based practice, flexible curriculum and pedagogy, community involvement, meaningful reflection, and necessary training and resources" (Loreman, 2007, pp. 24-33). Inclusive schools would not be as successful without a foundation of the collaborative idea that inclusion is beneficial and the attitudes created from these strategies. These attitudes are most likely beneficial to IHEs moving towards inclusion as well. The ways these pillars have shown up throughout this work are explained in Chapter 7.

Inclusion in This Work

This dissertation assumes the research and ethics-based idea that students with disabilities and individuals with marginalized identities need to be included in all spaces of

society. I am therefore not discussing in their entirety the arguments of special educationists, who deem separation essential for some students. Other researchers also hold a similar stance to mine in that inclusive education is a human right (As explained in Farrell, 2000; Lindsay, 2003; Lipsky & Gartner, 1996).

Although inclusion research has mainly been pursued in areas of K-12 education, the shift to a more overarching idea of "inclusion" is also seen in other areas of education and community living (Kramer et al., 2021). Scholars in higher education are beginning to research the ideas of inclusion, primarily when the term is used to describe a subset of programs, referred to here as IPSE.

Bacon and Baglieri (2021) recently proposed a new model of inclusion in IPSE programs which consists of three concepts; togetherness, access and opportunity, and belongingness. The guiding questions to determine success with these three concepts are included in Table 1. Within this framework of inclusion, there is a mix of the more traditional understandings of inclusion (seen in the concept of togetherness) and a newer understanding of the diversity and intersectionality surrounding disability (seen in the concepts of access and opportunity, and belongingness). This framework demonstrates that there does not need to be polarized thinking of inclusion, and there may be space for a mixture of historical and new ideas of inclusion in practice. I anticipated that this new and nuanced understanding of inclusion would be inherent in this work, as there is a necessity to have people with disabilities in physical spaces and that they are valued through access, opportunity, and belongingness.

Table 1.

Three Concepts of Inclusion and Their Guiding Questions

Concept of Inclusion	Guiding Question

Togetherness	How are disabled and non-disabled people integrated in ways that create or enable togetherness in college spaces, places, and resources?
Access and Opportunity	How are individuals able to benefit from educational experiences by… ● Ensuring disability rights and access; ● Reducing discrimination/ableism; ● Providing support and accommodations to allow individuals with disabilities better access to educational opportunities?
Belongingness	How can the institution transform and expand to engage and serve the diverse populations in their communities, welcoming and serving those who are seeking varied educational pursuits for personal betterment and advancement?

Note: Information from Bacon & Baglieri, 2021.

These theories and frameworks of inclusion in educational research work in concert with the DSE framework to support this research. These frameworks critically push forth the importance of diverse student experiences during college. Finally, a phenomenological approach allows this work to focus on students' experiences.

Intellectual and Developmental Disabilities in IPSE

Students with IDD are the focus of this study because they are a disability subgroup just starting to be given a place on college campuses. Someone is determined to have an IDD when they demonstrate "evidence of intellectual *and* adaptive impairment during the developmental period" (emphasis in original, Papazoglou et al., 2014, p. 166). Individuals must meet the criteria established in the most current diagnostic and statistical manual (DSM-V) to be categorized as having IDD, often defined by an IQ score and adaptive behavior "deficits." An IDD diagnosis is

required for many funding streams related to IPSE programs, such as Medicaid waivers and

TPSID funding[9]. Although the diagnosis of a disability is necessary for certain procedural

aspects of funding and acceptance into an IPSE program, there is a prominent belief in disability

studies theory that the environment surrounding someone is what disables them rather than any

impairment they may have (Oliver, 1996). This research recognizes this more nuanced look at

disability through the disability justice framework[10], acknowledging how the environment

impacts people with IDD and how diversity within the entire community is essential.

Experiences are not the same for every person with a disability due to their impairment and other

identities they embody.

There have been positive outcomes for students with IDD, specifically those who have

attended IPSE programs, so we must understand the positive outcomes and barriers still apparent

within the field. It has been found that individuals with IDD who have attended higher education

programs and/or have received Vocational Rehabilitation employment services are more likely

to find Competitive Integrated Employment (CIE) and higher wages within years after leaving

the program or service (Migliore & Butterworth, 2008; Sannicandro et al., 2018; Smith et al.,

2012a). In some cases, this is between 673-714 days (Migliore & Butterworth, 2008) from

beginning their program, while in other cases, the period to employment is unknown. This

increased likelihood of paid employment is crucial for students, as it has historically been

challenging for individuals with disabilities to find CIE, especially well-paid employment. Only

38% of young adults with IDD were employed after high school (Lindstrom et al., 2014;

Newman et al., 2011; Office of Disability Employment Policy, 2021). Although ADA Title I

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[9] There are many ways that students pay their way through IPSE programs. Federal funding streams are just a few, in addition to private funding and scholarship.
[10] The Framework of Disability Justice is discussed in greater detail in this chapter.

does protect individuals with disabilities from discrimination related to employment, there are many instances where it does not do enough (Grigal et al., 2022; Ridge, 2021; Wage & Hour Division, 2008). In terms of physical accessibility, for example, companies that are enforced by Title I only need to make buildings accessible to a certain extent and under specific circumstances. The ADA National Network (2013), on their Questions and Answers page, stated,

> Under title I, an employer is not required to make its existing facilities accessible until a particular applicant or employee with a particular disability needs an accommodation, and then the modifications should meet that individual's specific medical needs. However, employers should consider initiating changes that will provide general accessibility, particularly for job applicants, since it is likely that people with disabilities will be applying for jobs. The employer does not have to make changes to provide access in places or facilities that will not be used by that individual for employment-related activities or benefits.

This demonstrates the difference between requirements and suggestions within Title I of the ADA. This statement suggests that employers make spaces accessible for job applicants before a need arises "since it is likely people with disabilities will be applying for jobs" (ADA National Network, 2013). However, it is not a requirement until an applicant or employee has requested the accommodation. Employers who have not preemptively decided to create accessible workspaces are demonstrating biased thinking towards disabled folks, not anticipating their potential value in their organization.

In addition to employment outcomes, other positive outcomes seen throughout IPSE transition research are levels of independent living an individual has after leaving their program

and community and social engagement (Butler et al., 2016; Grigal et al., 2013; Miller et al., 2016). Although these outcomes are mentioned in a few studies about individuals with IDD, there is a need for more research to understand how postsecondary education can impact success in these areas.

Social Interaction

Social interactions with family and peers can be some of the most challenging aspects of life for any student, but they can also be some of the most important (Bynner, 2007; Finan et al., 2018; Richards et al., 1998). In different social contexts of college life, many interactions occur with friends, peers, faculty, staff, acquaintances, strangers, etc. These social interactions can be permeated with thoughts about making friends, dealing with peer pressure, and forming romantic relationships. These significant parts of social life for young adults in college can cause great anxiety and confusion for all students but especially for students with IDD (Adams & Proctor, 2010; Ferrell & Carter, 2022). This phenomenological study focuses on the experiences that IPSE students have with social interaction. Through this study I can understand better how individuals with IDD interact with systems within IHE and what meaning they make of their interactions there. As previously mentioned, the college system is entrenched in ableist ideals that created these institutions. These college spaces were not created with individuals with IDD in mind and still hold areas of both physical and attitudinal inaccessibility and inequity within them (Dolmage, 2017; Kelley & Prohn, 2019). My research recognizes the systemic ways in which ableism may be impacting these students' social interactions and how it shapes the meanings IPSE students make of their social interactions.

Although there is limited research on the social interactions of students with IDD in IPSE programs, there is a basis of social interaction research that is important to this study. One

study by Luo (2021) found that social interaction across diverse groups and ideological mindsets during college positively impacts student outcomes after college. Luo found that "compared with less interactive students, students who engaged substantially in ideological interaction during college indicated higher levels of skill development, reported higher career success and life satisfaction, and were more likely to assume leadership roles in civic activities" (Luo, 2021, p. 79). This study did not focus on disability influence in any way but demonstrates the general importance of interaction with various other students, leading to improved post-college outcomes. Other research has shown that emerging adults[11] with IDD are less likely to have friends they see outside work or school (Newman et al., 2011; Spruit & Carter, 2021). There has been more substantial research on the social interactions of students with disabilities in k-12 schools. This is partly because "friendship" has been a primary goal of pushes toward inclusive classes, and friendship is often understood as an outcome of social interaction (Bogenschutz et al., 2015). Although defining friendship is not a goal of this work, understanding how researchers have utilized friendship in previous social interaction research is valuable.

Friendship has been identified to consist of 11 components, according to Matheson (2007). Proximity, similarity, transcending context, and companionship are characteristics of children's friendships. Characteristics of reciprocity, mutuality, help/support, conflict management, stability, trust/loyalty, and intimacy/disclosure grow over time after childhood (Matheson et al., 2007). Rossetti et al. (2016) interviewed parents and teachers about the friendships of secondary students with IDD. They found that parents and teachers often focused on the "components of friendship that are central to children's friendships" instead of

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[11] The term emerging adults will be used in this work to describe individuals aged 18-26, typically seen as the years between adolescence and adulthood.

characteristics like intimacy (Rossetti et al., 2016, p. 250). They also found that many relationships did not leave school walls, as the parents and teachers explained. The Rossetti et al. (2016) study also found an emerging theme that "increased social opportunities in inclusive settings that became consistent over time led to higher-quality social interactions and the development of friendships" (Rossetti et al., 2016, p. 251).

Similarly to k-12 research, Spruit and Carter (2021) examined the friendships students with IDD have during IPSE programs. Their study determined eight qualities of friendship that IPSE students discussed; supportive, compatible, attractive qualities, provides companionship, involvement in the same experiences, stable, similar, and like family. I have used this previous research by Spruit and Carter and work on k-12 social interaction to inform this study design.

Other researchers have investigated the social experiences and interactions of disabled individuals in different ways. The examination of friendship and the quality of those friendships are often part of these investigations. In studying friendship, there is a sense of reciprocity that many researchers designate as necessary for true friendship (Block, 2015; Newcomb, 1956; Schaefer et al., 2010). I anticipated that participants would mention this concept of reciprocity and other possible characteristics of quality friendships in this work.

In k-12 research on social interaction, inclusion and peer access are essential for future success (Jorgensen, 2018). According to Hermon & Davis (2004), traditional college students are 18-23 years old and students aged 24+ are considered non-traditional college students. Mentors within IPSE programs are sometimes peers of the IPSE students, meaning they are of similar age to the students. In other cases, mentors are not considered peers to the "traditional" IPSE student or are not of a similar age[12]. Mentors can be an essential aspect of the social life

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[12] This concept of peer is complicated by the understanding that in some programs, including the focus program in this study, students do not have to be of "traditional" college age to attend the IPSE program.

of students in many IPSE programs. Studies have shown that programs that utilize mentors have more people connected to students regularly. These networks can be necessary for the feeling of comfort on campus as well as to help find future competitive employment (Spencer et al., 2021).

Although mentors are a big part of most IPSE programs, there are different ways that they are utilized and compensated. Many programs include a mixed model of voluntary and paid mentoring (Grigal et al., 2013). The ways mentors are utilized vary by the program as well. Some are used solely for social engagement opportunities, while other mentors support IPSE students in classes, assist with homework assignments, or work as job coaches (Culnane et al., 2016; Jones et al., 2020).

Carter and McCabe (2021) completed a literature review of studies that addressed the experiences nondisabled peers of IPSE students had while interacting with the IPSE students. They created distinct categories of how peers see the students during formal or informal moments. These relationships were most commonly described as friendship, but also used terms such as mentor and peer relationships were also used. Some of the peers also described themselves as role models or supports for the IPSE students. Overall, the studies demonstrated that non-disabled peers of IPSE students have a positive feeling about the programs and their impact on the school community. There were also challenges discussed by non-disabled peers, including being unsure about boundaries and how to best support students (Carter & McCabe, 2021).

Research shows that positive and supportive campus and faculty attitudes can lead to greater college student success or feelings of belonging (Cress, 2008; Edman & Brazil, 2009). If that research were to align similarly with students with IDD in IPSE programs, it would

mean that IPSE students were more likely to succeed when the IHE they attend is positive and supportive. Some previous research has demonstrated this connection (Plotner & May, 2017). In much of the research, the overall feeling non-disabled peers have toward students with IDD on campus is positive. However, there is some hesitation among peers due to needing to learn the best way to act around students with IDD (Griffin et al., 2012; Westling et al., 2013). Research has shown that the more experiences non-disabled students have with their peers with disabilities, the more likely they are to form genuine friendships with their disabled peers because they feel less discomfort. It was also found that if students initially had higher comfort levels with students with IDD, they were more likely to already know about the IPSE program and found more benefits from having students with IDD as part of their college experience (Harrison et al., 2019). This means it could be important to increase awareness of IPSE opportunities for involvement among non-IPSE students unfamiliar with disability and IDD. This is important when considering the need to reduce stigma related to disability (Harrison et al., 2019).

Although the nondisabled peer perspective is important, this DSE framed study focuses on the perspective of the IPSE students. The challenges of nondisabled students are apparent in many relationships analyzed within this work, but there is a different focus from the IPSE student perspective. Mentors and staff within the FutureLIFE program were mentioned often in my study. The social interactions in this research include those with other IPSE students and staff and non-IPSE individuals (non-IPSE peers, non-IPSE staff, faculty, etc.). As mentioned previously, not all social interactions constitute friendship, and it is more likely for friendship to occur when there are social interactions between individuals (Rossetti et al., 2016; Spruit & Carter, 2021). Therefore, through the methodologies of this research, different types of social

interaction were observed and discussed. Chapter 5, for example, examines the social interactions with IPSE mentors, staff, and peers found throughout the data collection and analysis.

The inclusion of IPSE students within campus organizations and the impact of the levels of inclusion on IPSE students' social experience on campus has been researched minimally in the past. One qualitative study investigated the social networks of students who have peer mentors at one IPSE program. The peer mentors were volunteering with the IPSE as part of their membership in Greek life on campus, meaning they were in a sorority or fraternity (Wilt & Morningstar, 2020). While the results were highly varied, they found peer support especially important for students without pre-college ties to the institution who were unsure about trying new social experiences independently but wanted to make connections. Other research has examined how students with IDD navigate friendly or romantic relationships during college and the role of mentors in this process. Retznik et al. (2022), in a qualitative study, looked at the romantic relationships of young adults with IDD from the caregivers' perspective. Overwhelmingly, young people with IDD want romantic relationships, but caregivers expressed their lack of training in supporting this desire (Retznik et al., 2022).

Faculty teaching courses that include IPSE students (both for credit and for audit) significantly impact the students' experience during their program. Faculty who opt to teach IPSE students often advocate for social justice and inclusion, but there are pedagogical areas in which they could use more research and training (Mock & Love, 2012; O'Connor et al., 2012). The program explored within this study collaborates with over 150 different course instructors each semester. Understanding this relationship is essential, especially considering the college's central goal is to support student's academic gains. In K-12 research, it was clear that teachers

significantly impact student outcomes, including outcomes of diverse learners (Bender et al., 1995; Leverett et al., 2022; Roorda et al., 2011; Subban & Sharma, 2005). I assume there is a similar connection between college faculty/instructors and student success in college.

I have explored the interactions between students with IDD in IPSE programs and other individuals within the various systems in which they interact (Bronfenbrenner, 1979; Gobec et al., 2022; Maxwell, 2018). These include the many systems within IHEs, such as those which regulate entrance into coursework, residential living, code of conduct violations, extra-curricular access, as well as others. Policies in use within IHEs concerning IPSE entrance and funding interact with students with IDD in college, such as CTP, TPSID, and Medicaid Waiver regulations. The individuals who are using or are regulating these systems are also interacting with students with IDD in college.

Theoretical Framework

This work is theoretically framed with Disability Studies in Education (DSE), recognizing disability as a social construction that has over time led to immense stigma and barriers for disabled people. DSE theory consists of four tenets, all of which are at work in this research study. These include, per Connor et al. (2008, p. 448),

1) Contextualize disability within political and social spheres;

2) Privilege the interests, agendas, and voices of people labeled with disability/disabled people;

3) Promote social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with disability/disabled people; and

4) Assume competence and reject deficit models of disability

I consistently recognized aspects of political, societal, and social spheres and their influence on the lives of individuals with disabilities throughout this work. The questions I asked and methods I used were discussed with disabled people before deciding what I would study. I worked to disrupt societal barriers that keep individuals with disabilities, specifically those with an IDD, out of higher education spaces. This work includes the experiences of individuals with IDD in authentic college spaces. In line with this, I paid great attention to understanding power and difference. The power imbalance was observed through blurred lines of friendship with staff or mentors who work with the students and the power imbalance between disabled and non-disabled individuals due to perpetuated ableism and nuances of competence presumptions throughout this study. Revisiting who held power in different environments and experiences was constant throughout this work, which is why DSE was chosen as the primary theoretical framework.

Other scholars use DSE to frame their qualitative work as well. In a recent piece, Kersten-Parrish (2022) illustrated how the IRB has been problematic within qualitative research through a DSE lens using autoethnography. She attributes her ability to "shift between privileged and marginalized status" (p. 131), as a deaf individual herself, to the DSE lens she worked through. Bacon and Blachman (2017) also utilized DSE in their qualitative analysis of the survey results and journals about the edTPA, a portfolio assessment often given to teacher candidates, prior to Covid-19. Through a DSE lens, they critiqued the existence of separate general education and special education edTPA portfolios, citing the "potentiality of the exam to concretize deficit and individualizing notions of the field of Special Education and further the siloes between the fields" (Bacon & Blachman, 2017, p. 285). Without the DSE lens, it is possible that this critique of the edTPA would be less concerned with societal impact.

Many disability rights movements, including disability studies and DSE, have been critiqued for their perpetuation of single-identity politics and focus on whiteness. I recognize how this work can be further improved by considering the Disability Justice Framework, created to combat those single-identity disability movements. By recognizing how rampant ableism has been throughout the history of society, the Disability Justice Framework "explicitly acknowledge(s) the complex nature of disability and discrimination against people with disabilities in the past (as well as present)" (Christensen & Dorn, 1997, p. 193), aspects essential to disability-based social justice theory. There are ten principles of disability justice, as has been articulated by Sins Invalid, a group of multiply marginalized disability and social justice advocates. These ten principles consist of the following from Sins Invalid (2019):

1. Intersectionality*[13]

2. Leadership of Those Most Impacted*

3. Anti-capitalist Politics

4. Cross-movement Solidarity

5. Recognizing Wholeness*

6. Sustainability

7. Commitment to Cross-disability Solidarity*

8. Interdependence*

9. Collective Access*

10. Collective Liberation

The Ten Principles of Disability Justice are the priorities of the disabled advocacy movements and disabled individuals themselves. The Disability Justice framework is rooted in

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[13] The principles of Disability Justice utilized in this work are highlighted with a * in this list.

disability experience and aims toward social justice. I could not frame this work in just disability justice because I am not disabled. This dissertation had to be designed and led by me, as that is the purpose of this academic endeavor. It is my responsibility to acknowledge and honor the work of disabled people of color in forming the Disability Justice framework in response to color-evasive disability research, which is often the case (Sins Invalid, 2015; Stapleton & James, 2020). As a white and non-disabled researcher, I was intentional to fully integrate these principles throughout this work as much as possible. This meant considering each of these principles throughout every step of the study. Ultimately, I only fully was able to integrate six of these principles. In hopes of transparency, I will explain how those specific principles of disability justice were understood and revisited throughout this work.

Intersectionality

Intersectionality, initially coined in legal scholarship to shed light on the multiply marginalized identities that individuals may have, acknowledges that each identity compounds on the other (Annamma et al., 2013; Crenshaw, 1991; Hernández-Saca et al., 2018). The oppression and discrimination pressed upon individuals with multiply marginalized or intersectional identities are uniquely situated depending on the intricacies of an individual's identities, environment, and social structure. My methods, as discussed in Chapter 3, will demonstrate my intentionality in recruiting from a diverse group of individuals, hoping to have a variety of participants with many intersectional identities. Many students who identify as people with IDD would also identify as having other important identities and/or identities which cause societal perception in an intersectional way when they are seen as a whole person.

Although many IPSE programs lack diversity, a subset of students would be considered intersectional or diverse based on the marginalized identities they have or are perceived to have.

It is important to note that intersections of disability with other marginalized identities have led to worse outcomes in employment. In turn, improvement in employment rates of those individuals due to IPSE programs has not been as significant compared to less marginalized students with disabilities (Crenshaw, 1991; Office of Disability Employment Policy, 2021). In much of the recent IPSE research, demographic data has yet to be explored (Grigal et al., 2019; 2022). Similar to how disability studies research has been critiqued for the absence of the intersection of race and disability (Ferri & Connor, 2005; Stapleton & James, 2020), IPSE research needs to be critiqued for this absence, and future research needs to remedy this. IPSE students embody intersecting marginalized identities that the DSE framework acknowledges. This study aims to combat the absence of intersectionality that has been overarching up to this point.

In creating the interview and focus group questions, I purposely asked questions that would invite the participants to discuss intersectionality. For example, in my final interview with the participants, I asked questions about any stigma students have felt during their time at the IPSE program. This discussion was expanded by inquiring about any identity other than the disability that may have caused them to feel stigma or marginalized.

Leadership of Those Most Impacted

Sins Invalid have said, "By centering the leadership of those most impacted, we keep ourselves grounded in real-world problems and find creative strategies for resistance" (Sins Invalid, 2019, p. 23). In this work, it is my responsibility to center the voices and experiences of the participants in this study, who all have a label of IDD. Before crafting a dissertation proposal, I discussed my questions with individuals with IDD. Through observations, I witnessed the everyday micro- and mesosystems the participants were within, but then I further

understood their perspectives of those experiences during interviews. Through the final interviews, I was able to member-check and ensure the findings and potential ways to move the field forward are things the participants agreed with. Although I recognize the power I hold as a researcher and acknowledge that it impacted this work and the findings, I intentionally center disabled folks as decision-makers in this research.

Recognizing Wholeness

In gaining an understanding of relationships and social interaction, this work is uniquely able to recognize the wholeness that is inherent in disabled people. Every transcript, fieldnote, and memo demonstrated different facets of life to each participant. They have thoughts, hopes, emotions, romance, worries, distress, laughter, and all the pieces that make any person whole. I discuss many of these pieces and moments throughout the findings and discussion of this dissertation. I hope the audience will see this wholeness and grow in their presumption of what is possible.

Commitment to Cross-Disability Solidarity

In addition to its ability to recognize intersectionality, DSE makes apparent the importance of "all of our community members, even and especially those who are most often left out of political conversations" (Sins Invalid, p. 25, 2019). This diversity across those with disability identities is something that this work will explore. Although all participants have IDD labels, there are differences in how their disability impacts them. Some of them also have other disability diagnoses in addition to IDD. I needed to recruit diverse participants with disability identities and other identity markers. In addition to this, I recognize how the experience may be different across disabilities. In doing so, my findings and discussion move the IPSE field towards cross-disability solidarity.

Interdependence

Independent living is often listed as an outcome or goal of IPSE programs (Grigal et al., 2013; Smith Lee et al., 2019; Miller et al., 2016), but interdependence more so is a reality for any individual moving into and through adulthood. It has been noted from research about the first Center for Independent Living (CIL) that

> …although these core services [peer counseling, independent living skills training, individual and systems advocacy, and information and referral] may be necessary to help people with disabilities live independently in the community, they may not be sufficient to guarantee an increase in their participation in the community... it may be necessary to position the model of independence further down the continuum toward interdependence" (White, 2010, p.236).

This is because the ultimate goal for many individuals is not independence but participation and involvement in their community. Interdependence was observed numerous times throughout the months of the study. Rossetti et al. (2008) discussed the problematizing of independence in their interpretivist and qualitative study about autistic individuals "working toward independent communication" (Rossetti et al., 2008, p. 365). Their findings suggested that an individual's agency is essential in understanding their independence, acknowledging that a person can have independence while also receiving support from others.

Collective Access

Every individual has access needs, yet college campuses and academia were not created with students with IDD and their access needs in mind. Through this study, I have observed the experiences of students who persist on these campuses despite the environment not being initially created for them. With greater knowledge of these experiences, this study suggests

where institutional and policy changes are needed to create a more purposeful experience for these students.

The creation of various aspects of this work, such as consent forms and interview procedures, were heavily focused on the access needs of the participants. I also see it as my responsibility to ensure this research is disseminated in accessible ways so that the participants and other disabled people can receive and understand the information. For example, the participant consent and assent forms were created in plain language with image cues of essential aspects, such as the different research methods (i.e., participant observation, interview, and focus group). There also were pagination cues with recaps of each page to ensure understanding.

Conclusion

This chapter gave an overview of the literature that already exists in three intersecting fields that this work utilizes (IPSE, IDD, and Social Interaction) as well as the theoretical framework of DSE, informed by some principles of disability justice. This dissertation is guided by the gaps and findings of previous research and theories, as explained thus far. The methodology and methods, which will be discussed in Chapter 3, are heavily informed by this past literature and aim to address the gaps illustrated throughout this chapter.

Chapter 3: Methods and Procedures

"Will you have bar charts?" ~Jerry

This chapter will give an overview of the methods used throughout this study. In venturing into this project, I wanted the IPSE students to be leaders in the research, which meant conceding some of the control I could have had as the researcher. In the beginning, I did not realize just how many of the pieces of the methods I would negotiate with the participants. Although completed within one calendar year, this data collection was the most creative work I have personally performed thus far in my life. As will be evident throughout this dissertation, my initial plans were but an outline of what would come to be my methods because of the inclusive nature of the research design and my reliance on participant input. Through this chapter, I hope future researchers can feel more comfortable with this inclusive research design and allow participants to shape the work reflexively. I will give a brief background on inclusive research as a methodology and then provide details on the methods used in this project.

Qualitative Inclusive Research Methods

The researcher-participant relationship in disability-related research has begun to shift. Oliver (1992) critically looked at research in the disability field. He described the typical "researcher" and "researched" relationship, with the researcher having complete control over the entirety of the research (Oliver, 1992, p. 102) and the researcher's views being an undercurrent of the entire process. Without a shift in these social relation roles, research about disability will not make positive changes for disabled individuals (Oliver, 1992). A shift from positivist to more emancipatory or critical inquiry-based research is necessary to amplify this social relations shift. Zarb (1992) agrees with this need to change social relations regarding research structure but notes a distinction between participatory and emancipatory research. The goal of

emancipatory research cannot happen "until it is disabled people themselves who are controlling the research and deciding who should be involved and how" (Zarb, 1992, p. 128). This study design empowers the participants through their inclusive participation in the research methods. This highly connects to my DSE framework and my focus towards being an accomplice to individuals with disabilities by creating space for community with the participants (Bourke, 2020).

I utilized qualitative methods to bring the participants' voices to the forefront of the new knowledge to help create a more inclusive space in higher education for students with IDD. This qualitative study utilizes a phenomenological process to understand the social experiences of students with IDD and the meanings they make from their experiences (Cresswell et al., 2007). A DSE framework was used to design the question and study methods. Phenomenology was used to inform the major research question and subsequent design, recognizing that I would be investigating the phenomenon of social interaction. I did this by utilizing the methods of interviews, focus groups, and participant observations. Phenomenology uses interviews primarily to determine the essence of participant experiences and can be enhanced by observations and other methods (Cresswell et al., 2007).

I observed students with IDD in their everyday environment and discussed with them the meanings they make from those events rather than speaking with *other* individuals who may be a part of their social lives. Fielding (2004) discusses this issue, explaining that "speaking about others, even in the sense of describing what you take to be the case, you may, in effect, be speaking in their place, that is, speaking for them" (2004, p. 297). By centering student voices or other marginalized voices, it is hoped that "speaking about [or for]" in research diminishes. Much research includes "speaking for" others on issues having to do with disabled individuals. This research allows students with IDD to share their views of what they have experienced and

have felt, allowing them to "speak for" themselves through the findings. Using students' voices has been a "critical factor" in changing k-12 education because it allows teachers to engage and rethink their teaching methods (Messiou & Ainscow, 2015; Steinberg & Kincheloe, 1998). This should also be the case in higher education, but not as much research looks at this topic. Rather than giving teachers a reason to change their teaching methods, these higher education student voices could give institutions and the many stakeholders within an institution a reason to rethink their ableist practices.

Listening to the voices of the most marginalized individuals needs to be done, but there are some limitations in doing this work (Bailey et al., 2014; Dedding et al., 2020; Martin & Finn, 2011). Leaving certain voices out of student voice based research design is a salient concern (Ashby, 2011; MacBeath & Moos, 2003), especially when considering students with IDD, those who use augmentative and alternative communication (AAC), and those who have other intersectional marginalized identities with disability. I have included diverse voices in this study to an extent greater than I have seen in previous IPSE research and have named this diversity purposefully. Even so, some intersectional identities that need more acknowledgment in the field will inevitably still be missing.

Research methodologies used for qualitative research with individuals with disabilities have improved through methods like inclusive research, which involves "people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Walmsley & Johnson, 2003, p. 10). Walmsley and Johnson (2003) have explored inclusive research and how it is best utilized in pursuit of a more equitable environment. The admittance of individuals with disabilities into college spaces is already on track to create a more equitable environment. Higher education

spaces were not created with people with disabilities in mind. It could easily be argued that they were created to keep disabilities excluded, considering the competitive and test-based nature of typical college admissions and the difficulty common in pursuing and receiving accommodations in higher education. College and university systems must shift in many ways to create an equitable environment for all. I explored the experiences students with IDD have on college campuses in various environments and during various events; sports games, hanging out in dining halls, classes and club meetings, and other typical college experiences.

"One of the fundamental characteristics of qualitative research is that it always studies the process of meaning-making in context" (Biklen & Casella, 2007, p. 3). A researcher can engage in the context of a specific inquiry setting through various qualitative methodologies to enhance their understanding of the phenomenon. This study engages in the setting of an IPSE to understand the meaning made by students with IDD concerning their social lives on campus.

This study engages in inclusive research, which implies unrestrained input from marginalized individuals with an identity of which the research is about throughout the process (Walmsley & Johnson, 2003). I aim to show true perspectives from the individuals participating in the research and let them share their voices through inclusive research. Unrestrained means that minimal to no barriers keep the individuals from speaking their truth[14].

Many barriers impede research participation, especially considering how ableism impacts research itself. This aligns with understandings of DSE and the importance placed on privileging marginalized voices (Connor et al., 2008). It is crucial to understand how researchers have discussed different levels of voice and participation. Mitra and Gross (2009) have created a

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[14] I understand the impossibility of finding a "truth" in research without recognizing my own impact on that truth. I often reflected throughout this work on how my presence may be impacting the "truth" I was finding. I explain more of this reflection in Chapter 6.

pyramid of student voice, which consists of the following facets from the bottom up: being heard, collaborating with adults, and building capacity for leadership. Of these three levels, the top of the pyramid and smallest level (Building capacity for leadership) was found to be the least in research but has shown the most significant positive outcomes for participants of the three levels. Students who participate in research in top-tier ways would be seen as "courageous citizens" by Steinberg and Kincheloe (1998, p.3), meaning they are informed individuals who demonstrate a desire to communicate with others to create a more socially just environment (Steinberg & Kincheloe, 1998).

Walmsley and Johnson (2003) propose a list of characteristics for inclusive research that would bring in disabled perspectives:

A research question owned by disabled people; furthers the interests of disabled people; it is collaborative – disabled people involved in doing the work; some control exercised by disabled people over process and outcomes; question, reports, and outcomes must be accessible to people with learning disabilities (p. 95).

In the initial design of this research, I consulted with students from IPSE programs whom I knew personally about the questions and phenomena I could investigate. The eventual participants were given control over what events I observed and how I would act in the space. For example, when I joined Clark in his gym class, he was very clear that he wanted me to participate and join in on the games. Conversely, when I joined Flynn for a film class, he only wanted me to sit and observe. I purposely discussed themes I found throughout the observations and interviews with participants, which illustrates how crucial they were to the analysis of this work.

Atkinson and Walmsley (1999) suggest including individuals with disabilities in research through the formation of autobiographies and autobiographical accounts or fragmented autobiographies. They state that "autobiographical research has a role to play in presenting different accounts, in a variety of forms, which can enrich our understanding of the lives of people who often have exceptional difficulty in getting heard" (Atkinson & Walmsley, 1999, p. 215). Autobiographies, such as those by Cooper (1997) and Deacon (1974), give full depictions of the lives of individuals who wanted to tell their stories to claim representation in the public eye. Autobiographical accounts, on the other hand, are fragmented narratives of an individual's life for research purposes that often become performative (Atkinson & Walmsley, 1999; Bogdan & Taylor, 1982). In other words, an autobiographical account is mediated by a researcher, while a traditional autobiography is not. This study aims to collect autobiographical accounts of the different participants in the pursuit of furthering research in IPSE. There is a moral imperative to utilize the perspectives of these individuals, even in a mediated and fragmented way, rather than ignoring their perspectives altogether.

Research Design

As with all research, I had to make many decisions regarding the research design for this work. This included decisions about where the research would take place, who would be eligible to participate, and what they would be asked to do. I produced IRB materials and was approved in the summer of 2022. I then used those materials to complete the methods that were planned.

Population and Recruitment

I recruited participants from all FutureLIFE program students and students who had graduated within six months before recruitment. More diverse participants still need to be part of inclusive higher education research. I recruited from an extensive program with a diverse pool of

students from various identities, some marginalized in terms of race, ethnicity, gender, sexual orientation, and disability, in order to address this gap.

The only inclusionary criteria related to demographics were a diagnosis of an intellectual disability and current or recent designation as an IPSE student. This broad criterion left opportunities for more diverse participants. I could not specifically ask the participants about their other demographics before their consent because it was separate from the inclusion criteria. The coexistence of other disabilities and/or the presentation of disability in the participant varied. For example, two participants in this research do not reliably use speech for communication but utilize augmentative and alternative communication (AAC). I required that all participants were willing to be recorded for any interview or focus group to participate. Participants were also required to be 18 years of age or older.

Site

I recruited participants specifically from an IPSE program in the Northeastern United States called the FutureLIFE Program[15]. The School of Education at a mid-sized private university, Imagine University, houses the FutureLIFE program with approximately 100 IPSE students enrolled. Of the total number of students, ~ 30% live inclusively on campus, while the remaining students commute from different locations in the surrounding areas, ranging from approximately 5-60 minutes away. In the aftermath of the Covid-19 pandemic, a few students are entirely virtual and live farther than 60 minutes away during the semester. Students who attend FutureLIFE come from local areas and across the United States. FutureLIFE has yet to enroll international students, but they have received international applicants. Students can attend all campus-wide events, including popular events run by the University late at night, clubs, and

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[15] All names of programs, spaces, and individuals are pseudonymized for confidentiality purposes, as outlined in the IRB for this dissertation research.

other extracurriculars. FutureLIFE students have majors and earn a meaningful certificate within

that major upon graduation. In addition to completing major area and elective courses,

FutureLIFE students typically participate in an internship during their senior year of the

program.

In striving for diversity among the participants, I reviewed potential participants

regarding the demographic information provided by the IPSE about these students. I anticipated

that potential participants would vary in the time commitment they want to give to a research

project. For this reason, I gave all potential participants three options of engagement, listed in

Table 2. Graduates of the IPSE program were only given Option 1 because they would no[16]

longer be on or near campus to facilitate participant observations. As Option 3 became full a few

weeks into recruitment, only Options 1 and 2 were given. Later in this chapter, I explain these

different methods more thoroughly. Participants who chose Options 2 and 3 were considered the

"core" participants, as most data collection cyclically revolved around their experiences.

Table 2.

Three Options for Participation

Option	What methods does this option include?	Who can participate in this option?
1	Focus Group Only	Current IPSE Students Recent IPSE Graduates (6 months prior to recruitment)
2	Participant Observations Semi-Structured Interviews	Current IPSE Students
3	Participant Observations Semi-Structured Interviews Focus Groups	Current IPSE Students

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[16] It turned out that some of the graduated participants were still close to campus, with on-campus jobs or apartments nearby. Even so, I only gave the choice of option 1 to participate in.

A recruitment email, along with an accessible recruitment flier, was sent to the FutureLIFE program Listserv of approximately 80 current students in late June by the program director. The flier and information were also posted on the program's social media pages (Facebook and Instagram) by the director of operations and communication for FutureLIFE. Half of the participants were recruited from this initial email and social media call (approximately 15 participants). The recruitment email provided detailed information about the study, including the eligibility criteria that participants would need to meet (enrolled in FutureLIFE or graduates within the six months prior to recruitment, 18 years of age or older, diagnosed with IDD, willing to be recorded during interviews or focus groups). In addition to these recruitment methods, I met with students during events occurring in person and on zoom during the Summer and early Fall of 2022. At these events, I gave an overview of the research and asked if anyone was interested in participating. Academic advisors provided incoming freshmen with the recruitment flier at admissions meetings, but none consented to participate. A few of them did show interest through email but did not respond to schedule a consent meeting.

FutureLIFE has students in the dual-enrollment program, which means they are students in FutureLIFE but are also enrolled in a local k-12 school district. They have supports, such as teaching assistants and a director, funded through the school district. They can take classes at Imagine University, attend events, and join clubs, just like the other FutureLIFE students, but they all commute on a school bus at 2 p.m. each day. Students who were part of the dual-enrollment portion of this IPSE were informed of the opportunity to participate by their director in mid-summer via the recruitment email and flier. Only one student from this dual-enrollment program became a participant in the study. One other student from this program was interested

but did not connect for an initial consent meeting. After these initial recruitment phases, some participants preferred alternative communication avenues to email, especially during the summer. Those were used when preferred (I.e., Facebook Messenger, Instagram Messenger, and text messaging).

I planned for two or three distinct recruitment waves, similar to the Bessaha et al. (2020) study. Although recruitment went smoothly, there was a need for more "rolling" recruitment rather than two or three waves. Due to the timing of starting recruitment at the beginning of the summer, it took multiple tries to contact participants. It also took time to schedule consent meetings with many participants due to jobs, camps, or vacations during July and August. It took longer to recruit freshman students and those who participate in dual enrollment as part of FutureLIFE, and ultimately only one student from either sub-groups made it to the point of consent.

Once I knew the students' possible interest in participating, I sent them a link to a Qualtrics questionnaire. The questionnaire instrument included (as seen in Appendix B) eligibility questions for participation. These included questions about their disability, identity as an IPSE student, and interest in learning more information. Every five days, questionnaire responses were reviewed to ensure that eligibility criteria were met. I was given access to guardianship records for all students per IRB procedures. After reviewing the questionnaire responses, this information was used to determine whom to contact. An email was sent to the possible participant and their guardian (if they had one), explaining the three different options for the study.

The initial participant pool included only participants who identified as white. As recruitment continued, I was able to gain more diverse participants. I sent information

individually to potential participants who I knew were from diverse and marginalized identities to ensure they saw the opportunity and knew they could participate. This helped with gaining a more diverse group of participants. I accepted the participation of all interested individuals if they were eligible. A few FutureLIFE graduates who did not fit the eligibility criteria of graduating within the last six months were interested. I declined participation to a group of students from a separate mid-west IPSE program interested in participating because they were outside the FutureLIFE program. One graduate participant consented but did not participate.

Consent

Once eligible students shared their interest in participating, the consent process began. Appropriate consent and assent forms were sent to these individuals for possible review, and they were asked for days and times to schedule a consent meeting. Gaining consent is difficult with any human research study, especially when including individuals with disabilities (Overmars-Marx et al., 2018). There are necessary safeguards through ethical review boards that require well-thought-out research and proof that harm will be avoided in pursuit of the research, to a greater extent than when doing research with the general population. The IRB considers individuals with disabilities that could impact their intellectual reasoning a "vulnerable population" or a "special category of research: cognitively impaired" (Perry, 2011; Syracuse University Human Research Protection Program, 2007). Adults in this "vulnerable population" category who do not have guardianship over themselves need to have a legal guardian complete an assent form on their behalf. Accessible methods of informing individuals about research are important (Barr & Mavropoulou, 2019). I created assent and consent forms in plain language and discussed them with each possible interested participant. I shared the plain language consent forms with other disabled individuals to ensure accessibility before submitting them to the IRB.

Potential participants met with me to discuss the study and any questions about its process, risks, benefits, and purpose. Participants who are not their own guardians had their guardian(s) in attendance at this meeting. Some students who were their own guardians still chose to have another adult on the call to assist with decision-making. Most of these meetings happened on Zoom, so oral consent/assent forms were used. Some of these meetings were in person, for which written consent and assent forms were used. Because the possible participants were given the forms before the meeting, they were asked if they wanted me to read the form in its entirety or if they just wanted to go over any questions they had. Many of the individuals requested that the form be read to them. These meetings were scheduled for one hour each, and most did take up this entire time.

Eighteen consent and assent forms were created for this study and a sample of these is in Appendix C. Separate forms were created for each potential option. For each option, there were both guardian forms and participant forms. All forms were created to be either done orally or written.

Confidentiality is paramount when considering the collaborative nature of some inclusive research and research using marginalized voices. It must be determined and reevaluated throughout the research and understood before consent is given. Bresler et al. (1996) discuss this, saying, "the fieldworker must carefully consider her or his ethical stance regarding confidentiality and the practical concerns that could arise in the relationship to confidentiality at the particular site" (Bresler et al., 1996, p. 20). These ethical considerations of risk and benefit were explained to participants during the consent process and revisited throughout the study. These discussions were critical when considering the focus group aspect of this project. As consent and assent were granted, the study began the first phase of three total phases. There was

some overlap between continuing consent procedures and beginning phase one with already consented participants.

Participant Pool

Ultimately, 16 participants in this research consented to participate. Of these 16, there was one graduated individual who did not end up attending the scheduled focus group. Therefore, only 15 participants participated in the research. I briefly describe these 15 participants in a way that minimizes any risk to their identity. Each participant was allowed to choose their own pseudonym for me to use throughout the work, similar to Zakrajsek et al. (2014). Some of their chosen names were adapted slightly for two reasons; 1) the name was too similar to their middle name or another identifiable aspect of their identity, 2) the name chosen was not "real" enough and might have led any listeners or readers to reduce the seriousness with which they understand each participant. I did not initially want to change the desired pseudonym for some individuals. However, considering the societal constraints and the infantilization that often impacts people with IDD and the potential for confusion due to unusual names (i.e., team names, food, superheroes) with the original pseudonyms chosen by participants, I decided it was essential to change some of the names slightly. For example, instead of using the preferred name of one participant's favorite sports team, I used the name of one of that team's players. The final pseudonym and descriptions were sent to everyone to confirm their approval before publishing.

The participant pool included individuals who identified as a wide range of demographic variables. As said previously, of the sixteen participants, only fifteen participated in the study. For that reason, I only listed demographics related to those who participated. The race of the participants consisted of 73% white (n=11), 13% Asian (n=2), and 13% Black/African American (n=2). The gender of participants consisted of 46% female (n=7), 46% male (n=7),

and 6% non-binary (n=1). When asked about sexuality, 86% (n=13) identified as straight. One participant identified as bisexual (6%), and one was unsure (6%). I did not ask specifically for a disability label other than confirming that all participants have an Intellectual Disability. Of the disability-related information that was gathered from participants, I know that approximately 47% (n=7) have an additional autism diagnosis, 27% (n=4) have a down syndrome diagnosis, and 27% (n=4) I do not know of any additional disability diagnoses. These participants have accrued many accomplishments at FutureLIFE, including self-advocacy learning and presenting opportunities nationally and internationally, as well as campus-wide and national awards. Table 3 gives a brief description of each participant.

Table 3.

Participant Descriptions

Arthur *Observation *Interview	A third-year student at FutureLIFE who commutes a few days each week to attend courses and events. Their dad drives them most of the time. Arthur's major is food studies at Imagine University. They have a job at a local grocery store and also obtained new employment within FutureLIFE during data collection. Arthur identifies as an Asian bro/they.
Clark *Observation *Interview *Focus Group	A senior student at FutureLIFE who attends almost every event that other FutureLIFE students go to. He is employed by the program and was completing his internship at the University public safety office during most of the data collection. Clark lives on campus and is over 5 hours away from his hometown. His major is information studies technology. Clark identifies as a white male.
Naranj *Observation *Interview	A senior "non-traditional" student at FutureLIFE who lives on campus, approximately 5 hours from his hometown. Naranj is a double major in broadcast and digital journalism and political science and pursues those interests often through clubs and other organizations. He is also very involved with the Catholic Center at Imagine University. Naranj identifies as a Black man.

Jerry *Observation *Interview *Focus Group	A junior student at FutureLIFE who lives on campus, approximately 5 hours from his hometown. He is a broadcasting and journalism major and has pursued those interests through internships and other organizations. He is especially involved with sports events and volunteers his time to help facilitate Nights at Imagine events. Jerry is very busy and this caused some trouble in scheduling observations and interviews. Jerry identifies as a white man.
Chadwick *Observation *Interview	A student in the dual-enrollment program also facilitated through FutureLIFE. Chadwick has a mentor, Jake, who has worked with him for multiple years and is employed by the local public school district. Chadwick communicates in a variety of ways, often not through speech. He is an active member of the Imagine University community, often going to work out in the gym, working at his internship once a week, and going to campus events. Chadwick identifies as a Black man.
Poppy* *Observation *Interview	A sophomore residential student at FutureLIFE who lives approximately 4.5 hours from her hometown. She is a double major in design and disability studies. She is very involved in the campus community, going to many events each week. She worked as welcome staff for move-in day during the beginning of data collection. Poppy identifies as a white woman.
Debbie* *Observation *Interview	A senior student to FutureLIFE, Debbie commutes with her interpreter (Destiny) 45 minutes every few days. She is completing her internship at a local elementary school, which connects to her disability studies major. Debbie communicates most of the time through sign language and her interpreter. She does sometimes use other means of digital communication. Debbie enjoys being around other people and asking about their lives. Debbie was open to sharing different parts of her life and her humor during interviews and observations. Debbie identifies as a white woman.
Faith* *Observation *Interview *Focus Group	Faith is a senior residential student at FutureLIFE, living less than 30 minutes from her hometown. She had an internship in the campus library during data collection. Her major is history. She enjoys being involved in many different FutureLIFE events on campus and being around other people. Faith identifies as a white woman.

Kent *Observation *Interview	Kent is a sophomore student at FutureLIFE who commutes into campus each day with his mentor (Laura). His major is food studies. He spends his free time playing UNO and eating lunch with his friends on campus. Kent identifies as a white man.
Flynn *Observation *Interview *Focus Group	Flynn is extremely involved in FutureLIFE as a residential student, pursuing his junior year as a film major. He has many friendships and cares a lot about them. He worked with the welcoming crew at the beginning of data collection. Flynn is very open about the things he loves about college as well as the aspects he would like to see changed. Flynn identifies as a white man.
Madelyn *Focus Group	Madelyn is a sophomore at FutureLIFE and lives on campus, approximately 30 minutes from her hometown. During breaks, Madelyn works at her local hometown coffee shop. She is very reflective on her own attitude and how it impacts her relationships with others. Her major is health and exercise science. Madelyn identifies as a white woman.
Clover *Focus Group	Rose is a graduate of the FutureLIFE program and currently lives in her own apartment, not too far from Imagine University. She grew up 30 minutes away from the University. She works at a local daycare and was very open to discuss the good and bad about being a FutureLIFE student during the focus groups. Clover identifies as an Asian woman.
Rosalie *Focus Group	Rosalie is a graduate of the FutureLIFE program and currently lives in her own apartment, close to Imagine University. She works in the dining hall on campus and pursues community events in the area, approximately 2 hours from her hometown. She enjoys meeting new people and talking with friends, which was the case during the focus group meetings as well. Rosalie identifies as a white woman.
Shirley *Focus Group	Shirley is completing her internship year at FutureLIFE and is very involved in the music school at the University. She takes lessons for various instruments through the university and is a member of community bands near Imagine University. Shirley identifies as a white woman.
Tyler	Tyler is a sophomore student at FutureLIFE and is living residentially on campus. His hometown is approximately 4

*Focus Group	hours away from campus. He likes to be involved in many ways on campus: going to events, joining clubs, and going to eat with his friends. His major is music history and cultures. Tyler identifies as a white man.

All participants were compensated, per the IRB protocol, up to $45. All participants received $10 after their first time participating. They were then entered into a raffle to win another $10 gift card and some $25 gift cards, which were given after the participation had ended. If any participants had left the study after participating, they still would have received compensation.

Research Procedures

There were three major phases of this research study, as shown in Table 4. Participants moved through different phases of the research at different times. All aspects of the data collection for each participant were tracked on a Trello board[17]. Phase one consisted of consent meetings. As listed in the participant table, each participant could choose what aspects of the data collection they participated in and consented to the specific participation option they chose. Phase 2 included pre-observation interviews with all the Option 2 and 3 participants (core participants). It also included at least two observations per participant and another interview to follow those observations. For Option 1 and 3 participants, phase 2 included a focus group, and phase 3 included at least two more observations with the core participants and one more post-observation interview. Once participants consented, I also asked about specific identities they embody through a demographic survey for Option 1 participants and interview questions for Option 2 and 3 participants.

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[17] The Trello board only kept track utilizing the pseudonyms of the participants. Real names were only kept in a private and protected folder; only I and my PI had access to that folder.

Table 4.

Research Phases

Phase 1	Phase 2	Phase 3
● Consent Meetings	● Pre-Observation Interview ● 2 Observations ● Post-Observation Interview ● Focus Group	● 2 Observations ● Post-Observation Interview

Semi-Structured 1:1 Interviews

The one-on-one pre-observation interview was conducted in a qualitative semi-structured interview. Qualitative semi-structured interviews have a general structure of what will be discussed and flexibility to follow the participant's direction. During the interviews, I aimed to understand "informants' perspectives on their lives, experiences, or situations as expressed in their own words" (Taylor & Bogdan, 1998, p. 88). Specifically, I was interested in understanding the experiences the students had and their feelings or understanding of those experiences. These interviews were video recorded and then transcribed verbatim. The video recording was crucial for fully understanding the participants, especially with some communicating through methods other than speech. For example, in some interviews, a whiteboard was used to draw and write responses to the questions rather than a verbal one. In the interviews, we discussed moments the participants felt included and/or excluded and whom they feel most connected to while on campus and why.

In many interviews, I also discussed specific events I observed with the students and tried to gather their thoughts about their experiences during those situations. This helped me better understand what themes were apparent across all the student observations and interviews

and if the students' understanding of those observations agreed with those themes. The final interview was also semi-structured, discussing the themes I had found.

The situational nature of being a person and having changing beliefs and perceptions makes interviewing difficult. Some participants may say things during interviews but oppose them in other settings. To recognize these differences, participant observations were also a significant aspect of this study.

Social Circle Diagram. Another critical aspect of the interviews was determining which events and settings the students wanted me to observe. This decision was made by creating, updating, and discussing each student's social circle diagram during every meeting. An example of a social circle diagram can be seen in Figure 1.

Figure 1:

Social Circle Diagram
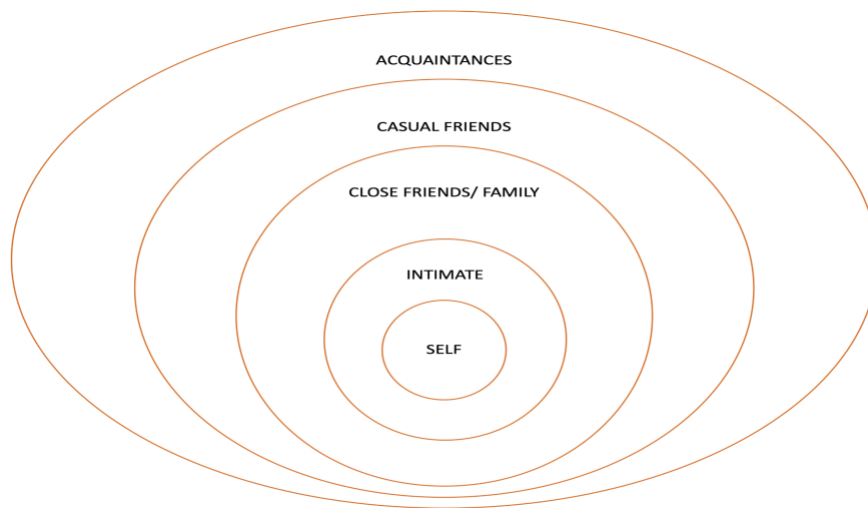
The social circle diagram is fashioned after those used in practice for many reasons with students with and without disabilities. Similar diagrams were used for social research studies previously under the names of "Circles of Friends," "Circles of Support," and "Social Network Chart" (O'Brien & Pierpont, 2007; Spruit & Carter, 2021). I have drawn on those frameworks to design this social diagram. The diagram and its different levels were discussed with each core

participant. The initial pre-interview was instructive in defining the different terms for the diagram. I gave the students access to the diagram before the interview, but they were not required to look at it unless they wanted to. Through discussion and conversation, each participant named different people in their life and where they would fall on this diagram. Each conversation surrounding the social circle diagram played out differently, some being more direct and some more abstract. For example, I transformed Chadwick's diagram into just two concentric squares. The inner square meant people he saw a lot, and the outside square for people he saw a little. I describe this further in Chapter 6. Each conversation during the pre-interview began with explanations of each diagram section, also written on the question sheet. The explanations for each section of the diagram are given next.

Explaining the Social Circle Diagram

This diagram shows how close you are to other people in your life. The closer you are to the person, the closer they should be to the SELF circle.

INTIMATE – People you are extremely close with. For example, a boyfriend, girlfriend, or partner.

CLOSE FRIENDS/FAMILY – People you are very close with. You might see them a lot or go to them for advice. For example, a best friend, a roommate, a sibling, or a parent.

CASUAL FRIENDS - People you might see often or have good conversations with, but you may not be very close to. For example, someone you hang out with occasionally, staff, or someone from a club you are both in.

ACQUAINTANCES - People you are around but might not know. For example, classmates, people you see in the dining hall, staff, or professors.

We'll circle any people who are usually working when you see them.

After creating and updating each student's social circle diagram during the subsequent meetings, we discussed what they would like me to observe in the upcoming weeks. We had conversations about what kinds of events they see the different individuals on their diagram at, like classes, sports games, club meetings, work, etc. Based on our schedules, one or two events were chosen for the upcoming weeks to pursue participant observation.

There were 1:1 semi-structured interviews after every 2-3 observations. I tailored these interviews towards each participant but with similar overarching themes. For example, ideas of infantilization came through with many of the pre-interviews and some observations, so I specifically asked the participants if they were ever infantilized on campus and how those moments made them feel. We re-evaluated the social circle diagram that was created during the initial pre-interview. I asked questions such as: Is there anyone new you would add to your social circle diagram? Did you become better or worse friends with anyone who was on the diagram previously? I also asked questions specific to the participant observations from that month, such as, "What were your feelings about that specific interaction?" Mostly, these interviews were shorter in structure than the pre-interviews. They were an opportunity to gain greater insight into the campus and how things changed throughout the semester of data collection. Appendix D includes sample semi-structured interview questions.

Participant Observation

Observations help qualitative researchers gain perspective on individuals' lives and understand experiences within a specific context. Observations can be used as a form of evidence to then lead to further thinking and reflection among a particular group of researchers, such as teachers participating in community action research (Ainscow et al., 2003). For example, Wickenden (2011) pursued participant observation with teenagers with cerebral palsy who utilize AAC devices to communicate. The students in the Wickenden study were observed

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in various settings, such as school, their homes, and clubs outside of school. Themes were found

and given "user-friendly names" so they could be presented to the teen participants, and they

could comment on them.

Similarly, my study includes participant observations in many different settings on the

college campus where these students live, work, and/or take classes. Observing the settings

chosen by the participants allowed me to witness a wide variety of spaces and social

interactions. The length of observations was highly dependent on the type of event the student

chose but ranged from one to four hours per observation.

There were some events where multiple core participants requested to be observed, and I

decided to split my time between the different participants in those cases. The participants agreed

upon this, which typically meant I spent approximately an hour focusing on each person. By

design, I focused on the participants who had requested that I observe at each event. At many of

these events, other participants and other students who were non-participants were also present.

Those individuals were noticed and sometimes written about in jottings if their actions somehow

related to the focus participant, but they were not named.

In terms of my actions, I told participants the background of participant observation and

that I would participate in any way they wanted. This often depended on what type of event was

being observed. When observing participants during their Imagine University classes, I typically

took more of an observer position than when I observed during late-night activities at the ice-

skating rink, where I joined in on the ice skating.

While observing, I utilized jottings as a form of note-taking to inform field notes created

soon after the event. Field notes were made after the participant observation, becoming the data

analyzed from the specific events. Topics of these fieldnotes included items such as participant

clothing, number of individuals in the space, closeness or distance between the student and the other individuals present, characteristics of the conversation (i.e., flow, pauses), and methods of communication being used (AAC, eye contact, sign language, etc.).

Photovoice

Agarwal et al. (2015) used Participatory Action Research (PAR) to pursue possible changes at their university to make it more inclusive for students with disabilities. The methodology PAR "invites and prioritizes marginalized community members' perspectives, needs, and knowledge into a research project" as co-researchers (Bessaha et al., 2020). In the Agarwal et al. (2015) study, they used the photovoice methodology (Smith et al., 2012b; Wang & Burris, 1997), which "empowers individuals to communicate about issues that impact their lives and concerns facing their community through photos and associated narratives..." (Agarwal et al., 2015, p. 244). This method typically consists of training participants or co-researchers on photography techniques and understanding how the photographs will be used (Agarwal et al., 2015; Overmars-Marx et al., 2018).

In McIntyre's (2000) study, participants could take photos and form a conversation around them with a group, and they created narratives that were also part of the conversations. In the second phase of McIntyre's study, community photography became action. The students were given a camera to take photos for five days. The photos were developed, and each student could choose three photos "they felt best represented their understanding of the issues we were addressing in the project" (McIntyre, 2000, p. 142). They then chose one of those three photos to be enlarged and displayed to promote change at community photography exhibits.

For my study, aspects of photovoice (i.e., participants taking pictures to position theoretically with narratives of their experience) were utilized to promote greater memory of

observations and enhance discussions during the 1:1 meetings. Throughout each observation, the

participants were encouraged to take three to five photographs or to ask me to take them. They

were told that these photos could consist of group pictures with the student and the rest of the

group, a picture of a table where they want to sit and study, with their study materials laid out

and a cup of coffee, or a picture of the student with a mascot at a sporting event. I initially

planned to remind participants during observations to decide what they wanted to take a picture

of. I was not going to take any pictures without their permission. The prompt for pictures was

"What picture will remind you about this event?". This aspect of the study turned out not to be

very useful. Only a few participants remembered to take pictures throughout the events, and

they were students who often took pictures anyway during social events. Other participants did

not remember to take pictures, and I did not remind them for fear of causing awkwardness or

discomfort. There were a few instances where I asked to take a picture of something related to

the setting, such as the slides on the board during class or a game played. These pictures of

objects helped prompt my memory for writing field notes.

Focus Groups

Focus groups were implemented as an additional way of gathering information from

diverse individuals. As Trevisan (2020) explains, focus groups are "central to the investigation

of the social dimensions of meaning-making, sensemaking, and decision-making, and have also

contributed to the growth of community-based research that explores the complex experiences of

minorities and marginalized groups" (Trevisan, 2020, p.619). As with the other aspects of this

research, the focus groups were voluntary for the students. The focus groups were an

information-gathering time to engage students before the observations. In addition to allowing

the core participants to be part of these focus groups, other IPSE students were also allowed to

participate. I was focused on gathering a few graduated students for the focus groups. By allowing a larger group of students to participate in the focus groups, there was an even larger pool of diversity to gain understanding. I also chose to do focus groups because they would essentially be a recorded social interaction in addition to the observations that were not recorded.

In Mitra's (2003) study on school reform, focus groups were a significant aspect of the work. The exciting part of their methodology is students' use in data analysis. They stated that "adults thought they understood the data, but often they needed clarification from students about what had actually been said" (Mitra, 2003, p. 291). This demonstrates the importance of the outside view from the students and could be said for other marginalized groups, such as those in this study.

During the focus groups, we discussed themes I had found in literature and throughout my reading of transcripts up to that point. For example, in some of the pre-interviews, it was discussed that students have places where they feel uncomfortable on campus. I asked focus group participants to tell me about sites they do and do not feel comfortable in on campus and what causes discomfort. Topic lists often structure focus groups; I used them also (Schelven et al., 2020). Appendix E contains sample questions and topics I focused on during the focus groups. These questions usually focused on general themes I noticed rather than my specific observations with each of them in hopes that the students may feel more comfortable discussing. There was less likelihood of information they did not want mentioned being shared with the group. Focus groups consisted of small groups of approximately four to five students willing to participate in a group setting. Due to the number of students who consented to participate in focus groups, and a request not to place one participant with another, I had two separate groups. Small groups such as this are "less intimidating" for individuals with disabilities to participate in

rather than large groups, partly because they allow each participant more time to articulate their thoughts and utilize other forms of communication that may be overshadowed in large groups (Trevisan, 2020).

These students were from the same IPSE program and knew one another from prior encounters. This was an advantage to the research because familiarity with others in a focus group creates a "more respectful environment for people with communication disorders, which puts them in a position to make more articulate and meaningful contributions" (Trevisan, 2021, p. 623). This, in some ways, was also a disadvantage because it was more likely that students would try to speak for one another. To combat this, I kept track of who communicated throughout the focus groups and called on specific names to encourage everyone to be part of the conversation. I also mentioned that the chat on Zoom could be used to answer questions. A few participants sometimes used the chat, and one text messaged me during the focus group to answer. Talking for one another did not become a problem during the focus groups, but I was prepared to tell participants to let someone else speak if necessary. The method of iterative checking or confirming important contributions from students throughout the focus group time was used to ensure I understood clearly what the students were saying. This was especially important for some participants who did not have easily intelligible speech. By confirming that I understood the student clearly or getting corrections from the participants, I could better transcribe the focus group recordings.

Consent was expected to be a challenging aspect of the focus group methodology because I worked with "vulnerable populations." Immense detail and clarity were given to the students about this aspect of the research procedure to ensure they fully understood what types of conversations would arise during the meeting and the semi-public nature. I clarified the

expectation for confidentiality and the inability to be promised in a group setting. Before scheduling the meeting and determining who would participate, I compiled a list of the themes and questions that might be discussed during the group meeting. In this way, participants could anticipate whether their level of comfort would be surpassed concerning sensitive topics (Sim & Waterfield, 2019). The focus group meetings were also recorded and transcribed.

Core Participant Cyclical Research Trajectory

The cyclical nature of the methods in this research were crucial to its success in understanding the experiences that individuals with IDD had with social interaction. Although I had the same general structure to how the methods would proceed with each core participant, there were variances in how this went in practice. To make the methods clear to those reading, I will explain the research trajectory for most of the core participants and the rationale for this iterative path.

An initial pre-interview occurred during the first week of August, approximately a week after the consent meeting. The participant was sent the pre-interview questions two days prior, in case they wanted to prepare. During the recorded pre-interview, the participant was reminded of the purpose of the study, and I asked them demographic questions. We then discussed questions about their social interactions on campus and talked through their social circle diagram. We looked at the people they put on the social diagram and then discussed, "Where do you see that person?" and "Is that something I should join you for during this research?" This began the cycle. I now had some ideas of where the participant wanted me to do observations. Sometimes, we scheduled that first observation or two right during the pre-interview. In other cases, it took more communication after the pre-interview ended. I analyzed the transcript for the pre-interview and determined ideas for observations to do and questions to ask in the future.

Next, I completed the first few observations, taking jottings down during and after the event. I recorded field notes and memos based on the jottings and the pre-interview. I consulted those field notes and memos to design the questions for the following interview. For example, when something seemed uncomfortable for the participant during the observation, I wanted to ask about that during the interview. Or, when I noticed a participant took pride in specific actions, I wanted to ask about that during the interview. During that next interview, I asked those personalized questions. We again discussed their social circles and determined if there was a different place I should observe during the next set of participant observations. This process was then repeated until data collection was completed for each participant, working towards six participant observations and three interviews. Each step was necessary to gain more insight into the participant and determine possible next steps to further the inquiry.

Analysis

Although DSE framed this work, I took a phenomenological approach to the methods. "Phenomenologists describe what all participants have in common as they experience a phenomenon" (Creswell et al., 2007, p. 252). I gathered data on the experiences participants had. Then I used the data to find more prominent themes that describe the "essence" of the phenomenon rather than working to create a model from their experiences (Creswell et al., 2007, p. 253).

Of Lodge's (2005) ideal types of student involvement, the collaboration of ideas used in these different studies could be considered dialogues or the "engagement with others through talk to arrive at a point one would not get to alone" (Lodge, 2005, p.134). The focus groups were an especially great way to get this type of engagement with the participants. The Messiou et al. (2016) study used strategies such as "scrutinizing events from different angles" to frame

discussions of observations collaboratively. I found that the participants could bring these different angles during each data collection aspect. For example, I initially thought Naranj was acting nervous during one observation because he was uncomfortable with me in the sacred space of a catholic church with him. When discussed in an interview later, it was found that Naranj was nervous that the priest would say something to make fun of him in front of me. I discuss this more in Chapter 4. Without that honest discussion with Naranj about the observation, I would have continued thinking that what I observed was the truth, even though I was wrong.

Collaborative methods of analysis and a component of self-reflection during the researcher positionality and bias analysis ensured the data was more validly analyzed (Walmsley & Johnson, 2003). During analysis, it was important that I recognized my positionality and how that might impact the results and conclusions made (Winter, 1996). I continued to memo my perspective throughout the analysis. Discussing and reflecting on differing opinions among researchers during the analysis portion of any research study is critical. There were differences of opinion noted during focus groups and when looking across different core participants' interview transcripts. Even though I was the only researcher analyzing the data in this study, I made sure to have input from the participants.

As a non-disabled researcher in a disability-related field, I needed input from individuals with disabilities during the data analysis. In Seale et al. (2019), for example, the researchers with disabilities were part of analyzing each participant's memories. They each "reflected upon and recorded the bits of the stories that [they] found interesting and [their] own reactions to these interesting aspects" (Seale et al., 2019, para. 30), and from this, they were able to determine themes. Some of these methods of collaborative analysis took place during the 1:1 interviews

and the focus groups, again demonstrating how I did this work as an accomplice with disabled people.

The coding and analysis of field notes and other data are often done thematically (Braun & Clarke, 2006; 2022), which was the case with this study. The analysis was happening throughout this qualitative research. Data was collected, transcribed, read through, and inductively coded, and then those codes were analyzed for themes. Due to the study's design, data from the observations and meetings were in different stages during the research process. The transcripts were pseudonymized to uphold confidentiality as much as possible before being put into a coding database called Dedoose.

Reading a transcript or fieldnote occurred 2-3 times before coding. After the pre-interview with each participant, I added the familiarization step (Braun & Clarke, 2022), which helped me get to know the participants better. After reading through the transcripts a few times, I did this by describing the main points I remembered from the data. I put down information about the participants and some quotes that stuck out to me. I noted any common ideas I noticed during these re-readings of the data and memoed my thoughts.

I did initial inductive coding on Dedoose, starting with the pre-interview transcripts. I then reviewed each excerpt to confirm that the code made sense and to consolidate the codes into clearer and distinct potential themes. At that point, I could code the other interviews and field notes more deductively, using the consolidated codes. As I was coding, I determined if there were consistent overarching themes from the experiences the participants had. I added new codes as needed, which was different from true inductive or deductive coding. Toward the end of the data collection, I consolidated the codes and checked excerpts for clarity. I then completed coding on the final pieces of data, again mostly deductively with inductive coding

when needed. After this coding, I could discern major themes (Taylor & Bogdan, 1998). I

triangulated the analysis with data from all aspects of data collection to ensure the themes stayed

consistent with what the participants said (Messiou & Ainscow, 2015). I coded and analyzed

data simultaneously and refined the relationships between different themes and concepts I

noticed (Taylor & Bogdan, 1998). Figure 2 illustrates the data analysis procedure I used.

Figure 2:

Data Analysis Procedure
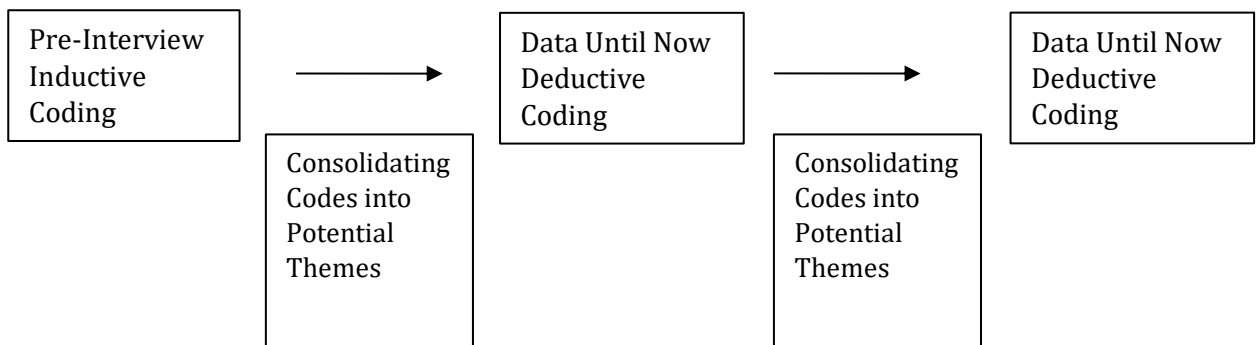
Researcher Memoing and Reflection

There was also an element of self-reflection that occurred throughout the study. After

many observations and interviews I wrote memos and I also memoed my thoughts on possible

themes and other things I noticed while reading through and coding each transcript. It was

unclear until working with the students what the outcome of this project was and if it would be

actionable. I intended to make the study as inclusive as possible by creating accessible ways for

the students to be involved. I hope they will create some actionable product, including co-

authoring an article or presentation or proposing changes on campus through meetings with the

university administration. In addition, I hope what we discovered will help determine the

barriers at IHEs, inhibiting access and success for students with IDD. With that knowledge,

incredible growth and advancement in the field and life experience improvement for IPSE students can come.

Remaining Structure

As mentioned throughout these first few chapters, I found a variety of themes throughout this work. Chapters 4 and 5 discuss the thematic findings related to systems and relationships, and Chapter 6 examines the methodological themes and findings apparent throughout this work. Chapter 7 will then discuss this work's limitations and implications for future work and research.

Chapter 4: Ableism Across Campus

"... I said something to myself. Like, what happens if I don't fit in?

Because I'm a FutureLIFE student?

... What happens if they don't like me?

What happens if they make fun of me?

... I thought to myself, am I not?

I don't really fit into this college." ~Clover

Higher Education is an opportunity facilitated through small- and large-scale institutions encompassing numerous complex systems. These institutions and the systems that make them are both ever-changing and, at times, slow to change, especially considering the recent pandemic, racial unrest, and discrimination in the world that are echoed in higher education. Calls for increased diversity, equity, inclusion, and accessibility (DEIA) in all systems within higher education have been pushed forward. Considering DEIA plans that many institutions are now creating and implementing, it is necessary to understand what the systems within IHE do for students with IDD who are also on these campuses. In this chapter, I will illustrate how the data I collected throughout this research study specifically spoke to the idea of larger systems and inclusion.

A key aspect of this work is how the participants discussed one of Lyons et al.'s (2016) eight qualities of an effective inclusive school. The eight qualities were written regarding k-12 school buildings, but similar attributes can be applied to making higher education spaces inclusive. Specifically, Quality B, "all students are valued members within classrooms and are educated together," was underlying much of the data I collected. The reason that Quality B stuck out throughout the data, I believe, is because it is the only quality that focuses outwards of the IPSE program itself. The study participants and I were discussing and looking at their social

experiences[18]. Those experiences do not happen within the confines of the IPSE program, nor should they. Although Quality B specifies "within classrooms," I would extend this to be "within classrooms and all University spaces" to fit the IPSE context.

Any discussion of inclusion needs to include the concepts of togetherness, access, opportunity, and belongingness (Bacon & Baglieri, 2021). These concepts of inclusion appeared throughout the data constantly, and belongingness was a concept that became prominent in later interviews with the core participants. Many of the participants pointed out a difference between the terms inclusion and belonging. The differences participants spoke about align with how the perceptions of inclusion have shifted historically from space-based, as discussed in Chapter 2, to an understanding with more depth than just people with disabilities taking up space with those without disabilities.

In the experiences I witnessed and then discussed with participants, it was apparent that many individuals on campus value people with IDD who are part of the campus community. The campus community, which includes matriculated students, staff members, and faculty, has positive feelings toward the IPSE program being present at Imagine University. I had the opportunity to observe 37 different events or activities throughout this research. Approximately 20 of these events were campus-run, while the FutureLIFE program itself facilitated a smaller portion (17). At many social events I observed, I saw matriculated[19] peers from Imagine University engage with the FutureLIFE students unprompted.

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[18] The term experiences is used interchangeably with interactions throughout this dissertation. Social interactions are inherently also social experiences, and this language use is more accessible to the participants within this work.
[19] Students in FutureLIFE typically audit their courses, so they can be modified to best make the course accessible to their disability. Individuals who take classes at Imagine University who are not in FutureLIFE typically take courses for credit and are called "matriculated students" or "matriculated peers" throughout this dissertation.

Positive Social Interactions at IPSE

One of the University run events was a night at the local trampoline park. I drove myself to the event and waited in the parking lot until the Imagine University students arrived on six big yellow buses. The participants I observed that night were already texting me that they had arrived, and I met them outside the trampoline park. We first had to wait in line with over 400 other Imagine University students. Once we finally got the cool rubbery trampoline socks and signed our waivers, it was around 10 p.m. This event was supposed to go on until 1 a.m.. In line with me were about seven FutureLIFE students, including the two participants I was observing (Flynn and Clark). I also noticed another participant, Jerry, waiting in a different place in line with some other matriculated Imagine University students. The participants I observed that night were friends, so they were together for some of the night. They separated a few times for various reasons, like wanting to grab something to eat, have some alone time, or wanting to hang out with someone else.

In one instance where Clark and Flynn were separated, I stayed with Clark. He was with a few FutureLIFE students who wanted to get some pizza and Gatorade. The peer mentor working that night stayed with Flynn and some of the other FutureLIFE students. The food was all in a room upstairs from where the trampolines were. To the left and the right of the stairs, there were two connected but semi-separate rooms for people to sit and eat. Each room had five long rows of picnic-style tables. Many were filled with other Imagine University students eating pizza, replenishing their energy with water and Gatorade, and chatting with friends. Clark's group went to the room to the left of the stairs, got some slices of pizza, and then sat on one of the open ends of the first long table near the wall. I stayed standing because the table was now full. I had a pleasant conversation with another student about relationships when I noticed Clark

get out of his seat. He got up and walked behind a person whom I did not know. Shelly was sitting in the middle of our long table, in between some friends. Clark was behind Shelly and loudly told her to "get off your phone!" I was surprised and anticipated a confrontation. However, then something happened that I did not expect. Shelly laughed and took the prompt from Clark as a cue to be more engaged with the present moment. She put down her phone and started talking with Clark and the people around her. When some of her friends got up a few minutes later to return to the trampolines, Shelly stayed and chatted with Clark and other FutureLIFE students at the table.

A few weeks later, I observed another one of the late-night University-wide events. This time it was at the campus ice-skating rink. Before meeting up with the FutureLIFE group to attend the event, Flynn and other students were together for his birthday party at his dorm lounge. Flynn was very excited to extend his birthday celebration to the ice rink. We all got to the ice-skating rink by carpool after meeting in the Education building foyer, where FutureLIFE students often met before events. When we arrived at the ice rink right in the beginning, around 8:30 p.m., the lights were still on, and only a few other Imagine University students were there. By 9 p.m., though, there was a DJ set-up, the main lights were off to show the glow paint the organizers put on the ice, and the place was packed with Imagine University students. At this facility, there were two ice rinks - a smaller one right when you walk in and a larger full-size rink when you walk farther in. The space between the two rinks is where people can sit on the extended bench, put their skates on, eat food, and chat with friends. The FutureLIFE students who had carpooled together and the two peer mentors who were working put their belongings near the middle of the bench. This space became like home base for the FutureLIFE students I

was with. Everyone returned to that area in between venturing onto the ice. A few FutureLIFE students only came to hang out and did not put on skates.

Mostly, I skated near the participants on the ice or talked with the students sitting on the bench. I also took the opportunity to skate around and observe the participants having fun with other people at the event. On the ice, it became effortless to skate around and observe what was happening. During one of those circles, I heard the Happy Birthday song blaring out of the DJ booth. I had a feeling someone told the DJ it was Flynn's birthday, so I skated quickly over to leave the rink and see if Flynn noticed. When I got near the DJ booth, about 100 ft from the long bench where many people were sitting and directly next to pizza and drinks, I saw Flynn and his friends tearing up the dance floor. The DJ announced that it was Flynn's birthday, and the people all over the event cheered. The DJ even had a camera recording the people dancing and cheering around the booth.

In addition to observing University-wide events such as the trampoline park night and glow ice skating, I also was asked to observe participants being highlighted around campus. For the last observation of this study, Naranj encouraged me to watch a celebration of his film work in the Student Center. The Friday before winter break, one of the University organizations decided to play all of Naranj's recent short films on the two-story screen that towers through the Student Center. This is a space where there are typically a lot of Imagine University students sitting in various types of seating, either doing work or eating food from the nearby food court. On this particular day, the World Cup was being played on the big screen until the celebration of Naranj's films. At first, the students in the audience looked confused when the show on the screen switched. A few organizers stood up in front of the screen and talked about what was happening. They said they loved Naranj's short films and wanted to highlight them, so more

Imagine University students knew about them. In addition to the World Cup crowd, more staff from FutureLIFE joined the audience. It was standing room only at this point. There were also friends of Naranj's in the audience from the safety team, FutureLIFE, and some of his co-workers from the Student Center. Everyone who knew Naranj was so excited to see him celebrated. I could tell by the genuine smiles on their faces. The audience of at least 50 matriculated peers who were now unexpectedly at a film showing also started to enjoy the event. They laughed along with the jokes in the films and clapped at the end of each one. The clapping got louder after each film, culminating with cheers after the final fifth film. The initial looks of confusion turned into looks of joy from the matriculated students in the audience. Naranj went to the screen to thank everyone who watched and enjoyed his films. People in the audience cheered and told Naranj how much they enjoyed his work once he was done speaking.

This positive energy toward FutureLIFE students, shown through these experiences, aligns with research already present related to peers and IPSE-adjacent[20] individuals thinking positively about their presence (Carter & McCabe, 2021; Westling et al., 2013). However, a majority of the data that I will discuss throughout these findings chapters complicates this perception that the communities surrounding IPSE programs are overarchingly positive. Although I could share several other examples from my data related to the Imagine University community's positive understanding of the IPSE program and its participants, I am using this space to expand upon the moments that illustrated possible areas of growth.

This work aims to contextualize disability within "political and social spheres" (Connor et al., 2008) as a DSE theoretical framework necessitates. I knew I had to discuss the positive

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[20] I will be using the term "IPSE adjacent" to mean individuals who are not affiliated with the IPSE program in any official way. Therefore, they are with or near the students but not through any specific facet of the IPSE program. This includes staff, students, faculty, and others without affiliation with the program.

experiences and the experiences where participants had obstacles and difficulties in giving the true context of disability within an IHE space. The participants were experiencing a combination of positives and negatives, and understood their experiences through different lenses and perspectives. I discuss these experiences as fully as I can to push IPSE programs forward and not lead to the stagnation of or backward movement of IPSE programs that is possible. Ableism was inherent in different ways across all the findings. I compiled the main findings from this work into this chapter and the two following chapters.

Noticing systemic stigma

Jerry was unafraid to speak to me about the issues he had seen at Imagine University during our interview. He mentioned some obvious instances where he has noticed FutureLIFE students being undervalued as college students or misunderstood. He discussed how his perception of disability has shifted over time. Jerry explained his choice not to disclose his invisible disability and how that choice is rooted in the past treatment he experienced at Imagine University. Specifically, he discussed the discrimination and stigma he has noticed on campus related to three main areas: the non-disabled campus community, the pedagogy of instructors, and extra-curricular opportunities. These examples of discrimination and stigma are rooted in deficit-based ideologies of disability. Their presence throughout the data makes clear the ableism within IPSE programs and the communities surrounding them, which are seen through the social interactions IPSE students have.

Ableism Outside of FutureLIFE

During our first and only interview, Jerry discussed how his relationships with non-disabled peers have shifted during his time as a student at FutureLIFE. Not knowing the individuals he was referring to, it is unclear if they were non-disabled, but they were not part of

the FutureLIFE program. In one of the most profound instances, Jerry spoke about when people he called his friends "found out" he was part of the FutureLIFE program. According to Jerry, this led to them not being his friend anymore. Being known as part of the IPSE program was a significant factor in Jerry's loss of genuine friendship. As was seen in the quote from Clover at the beginning of this chapter, the worry of not "fitting in" because of disability was echoed across many participants. Jerry mentioned, "You have some kids who are just all-around jerks and don't want to hang out with people with disabilities, and they make fun of them. They got made fun of in FutureLIFE." When I asked why he thinks that happens, Jerry answered, "Because they think we're not the same as them." Tensions between matriculated Imagine University peers and FutureLIFE students also impacted students other than Jerry.

P.E. With Clark. One example of this tension was apparent during my observation with Clark. I carpooled with Clark and his mentor to a physical education class on the other side of campus. This was the very first observation that was done for this study. This physical education class was about team-building games and working outdoors together. We carpooled because the part of campus where the class takes place was approximately a ten-minute drive from the main campus. When we arrived, we got out of the car and went over to a pavilion-style building with rooms on both sides and a center made of a cement floor, with openings to the outside rather than doors. In the middle of the cement floor was an older wooden foldable table. Clark's classmates were starting to gather around the table. Clark said "Hi" to people in the class and told me to show them the video of the Corn Kid, which was a popular TikTok video we had been watching while waiting for his mentor to pick us up. He specifically talked to a soccer player in the class to see if they knew his relative who used to be on the team.

After a brief introduction from the professor, the class started their first task of stacking a bunch of nails on top of one nail. The professor initially did not indicate how this was to be done and encouraged each student to figure out the puzzle. Two guys wanted to lead the way with this activity and kept trying different ideas. Other students would occasionally chime in, or the professor would ask for someone else to try something. Clark went up to the table a few times and was up there when a group of about four of them got really close to completing the task. When the task was completed, the professor asked everyone what helped them succeed. Clark was the first one to answer, saying, "teamwork." The professor acknowledged Clark's answer but then corrected him, saying the answer was "all the steps working together." The class tried this activity several times before moving on to the next activity.

In all, they did about five different activities throughout the class. The last activity was one I called the Feather Game, where small groups of students each stood in their own circle. Each group had one interesting contraption, including a ball and feathers sticking out of it. The item reminded me a bit of the thing you hit during badminton. The goal of this game was to keep the feather ball in the air by hitting it around the circle. The group that included Clark, myself, and his mentor was a larger version of a group we had been with for a few of the previous activities. This was only the second day of this class, but the classmates talked with Clark a bit, mainly about the tasks. During this activity, everyone counted how many times the feather ball was hit before falling to the ground. Clark is especially interested in different countries and languages, so he started counting in Spanish. The group started laughing because he kept counting in Spanish. As Clark continued to do this, they started to laugh even more. It was unclear in that instance if the laughter was a demonstration of mocking or joy of Clarks'

classmates, but it was clear that he was being laughed at. At that moment, Clark's reaction was very neutral to the laughter, and he just kept counting and playing the game.

Clark's interactions with his classmates throughout this class illustrated a competence that Clark had to converse with the matriculated students and participate in a credit-bearing course, despite him taking the course for audit. He initiated a few conversations and added humor to the group during that last activity, possibly at his own expense. Clark did not have any conversations with his classmates that he did not initiate during the observation, except with his mentor. Many of the classmates' inexperience with disabled people was illustrated through this lack of reciprocal engagement with Clark. My experience with Clark at his PE class illustrated the tension that is apparent within much of the data in this study. This tension made me question the meanings I was making from what I was seeing. Were those students laughing at Clark or laughing with him? Were the peers in his class not initiating conversation with Clark because they were shy or because he was autistic? Considering DSE and understanding the complexity of perspectives, I ultimately decided that there is no one answer. Life is not a dichotomy. Two things can be true at the same time. Clark was being laughed at. But the students seemed to also be enjoying their time with him and were laughing without any apparent ill intent. Clark was not laughing, so he was not laughing with them. But he also was not acting angry or embarrassed. I have become comfortable with not having one answer or judgment as to the positivity or negativity of any situation I witnessed in this study.

Conversations with Naranj and Faith. Naranj talked in a few interviews about how he likes to greet people around campus. However, sometimes other people do not engage with him, demonstrating this lack of reciprocity towards disabled folks by matriculated Imagine University students. He said,

Well, everywhere I go on campus, I like to speak to everyone. And when I talk to people, some people speak back. Some people don't. So, it's not, but it's not my fault if people don't. I try to be a friendly person, but it's just, some people are just not a talking person.

When I asked how it makes him feel when people do not respond to him, Naranj said, "sometimes I feel bad." Naranj is not alone in being ignored or dismissed by peers and others within his community. He told me that his other friends had experienced the same thing and talked about it with each other. It is understood that all the participants have different preferences related to socializing, as do all campus community members, and Naranj assumes these differences in the previous quote. The intentions behind those responses, or failures to respond, cannot be deciphered from mere observation. However, I observed some instances where it seemed like disability affected why or how someone responded to Naranj. For example, I witnessed individuals talking in condescending ways to Naranj on multiple instances. In an example mentioned later, for example, I could see the uncertainty that some club members had with knowing when and how to end a conversation with Naranj and the tones in which they spoke to him in those moments.

When observing a group dinner with Faith, I witnessed the vast differences in how she communicates with others compared to Naranj and other participants. Faith was very quiet and kept to herself. She only initiated conversation a few times during the group dinner and only with peer mentors. Other FutureLIFE students only started a conversation with her a few times. Faith expressed that she enjoyed not being "bored" by going to events with other FutureLIFE students but experienced these events in a much more subdued way than many other participants. I again acknowledge the complexity within this data and how it showed up within the experiences of Naranj and Faith. Two residential students with very different ways of participating on campus

socially. Naranj was one participant who enjoyed talking to everyone, even if they did not

always talk back. Faith preferred to be around people but did not initiate conversation often.

Mckee et al. (2021) discuss the importance within DSE of accepting students with disabilities as

they are. Understanding that Naranj, Faith, each of the participants in this study, and all college

students have different experiences and understandings of those experiences.

      Course Access with Jerry. Explicitly related to coursework, Jerry mentioned a very

painful moment during class a previous semester. This example demonstrates a need for more

understanding on the part of the matriculated students at Imagine University and how they value

IPSE students who are also part of the campus community.

      Jerry: Like, everyone else says, 'Oh, a FutureLIFE student.' And the kids roll their eyes.

      Like, 'What the hell. What's a FutureLIFE student doing in this class? You took my

      friends' spot.' That's what people say.

      Researcher: Do people say that?

      Jerry: Sometimes they say, 'you took my friend's spot in this class. Why are you in it?'.

      Yeah, buddy. Your friend maybe is not quick enough to get in. I don't know.

      This moment for Jerry showed discrimination and misunderstanding towards people with

IDD in college. At that moment, though, Jerry found solace in joking about their friend not being

quick enough to get into the course. While discussing this issue of getting into courses, Jerry

acknowledged that some of his matriculated Imagine University friends have to "fight" to get

into classes, just like FutureLIFE students sometimes do. However, the thinking that

matriculated students may deserve the spots in the class more than the FutureLIFE students is

detrimental to the pursuits of the program. This societal view towards FutureLIFE students

undermines the pursuit of meaningful access towards higher education that advocates of IPSE are pushing for.

Students in FutureLIFE typically audit courses that they take. Shirley was one participant who took all her courses for credit. When Shirley mentioned this during one focus group, Clover said, "I wish I could take credit classes. I really wanted to. But they didn't let me". When FutureLIFE students audit a course, they take the class for no credit. This grading option allows the student extra supports and modifications they may need to be successful. In this process, the professor must approve the spot for them in their class before registering. This implies that the professor can deny any spots being given to a FutureLIFE student. Getting into classes was a stressor for a few participants like Flynn, who mentioned that just that semester, as a junior, he was able to get a spot in a course within his major.

The process to request entrance into a course at Imagine University is very dependent on the course itself, the prerequisites for the course, and the school the course is housed within. FutureLIFE advisors ensure their students are aware of the University course catalog, and then the students determine which courses they want to take. They typically will look for courses related to their major but also have the option to take courses outside of their major. To receive the culminating University certificate at the end of the program, students must complete five courses within one major. Once students discuss their course preferences with their advisor, the advisor reaches out to the particular school or course instructor to determine permissions for the student to register. Students are sometimes denied registration due to class space, lack of prerequisites, and professor's opinion about a FutureLIFE student's potential success and level of need within the course. Jerry, someone who spoke about getting into all the courses he wanted, recognized that this was not the case with other FutureLIFE students. He said, "why are

professors not letting people who have disabilities into their classes? I might do some research on it. I might start it, be like, yeah. I'm gonna start a research project."

These examples illustrate how FutureLIFE students are sometimes treated as wanted or unwanted guests within the campus community rather than integral parts of the community. This finding is not uncommon. Students with disabilities in k-12 schools are not often seen as full members of the community, distinguishing between "the alien," "the squatter," and "the citizen" (Kliewer, 1998, p. 11-12). I suggest that FutureLIFE students are represented in a mixture of these three ways. Disability studies scholars have previously discussed the transformation that occurs in the environment when a disabled person is transitioned into it, saying,

> …the fragile shift toward a discourse of connectedness is a transition in which those around the individual come to understand him as a valued, able learner and a full participant across the breadth of social and cultural opportunities presented in nurturing contexts (Kliewer et al., 2015, p. 11).

Within society, many systems are still in the beginning stages of this transformation. The examples thus far and forthcoming illustrate how social-specific environments are much farther along with the transformation, representing FutureLIFE students as campus citizens. Academic environments, such as courses, represent FutureLIFE students as "squatters" and "aliens" (Kliewer, 1998). It is necessary to transform higher education spaces to create equitable and meaningful inclusion for students with IDD in all aspects, including academic coursework.

Pedagogy of Instructors

Faculty members and TAs who teach several of the classes that FutureLIFE students take were mentioned as having social interactions that were both helpful and friendly to the participants. Some of these positive experiences will be mentioned in Chapter 5. Although this optimistic view of instructors was present, many experiences were also seen and discussed where

the instructors acted as a barrier to meaningful inclusion. For example, there were multiple

observations where the participant I was observing was left out of a project or group.

Flynn and Arthur's Courses. In one of Flynn's film classes, he almost started crying

and said he was "very upset" because he did not have a group for a significant assignment. Each

film group put its name on the whiteboard at the beginning of class. The professor announced

that each group would present their film project, and the rest of the class would critique it. Flynn

mentioned to me that the professor had emailed him regarding the assignment and was trying to

facilitate some way for Flynn to do it. The professor also came over to talk to Flynn about the

email he sent at the beginning of class. In the moments throughout the observation, though,

Flynn said he felt like an outsider. He was the only one not presenting a film that day. I only

stayed for about an hour of that three-hour-long evening class. While I was there, the first and

second groups showed their films a few times and then were critiqued. The class members were

very detailed in their critiques of the groups. The professor was also very constructive and

critical of the two groups' films. Flynn, who was sitting next to his class mentor, did not give any

critiques to his classmates. He sat there and listened while his mentor took some notes. His

mentor had not been in the class every week, so according to Flynn, they did not help with

figuring out the group film project. In a later interview, Flynn said that having no group projects

or having the same assigned group all semester would substantially add to his "dream class." In

speaking of that difficult situation from his film class, Flynn said,

> …that will help because it will be better. We would turn in assignments on time instead
>
> of late. Because, like, this whole semester in the class you observed. I mean, that's when
>
> I had. I don't know if you noticed that my video was not there… Because I turned in my
>
> assignments late. I know that's unlike me. I always turn in every assignment on time. But

the professor didn't assign a group.

This group issue with Flynn became a topic he mentioned months after data collection was complete. His feelings of missing out on coursework and not completing his work in a timely fashion typical of him have stuck with him. Arthur was another participant who talked about how groups were an issue in their cooking class. They said,

Like in one of my food classes, I would be told or asked if I could do this. And I'll get these, and [using hands to show going to get things off a shelf] you get those. Cuz it would be harder for me to measure out those, but easier for me to do this. So, I would just pick what I was doing, they would do what they were doing, and I would just kind of get my stuff done and then, do whatever else I need to do.

Arthur had illustrated how they were leading their group mates to ensure the tasks everyone was in charge of were accessible to everyone. This seemed to be driven by Arthur's actions rather than any made by the professor in the class. It is unclear what would have happened had Arthur not stepped up and delegated. In other moments though, Arthur discussed a sense of not wanting to take up too much space in the group. Arthur used their hands with palms together and moved them around like a snake to demonstrate trying not to get in other group members' way during cooking time.

These examples and other moments I witnessed showed a lack of structure in assignments and a lack of intentionally designing groups for group work. There were less obvious examples where it seemed microaggressions and unconscious biases were present, which are both critical aspects of systemic ableism. Type or method of communication is one of the common causes of discrimination related to disability in society. I witnessed poor treatment for individuals who do not communicate through speech or do so in ways that are not "typical"

to society. These underlying beliefs that were illustrated through the professor's actions and inactions perpetuated ideas to matriculated students that devalued people with IDD.

Communicating with Debbie. Debbie was devalued by a staff member teaching an employment-related seminar in one situation. This observation was planned and scheduled with the understanding that I would attend in person, but I tested positive for Covid-19 the day it was supposed to happen. Luckily, the class happens in hybrid, in-person, and on zoom. This is because some students, including the participant Debbie, live over an hour away from campus and only come to campus when necessary. When I arrived on zoom, four other students were on zoom, including Debbie. The visual of the in-person classroom consisted of the front desk where the instructors were standing and a few students as they walked in.

This class typically has around 20 students, all senior-year interns with the FutureLIFE program. To start the class, every student was supposed to communicate their name and one thing they had learned in the previous class. A new person from an outside disability-related organization joined the class in person. She was going to be instructing the class on some employment-related topics. This introductory activity allowed each class member to introduce themselves to her. The woman leading the class called on every student, both on Zoom and in person, but never called on Debbie, who often uses an interpreter to communicate. Debbie could be seen on the screen with her interpreter present the entire time this activity happened. This demonstrated a need for more understanding on the instructor's part as to Debbie's competence to communicate and devalued her as a member of that class community. Although Debbie did not claim to recall this experience when I brought it up during our final interview, she did mention that if someone did not communicate with her, "I would feel bad." I will continue to discuss classroom pedagogy and the implications of this finding in Chapter 7.

Extra-Curricular Opportunities

Many aspects of everyday college life happen outside of an academic classroom. As mentioned in Chapter 2, the opportunities available for IPSE students on college campuses vary widely. At the FutureLIFE program, there are a wide variety of extra-curricular opportunities. The study participants have pursued many extra-curricular opportunities, including internships, work-study jobs, joining clubs, and joining organizations, etc. A few main barriers in the data related to these extra-curricular activities were: not being taken seriously, not being given access to clubs or activities, and the challenges of commuting.

Not Taken Seriously. Naranj got emotional while speaking about how leaders of various clubs and organizations he is part of were not valuing him. During my observations with Naranj, I noticed the lack of respect or value given to Naranj by matriculated students in some circumstances. At other times, Naranj was greeted and engaged with by other students and staff to a great extent. My first observation with Naranj illustrated a mixture of both ends of the spectrum in terms of engagement and communication with Naranj by the Imagine University community. Naranj had asked me to a club meeting with him on a Sunday afternoon at 1 p.m..

Interestingly, this club meets in what I thought was only a dorm building that also has a few spaces meant for campus clubs, specifically related to journalism and film. I wasn't sure where to meet up with Naranj, so I waited outside the building and texted him. After sitting on the outside bench for about 20 minutes, I finally saw Naranj walking quickly toward where I was seated. He told me he was running late because he was over at church, where he volunteers some of his time and attends Sunday services.

He did not look worried about being late for the meeting. Naranj led me into the building and explained the purpose of all the rooms we were walking by. Then we made it to the space

where this meeting was. We were so late that it looked like most people there were leaving. Approximately seven people were gathered towards the front of the room, discussing what topics they wanted to discuss in their film projects this week, while seven more were walking out of the room. Naranj led me to the other side of the room, which was the beginning of rows of lecture-style seats. We sat down in the first two seats in the first row. We sat there in almost complete silence for a few minutes. No one came over to talk to Naranj while we were sitting there. Naranj started to make some small talk with me to break the silence. I was not initiating conversation to let Naranj do whatever he usually would in meetings like this. After we made small talk for a little while, I asked Naranj if he would be going up to talk to the people in the front of the room. He said he "wanted to make sure I was taken care of." I made it clear that I was okay and that I would get up or sit down, whatever he wanted.

At that point, he got up and went to talk to the people in the front of the room. He told them I was there to see what he does at this club. They told me they "love working with Naranj" and that he is "awesome." Then Naranj asked me if I wanted a tour of the other part of the building where they have a film studio. I said, "I'd love one!" Naranj then walked through the studio, showing all the different parts. He turned on the lights inside, opened locked doors, and acted like he ran the place, which made sense because he had been part of this club for all his years at Imagine. I was told all the different types of filming that happen in the different spaces and the names of all the people he works with. Naranj introduced me to some of his peers from this club who were in some of the different spaces on the tour. We walked around the studio for almost half an hour, and Naranj even took me to a plaque with a list of people who had won an honor within the club in previous years. He proudly showed me where his name was on the plaque from when he was given the honor the previous year.

The tone in which people talked with Naranj in this setting was mixed. One individual, who also happens to go to church with Naranj, offered to drive him from church to the club each Sunday in the future so he is not late as often. Other individuals did participate in some small talk with Naranj but looked as though they were uncomfortable, wanting to end the conversation but not knowing how. Within the months after this observation, I learned from Naranj about some specific ways that some of the other club members have treated him in negative ways. The conversation in the following vignette demonstrates this.

Naranj: And I want to be more involved in the news. I asked her [News Director] like, 'Can I do a live broadcast one time?' She never got back to me. What am I supposed to do here? She always has some kind of excuse... every time I see her, she's like, 'oh, let me get back to you.' Okay, well, let's talk right now [Naranj nervous laughing/crying].

Researcher: Are you going to keep asking?

Naranj: I want to, yes… But sometimes it just makes me frustrated [crying/laughing]... Because she is not giving me the opportunity… I'm interested. Is she gonna take me seriously? I think the GM, I think this is ridiculous. You know, it's starting to get on my nerves.

Naranj felt like the leader of this club was not taking him seriously and was avoiding him, saying she always had an excuse. This caused an emotional reaction from Naranj in that he cried during the interview. He felt as though the opportunities that he deserved were not being offered. Naranj's experience of feeling like he was not taken seriously were not unique to that film club. He also felt this way when co-workers and a leader in his religious organization were joking with him in ways he found insulting. While observing Naranj at a religious service, I

noted that he seemed overly nervous and uncomfortable. I planned on bringing this up to Naranj during our following interview, but he brought it up first. He mentioned that,

> [religious organization leader] likes to be funny sometimes. And sometimes, he can joke around, but at the wrong time. So that's what I think because I never know, and you never know what really comes out of his mouth. And he says something mean. That's not funny to me.

He did not specifically say what this religious leader had said to him other than alluding to being yelled at once and being joked about his "fame" often. Naranj said, "I don't want him to talk about certain things at a certain time because that's not the time and place." Although he felt this way about both situations, he did not say anything to the individuals for fear of hurting their feelings. Naranj is a FutureLIFE student who additionally has a societally marginalized racial identity. I did bring up during one of our interviews the idea of intersectional identities and his thoughts on if that is a cause of this perceived discrimination. He did not have an answer to that question but explained how he could not know what other people were thinking. Naranj's unwillingness or discomfort with naming a possible root of his discrimination demonstrates that he may be so used to forms of intersectional discrimination that it does not get named. There also is the possibility that he did not name this because he did not feel comfortable sharing that aspect of his life with me. So although he was willing to discuss feelings of discrimination and intersectionality, there are still many areas of unknown.

These experiences of not being taken seriously were common to Naranj but also occurred with other participants. During an observation with Debbie, I witnessed her not being fully taken seriously during her internship at an elementary school. While playing on the playground during recess, one of the preschool students hurt her head. The classroom teacher let Debbie, the little

girl, and me inside the building and sent us toward the nurse's office. Debbie's interpreter did not join us for this trip inside. I, Debbie, and the little girl walked through the building to the nurses office, but she was not to be found there. We walked around more and eventually saw her walking down the hall. Another teacher also was nearby and stopped to say hi. Once the nurse saw us, Debbie signaled toward the students' head to communicate that the little girl needed an ice pack for her head. Even so, the nurse looked at me and the other teacher, who happened to be in the hallway, for an explanation. The nurse asked, "is someone going to tell me what is happening?" Debbie already was. The nurse was not trying to communicate with Debbie, even though she acknowledged that she knew of Debbie from her internship. She knew Debbie was using alternative communication but ignored it at that moment. She instead turned towards me, a stranger, and the other teacher who was not involved, for answers. These breakdowns in social interaction during non-academic activities relate to belonging on campus. Being taken seriously and people trying to communicate with you are important aspects of belonging to most individuals, including these participants.

Access to Clubs, Organizations, and Campus Activities. The bare minimum of inclusion is giving students with disabilities access to all spaces. The Imagine University campus did not do the bare minimum because FutureLIFE students were not given access to certain spaces. Many participants mentioned areas of college student life in which FutureLIFE students still needed to be included. Multiple participants mentioned the need for opportunities to be part of Greek life, and missing out on studying abroad was also mentioned. Jerry said:

It seems like we're excluded from the whole university. We're on your campus. Imagine, you should figure it out. Like, get us, like I don't know. Make it more like equal. Because I think it's like discriminated against people with disabilities. And I'm really gonna talk

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to the dean.

Only some participants were as open about feeling excluded while in FutureLIFE, so I was encouraged by the honesty Jerry brought to this interview. Unfortunately, due to Jerry's busy schedule, we only had this one interview and a few observations. I did not get to continue this conversation with Jerry as the research continued. However, I used his sentiments to frame interview questions with others, hoping to make them more comfortable giving honest answers.

Commuting. Participants who commute to campus also demonstrated feelings of missing out because the campus community did not fully consider their experiences and needs. Arthur mentioned how they would often miss meetings of the LGBTQIA+ club because they held meetings on days they were off campus. Arthur repeatedly spoke and texted me about planning the events they wanted to attend and communicated with their parents to ensure a ride to events. They put a lot of effort into getting the most from the college experience but recognized that others have an easier time without worrying about long commutes.

Chadwick is also a commuter, and I found out that he does not attend the lab portion of a course because it happens after he leaves to go on the bus home. Chadwick is part of the dual-enrollment program that works within FutureLIFE, which offers high-school students with IDD from the local urban district access to college at Imagine University. This makes his experience with commuting even more complicated because many of his supports are contracted to only school hours. So even if he wants to participate in evening activities, he must find alternative rides and support. Chadwick's family and his school-funded support did their best to keep him involved in some evening activities. For example, it was mentioned that his father takes him to one of his classes outside school hours. I also observed Chadwick at a University-wide film premiere event at the local mall where his support worked after hours, most likely for free,

because it went on until 1 a.m.. Activities like that necessitated a lot of planning on the part of

Chadwick and his supports. That film was planned as an outing months in advance.

Understanding the IPSE experience for commuters is especially important because, nationally,

most IPSE students are commuters. Without creating an IPSE and University System that honors

the value that commuter students, with or without IDD, and their desire for social interaction,

they will continue to face barriers

Working Against Systems

As Jerry alluded to in many of his statements, like "I'm going to talk to the dean" or "I'm

going to email the Chancellor," action is essential to the participants. Discussing solutions

became especially important in the final interviews with the core participants. We talked about

how I had seen disabled students treated poorly in some of the observations. We talked about the

quote, "disability is diversity." We talked about how *they* suggest we change people's minds.

Their answers overwhelmingly were things like, "bring them here," "invite them to a holiday

party," and "show them how cool we are." Their solutions almost always involved socializing

with these folks whom I would call ignorant of the truth of disability. Advocating through

discussion and exposure to disability is not new.

Power Structures

Christensen & Dorn (1997, p. 193–194) describe the importance of considering power

relationships:

> A theory of justice predicated on relationships would encompass a set of critical issues
>
> of concern. At a level close to individuals, this would include material sufficiency, close
>
> emotional ties with adults when growing up, one's skills in relating to others as social
>
> and intellectual beings, and the social environment in which others expect us to develop

and display those skills. At a broader level, justice in relationships must incorporate an understanding power differences among people.

Many of the social interactions throughout data collection included power differences. As shown through the examples within this chapter, who holds the "power" in any situation depends on the perception of the individuals and/or society. The idea of paid staff holding more power than the people they work for is sometimes shifted with the idea of paid roommates and mentors gaining course credit for volunteering their time within an IPSE. Participants had an understanding that the administration of Imagine University holds the power to make changes and acknowledged that with their sentiments of wanting to talk to the administrators. Regarding people listed on the social circle diagrams, all participants had folks listed who are paid by the IPSE program or an outside disability-related organization and folks who are unpaid. There was no distinct difference between where the participants placed paid or unpaid individuals in their life.

Although society often assumes more power is held by paid staff and non-disabled peer mentors, the participants did not act as though that was true in most examples. Power is often demonstrated through direction, and parents were the only group who consistently gave direction to the participants or whom the participants were somewhat fearful of. Flynn, for example, walked into our first interview late because he slept through his alarm. He walked in fearful that he would have to go home. He told me that his mom only gives him three chances before she comes to pick him up. His mom knew he had an interview with me and followed his location from her home, hours away from Imagine University. She knew he was late to our interview and Flynn said she was mad. Flynn said he had one more strike left. In a situation explained in Chapter 6, multiple students were fearful of another FutureLIFE students' father. They wanted

me to get involved and help because they were worried that the father was mad. The judgment or perceived future judgment from parents was a common thread in the data.

FutureLIFE staff and non-disabled peers were sometimes talked about as giving direction or giving suggestions, but more so, the participant was telling the staff or non-disabled peers what they wanted. Jerry was asked about his paid summer staff and if having a paid friend[21] made him uncomfortable, to which he said, "No, it's what I wanted."

In contrast, there were apparent hierarchies of position when considering the moments of Naranj and the leader of his religious group, as well as with certain bosses and faculty, understanding that they have a role of power. A few participants also demonstrated an affinity for those with titles of power, such as leaders of University events or different clubs. When talking about friends they had, Arthur said, "leaders of the group, yes, friends, but the other kids in the group, no, just acquaintances." Some participants felt more comfort and belonging with the paid or volunteer staff than with the public. This demonstrates the possible knowledge that comes with a leadership position to understand and value diversity more. Does this comfort and friendship the participants feel with staff and/or leaders come from the mere fact that those individuals have been instructed to communicate with people with disabilities? Are those individuals more open to diversity and disability, which brings them into leadership positions on a college campus?

With higher education systems being retrofitted constantly to bring more individuals with IDD to them, there is no question that there are ways they are still not inclusive or facilitating belonging for the students in them. Even so, the participants said they were having positive

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[21] Participants mentioned whether people were friends or not throughout my conversations with them. I only use the term friend to describe different individuals if the participant explicitly said it.

college experiences and were grateful for them. There could be an argument that this was acquiescence bias towards me, a researcher they know is highly involved in IPSE. However, that was not the case with these statements. I will discuss this more in Chapter 6. However, in continuing this thread of power and ideas of inclusion and belonging, I wondered how these participants are having an overly positive time and feeling like they belong with all the barriers and stigma surrounding them. The relationships participants had directly through the FutureLIFE program gave them enough support and engagement to feel those positive things, despite difficulties. Chapter 5 will take a closer look at this idea by examining the data related to relationships the participants have while in IPSE, which typically include individuals closely related to the IPSE program itself.

Feelings of Inclusion and Exclusion

Participants' feelings about inclusion, exclusion and belonging were discussed throughout the data collection. Participants' understandings of inclusion and belonging aligned with the more profound understanding of inclusion that is not just people with disabilities taking up space. Inherent in that profound depth is the worth or value of the included individuals, which is highly connected to Quality B, mentioned in the beginning of this chapter. The areas of related concern that some participants discussed when specifically explaining inclusion and belonging did not have to do with space itself but how others valued them within the space. To know they belonged somewhere, the participants wanted opportunities to interact with the environment, not just be in the environment. They also mentioned feelings of exclusion when they were not treated like everyone else. The systems that form and facilitate IHEs and IPSEs impact how ableist ideas are perpetuated by the people within them.

Mini-Golf. In one instance, a few participants were together at a mini-golf event along

with hundreds of other students from Imagine University. When the seven school buses arrived at the mini-golf and laser tag facility, I met up with the core participant who had requested that I attend this event. There was a group of eight FutureLIFE students, including the attending participants and a peer trainer. FutureLIFE students and the peer trainer stayed together for the mini-golf. After a few quick exchanges between some students, the peer trainer, and the staff working at the mini-golf station handing out the clubs, it was decided to start at the 18th hole because the course was packed with students all starting at the same time. Other matriculated students at the golf course also decided to start in different places on the course.

As is typical with mini-golf, everyone takes turns hitting the ball, trying to eventually get it into the hole. With a group as large as ours, with players who could have been better, including the researcher, each hole took a long time. We also needed to wait for the large group of other students in front of us, who were also going backwards through the course. Conflict arose a few different times throughout this game of mini-golf. A moment that Arthur later discussed from the mini-golf event was how another FutureLIFE student kept hiding Clark's golf ball or making Clark find it. There were also moments when this other FutureLIFE student was taking turns for people slower at golf and trying to make the turns move faster. Arthur lamented that this was uncomfortable for them, but they did not say anything. Arthur felt like that action by the other FutureLIFE student was being exclusionary towards the students by not letting them play the game on their own. Our discussion was as follows:

Researcher: So, okay, now, did you feel like you were included at those events? Or did you feel not included? Because we were like this huge group.

Arthur: Yeah. I was included, I liked it.

R: Okay

Arthur: So yeah. I did feel like, no offense. [The FutureLIFE student] was kind of excluding people by doing what they wanted. Like, he kept hitting Wayne and Knox's ball. It's like, let them do it. Yes, they may be slow but let them do it. It's their ball. They want to play too. Like, I constantly saw him hitting Wayne's ball and it's like, I was gonna say something but I'm not good at that. But it's like, that's not your ball. You've already made it in and let him make his own in. Yeah. So it's like, annoying that he does that.

Arthur noticed the intrusive "helping" without the explicit permission that another FutureLIFE student was doing during the mini-golf game and how that was reducing the level to which the other students were included. With Wayne and Knox not being able to finish their turn, they were being excluded, according to Arthur. Although this experience was highlighting how Arthur saw exclusion because of another FutureLIFE student, it is illustrating a theme that is common with both FutureLIFE-FutureLIFE and FutureLIFE-Matriculated Peer interactions.

Clark felt he belonged at those same University-wide late-night events "because [those events] just make me want to go out at night." The desire to continue participating in similar events made Clark feel like he belonged there. These events, as explained previously, include any students from Imagine University who want to attend and typically have hundreds of students. Rosalie discussed similar sentiments with the focus group she was in also. Although the FutureLIFE students were sometimes in close proximity to one another at these evening events, they were campus-wide activities with other matriculated students. The FutureLIFE students explicitly felt campus belonging or exclusion while at these events, depending on their treatment by others.

Being treated differently than others was something that came up in the data. In a few

conversations, I tried to understand feelings of difference rather than *inclusion*. I asked if there were differences that the participants felt between themselves and other matriculated students on campus. Flynn only mentioned a difference in time management, saying, "Yeah. It's different because they're [his matriculated Imagine University friends] more busy." He recognized that there are perhaps responsibility differences impacting their available time, or he was acknowledging the difficulty he sometimes has in making plans with his matriculated student peers, both of which I saw evidence of during the observations. Jerry also discussed this topic, specifically related to his on-campus job. Our discussion is below.

> Researcher: So, when you're doing things like working there, do you feel like you're just
> another employee there or does it feel different because you're from FutureLIFE?
> Jerry: No, I feel like an employee. I feel like a regular student. I can do this.

Jerry was exclaiming that he is just like a "regular student" and does not feel different. However, his addition of the statement, "I can do this," made it apparent that being part of FutureLIFE can cause deficit thinking for some about the competence of students in the program. He was also demonstrating the need to reach a perceived norm of productivity and show his capability to reach that.

This chapter focused on potential problem spots surrounding IPSE programs impacting student experience. The institutions where these programs find a home are entrenched and based in societal stigma, especially towards disability, demonstrated through many participant excerpts and my view during observations. The systems behind getting into classes, who can join certain extra-curricular activities, and how commuters are thought of all have inherent barriers causing a reduction of positive social interaction for FutureLIFE students and probably other IPSE students across the country and the world.

In conclusion of this chapter, it is necessary to acknowledge the wide variety of ways that systems external to FutureLIFE and the students in it are impacting social interactions. The higher education system consists of Universities, Colleges, and schools, each having distinct rules and procedures. They all include specific procedures for aspects like auditing courses, which at FutureLIFE is decided within the College of Professional Studies. Political and societal decisions have also given FutureLIFE students limited options as far as funding, leading to the high prevalence of auditing courses. Aspects of external systems such as transportation and the distance individuals have to travel to get to school if they are commuting are also necessary to look at. Social constructions that have created the campus community of Imagine University, which FutureLIFE is a part of, are also impacting the interactions within the University spaces. It is important to also acknowledge when this research was done and the logistics of the transition after leaving high school. College for people with IDD is happening, which was not the case very recently. That fact is important in understanding the societal constructions and biases people hold towards disabled people. The findings illustrated throughout this chapter demonstrate these impacts as they were seen for the FutureLIFE participants in this study.

Chapter 5: Exploring Relationships

"I do love to socialize. And I do love helping people as well.

I love that." ~ Clark

By looking phenomenologically at the social interactions of IPSE students and graduates during their time at FutureLIFE, I have become more keenly aware of the importance of the IPSE program to the social interactions of individuals with IDD. As in the previous chapter, it is necessary to highlight, and potentially change, overarching policy and academia to enhance students' social experience. Nevertheless, the larger systems impacting IPSE students cannot be adjusted independently, and students' daily interactions cannot wait for stigmas to be changed. The IPSE programs themselves, their students, and the supports they facilitate, can impact those larger systems and ableism. Many of these supports are in place to mediate social interactions with peers, faculty, and co-workers. This chapter explores the relationships[22], and social interactions participants had while in the FutureLIFE program. The participants' variety of interactions and relationships illustrated an essential aspect of college life for IPSE students that is often overlooked.

FutureLIFE Student Relationships with Others

Relationships that any person has throughout life have the potential to benefit them and need to be valued (Gravett & Winstone, 2022; Szwedo et al., 2017). The relationships specific to those that individuals with IDD have with others are just as critical (Corby et al., 2020; Rossetti et al., 2016). I will discuss the relationships that FutureLIFE students have with other disabled individuals and with non-disabled individuals in various roles. I will also discuss how aspects of ableism impact the interactions that IPSE students have on campus.

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[22] The term relationship is used throughout this dissertation to discuss platonic and romantic social interactions individuals experience. When a romantic relationship is discussed, this is expressly stated.

Internalized Ableism

Although much of the data demonstrated that FutureLIFE students had many interactions and connections with other IPSE students, the topic did surface about individuals who are students in FutureLIFE who try not to associate with the IPSE program and its students. One participant alluded to how he sees disability as a hierarchy that puts himself above others who communicate differently or need "more help." He spoke about another student in the program (not a participant in this study):

> Participant: That kid does not want to be involved with FutureLIFE at all. He's like, no, I'm not… I was like that freshman year because I was like, I'm so cool. I'm so amazing. I don't need any help. And then I figured out that I actually do need help. And, eh, maybe less than other people in FutureLIFE. But we're all the same, you know. We're all family, so…
>
> Researcher: …but you said you were like that your freshman year.
>
> Participant: I've changed.
>
> Researcher: Why do you think you were like that?
>
> Participant: Because I was like, I'm so excited to go to Imagine University. I don't even really need to hang out with these kids. Like I thought they were something other than. I thought they were not, like, nah. Take it or leave it. But now my mom's like, we're gonna kick you off of FutureLIFE if you don't hang out with them. I was like. I don't know. Uhh, I felt like, kind of like, a jerk freshman year. I was, like, so mean to everyone. Thinking like, I'm gonna graduate with a job. I still probably think I will because I'm working my butt off…."

As this conversation shows, this participant changed his mind about the value of the other FutureLIFE students when his mom told him he had to. It is questionable if the direction from his

parent had a genuine impact on the feelings of this participant, but he suggests that his outward

actions have changed because of it.

Some participants specifically discussed variances in communication styles and how it is

challenging to understand people who communicate differently from them. One participant

shared interesting views on this topic, stating she did not want to befriend individuals who

communicate differently. I brought this topic up multiple times throughout the interviews with

this participant.

> Researcher: Do you think you would ever be friends with someone who communicates in
>
> that way? Like on a keyboard or computer? [Examples she had given previously in the
>
> conversation]
>
> Participant: Well, I've been around people like that.
>
> Researcher: Do you find it difficult?
>
> Participant: A little. Because they don't talk and don't communicate that well, I prefer for
>
> like, for like verbal people that can talk, that communicate well.
>
> Researcher: Okay. Do you think that there are people who would say the same about
>
> you? … That it's hard to be friends with you because of your disability? Have you ever
>
> had someone that says that to you? Do you think that would ever happen?...
>
> Participant: No. I don't think so. Because I can speak clearly.

This excerpt again demonstrates that individuals with disabilities are susceptible to the

same ableism that permeates the rest of society. In this example, the participant demonstrates a

preference for speech, which is shared within the structures of society. The participant previously

acknowledged that she has a disability but can "speak clearly." That fact alone was the only

important part of communication for this participant. This conversation was continued later when discussing if college is essential for people with disabilities:

Participant: And I sometimes keep hearing if college is good for people with special needs, for students with special needs to go.

Researcher: Do you agree?

Participant: Ah, [unsure voice] I do. I sometimes disagree.

Researcher: Okay. Why do you sometimes disagree?

Participant: With, well communicating and socializing.

Researcher: So, do you think that people who have trouble communicating shouldn't go to college?

Participant: Well, they need to have a good experience.

Researcher: And how does someone have a good experience in college?[23]

Participant: … To make friends. Have things to do.

Researcher: … Do you think that someone needs to be able to speak verbally to do those things?

Participant: Probably.

This excerpt demonstrates how the ableism this participant had encountered throughout her life impacted her perception of who should and should not be in college. Even as a disabled person who benefits from the opportunity of college access, she is not fully supportive of all students with disabilities going to college. This internalized ableism has been seen across the disability community (Campbell, 2008). Interestingly, this same participant spoke about how the inability to communicate in a "traditional" way did not mean someone should be treated poorly.

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[23] The participant had difficulty understanding the question, so the researcher wrote it down on paper and broke it down a few times. This was done to lower the cognitive load. These pieces were left out of the excerpt.

With a DSE framing, it is essential to recognize how ableism impacts not only those who are non-disabled but also those who are disabled. It should be noted that the participants who most commonly spoke candidly about their own ableist thoughts towards others were those with what are deemed to be "invisible" disabilities and who did not have other apparent marginalized identities.

Staff Infantilization

The same participant who did not think all people with IDD should go to college pointed out that there was a difference in how the dual-enrollment staff and the FutureLIFE staff treated the students. Speaking of the dual-enrollment staff, "They treat them like kids. They bend down to them, and they're close, and they're in your face", then extending this to say,

> Participant: FutureLIFE students being like elementary students or a kid. And then it's like an elementary.
>
> Researcher: So they're treated like elementary students?
>
> Participant: Yeah,
>
> Researcher: And do you think the dual-enrollment students [interrupted quickly]
>
> Participant: like daycare or nursery.

This excerpt was crucial to my understanding of the data. I witnessed moments of infantilization throughout the observations. For example, when I was at Faith's internship in the campus library, I spoke briefly with her job coach during her lunch break. After observing them working together in a quiet library study room, we all went downstairs to the library cafe. The mentor was especially concerned about finding Faith a place to sit. He talked to me about how he "scopes" out a spot for her because sometimes it gets busy in the cafe. Faith was buying her food while I spoke with the mentor. I would guess this mentor was an older man in his mid-50s. In

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one instance that I found to be especially infantilizing, the mentor told me how "cute and innocent these kids are" while pointing to Faith and another FutureLIFE student who also happened to work there. This conversation was happening amid the lunchtime rush at the busy library cafe. In that brief conversation, the mentor spoke about how he thought the other FutureLIFE student in the library had a crush on Faith, but he did not give any actual reason for that suspicion. This infantilization stems from a lack of genuine presumption that IPSE students can have true romantic relationships or that they are competent to consent to them. An excerpt from Flynn later in this chapter also illustrates this.

In addition to instances of infantilization of students committed by the FutureLIFE staff, there also were instances when other IPSE adjacent staff were infantilizing. For example, while observing during a late-night "takeover" event in one of the on-campus recreational buildings, I witnessed an instance of infantilization from the on-campus security team. The security team demonstrated a strong relationship with the FutureLIFE students throughout many events, especially the late-night University events. They knew many of the FutureLIFE students' names and quickly engaged them in conversation when they had the time. Two non-participant IPSE students wanted to leave the event early during this on-campus instance. The security team offered to take the students back to their dorm and told the peer mentor who was working that "if any of the students need someone to go back to their dorm with, have them call us." Although a well-intentioned gesture, I could not help but wonder why they felt the need to offer this service at that moment. There are avenues for matriculated students to call the security team if they need help, but I have never seen it offered this way. The way the security team spoke that night made it seem like the FutureLIFE students could not keep themselves safe walking back to their dorm. Safety was something that a few students mentioned as a concern at times due to the urban

setting of the campus. However, they typically addressed this concern by going with groups of

friends across campus rather than utilizing the safety officers to get from place to place.

I brought up the topic of infantilization with many core participants during interviews.

The previous interview excerpt was one of the only times a participant engaged explicitly with

the topic. Because this excerpt was from a participant who had made bold statements about

people who communicate differently, I found it extremely telling about disabled individuals'

perceptions of dignity. Even though this participant did not want to be friends with specific

individuals because of aspects related to their disability, they recognized the necessity of being

treated with respect and dignity. People with disabilities can and will decide whom they will be

friends with. They have standards and ideals about people that can be ableist or biased, just like

non-disabled folks. The participants in this study also recognize that the treatment of those

"different" individuals should be up to a certain standard. This connects to the Disability Justice

principles of cross-disability solidarity. The ways I understand this, and the implications of these

findings are discussed more in Chapter 7.

Characteristics of Friendship

Due to the nature of the main research question in this study, the topic of relationships

and friendships often came up. I could organically fit the "What makes someone a good friend?"

question into many interviews, to which I received similar answers. These answers referenced

characteristics that make someone either a good (positive feelings, helping, telling you things) or

a bad friend (dishonesty, disrespect, not making plans). Interestingly, when Rossetti et al. (2016)

asked parents and teachers to define friendship for their students with IDD, they found that most

instead exclaimed about the difficulty their students experienced with friendship. Similarly, I

noted how the participants in this study framed the characteristics of friendship, both positively

and negatively. For example, some chose to say what a friend is not, while others chose to say what a friend is. These characteristics could be flipped to be the opposite characteristic (good or bad). However, I have written about the characteristics in the ways the participants spoke of them. There is importance in understanding the characteristics of friends for people with IDD because society does not always recognize that they can have preference and should be able to make decisions about who they are friends with.

Characteristics of a Good Friend. When the participants discussed good friends or people who were best friends, they often spoke of their demeanor. They mentioned how the friend acted when they were together. This coincides with how Block (2015) spoke about friendship as having two main interdependent processes: interaction and positive evaluation. Individuals need to interact to recognize aspects of how the friend is acting and to feel optimistic about their actions, thus defining them as good friends. A few participants discussed the ease of making friends with people outside of FutureLIFE. During a focus group, Clark agreed with Flynn, saying, "Same thing for Flynn. It is really easy to make friends with non-disability people. It is really easy."

Positive Feelings. Understanding the feeling of a friend's happiness and positivity was mentioned a few times throughout the data. This was especially true with participant Kent. On numerous occasions, Kent would name his friends and exclaim their positive characteristics. For example, he mentioned how his best friend was a nice person. When I asked what makes him a nice person, Kent said, "Cuz, um, he is great. And he is very happy." Spending time with people who were happy and enjoyed spending time with them was essential to the participants. To many of the participants, it did not matter whether or not the friend had a disability or not. I asked Tyler, "Is it important to have people with disabilities at college?" He responded, "I think yes.

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But for me, I don't care who is which. But everyone has; everybody who goes to college can have a good college life together." As Tyler suggests, the general positive feeling of being together seemed to matter most in making friends and hanging out.

I witnessed positive interactions with participants during many of the observations. One was when I was observing Clark and Arthur at a late-night event in an on-campus building. During this event, there were a lot of different options for activities. Three participants had asked me to observe them during the event, so I spent about an hour with each. Many of the times, though, participants were together. At one point, Clark and Arthur wanted to go roller skating. The building had a gym for rollerblading and a DJ playing music. There were only a few other groups of students roller skating at the time. Both participants had a great time during this part of the event. They were smiling and joking around. Clark, for example, started jokingly sneaking up on Arthur and me, hoping we would be startled. There was a lot of laughter and smiles. We circled around the gym-turned-skating rink over ten times before deciding it was time to stop. While skating around, a few songs the DJ played made everyone want to dance. Clark and Arthur named each other friends throughout numerous interviews. This was also illustrated through their positive times together at this event, and others.

Helping. Having a good friend who would help you was something that almost all the participants mentioned. Flynn mentioned his relationship with one of his good friends, who used to be a residential mentor with FutureLIFE, saying, "Well, my relationship with her. It's really good because she helps me through every problem between [my two other friends.]." A significant aspect of the characteristic of helping is the idea of reciprocity. "Reciprocation describes the increased likelihood of individuals to send ties to those from whom they receive a tie" (Block, 2015, p. 3). This aspect of reciprocity within friendships and social interaction came into the discussion earlier than expected, sometimes as early as the pre-interview. Whether or

not the participants themselves help the different people on their social circle diagram or if the people in the diagram help them was a common discussion. Many friends were spoken about as people who "help" the participant to do things or listen to them and give advice. When I would then follow up these statements by asking if the participant also helps their friend, they always said yes. Past friendship research has discussed reciprocity as something essential but not something that needs to be equal. It should be balanced and satisfying among both individuals (Block, 2015; Rossetti et al., 2016; Rossetti & Keenan, 2018).

During the residential student focus group, which was recorded on zoom, I witnessed another instance of helping firsthand. Tyler was answering a question about where he feels most comfortable on campus. While answering the question, his friend shows up on the side of the screen. In the next second, Tyler had a smoothie in his hand. His friend, another FutureLIFE student who is not currently Tyler's roommate, had come to bring him a smoothie. This small act of giving seemed to be appreciated by Tyler, as he smiled and was happy after being given the smoothie.

Madelyn also mentioned the importance of helping as part of socialization while on campus. She mentioned, "I don't really [socialize] that much, so I would say, sometimes, if you need help. If you're doing homework like that, I just, I need my mentor to do my homework with me." Madelyn is very protective of her time and sleep, so she often does not attend the late-night activities that many other participants do. To her, socializing is something she does with academic mentors when they help her with her homework. This aspect of helping is important to her social interactions.

During a few different data collection moments, Clark illustrated how he was a good friend through how he helped one of his newer friends. This friend was not a FutureLIFE student but had recently disclosed to Clark that she was autistic. I was introduced to this friend at several

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evening University-wide events. When I asked one of the focus groups if it is vital to have

people with disabilities on a college campus and why Clark quickly wanted to answer. He said,

> Yes. Because I just taught that to a friend of mine who is not from FutureLIFE. So this
>
> girl, I met her from Clover. I just found out that she might have Autism… her boyfriend
>
> left her because of her disability. And her mom does not support her disability. But I do.
>
> And I do ask FutureLIFE to support her too.

In this example, Clark explained how his new friend confided in him and how she was

having difficulties after getting diagnosed with a disability. He wanted his friend to feel

comfortable and supported with her disability. He acknowledged the systemic ableism that she

was encountering with the negative perceptions of disability from her family and boyfriend. As

is demonstrated in these examples, there were many examples of participants helping and being

helped by others they consider friends. This positive perception of helping was complicated by

instances, such as the mini-golf excerpt discussed in Chapter 5. There were circumstances when

unwanted helping became harmful to the student experience.

Tells You Things. Talking with good friends was also very important to some

of the participants. There was a reciprocal nature to this characteristic in that not only would

your good friend tell you things, but they would also listen to you tell them things. Arthur

demonstrated this when they talked about a friend on the line between close and casual. Arthur

justified their level of friendship by saying,

> …because he likes to tell me a lot of things. Sometimes I'll tell a lot of things back;
>
> sometimes I won't… But we've definitely become closer friends with other things, as
>
> you know [alluding to the drama I was told about previously], that's going on.

Other participants also mentioned in interviews the importance of being able to talk through

other relationships and hard times with friends. During observations, I witnessed back-and-forth

conversations often. For example, I noticed that Poppy was upset at the end of one late-night University event. Her head looked down towards the ground, her arms crossed, and she looked like she might be crying. One of her newer friends, whom she often mentioned during interviews, went over to her to see what was wrong. They talked for a few minutes and then exchanged a long hug. After that point, Poppy was ready to keep walking with the group again as we all continued to leave the event. They mentioned how they were talking about being homesick. Poppy and her friend bonded over this common emotion that happens during college.

In a focus group with the residential students, Clark gave an example of how he likes to socialize. He said, "social experiences. I can have like a mentor in class or a peer trainer to talk to me. And a lot of students. Like, some of you all [in the Focus Group] can talk to me, as social." Talking with many different types of people was important to Clark, and he demonstrated this with many of his interactions throughout campus. He was often the first to introduce himself or say "hi" to folks when they got to an event. In discussing his friends, he considered many of these people that he talks to friends. Debbie was another participant who had conversations with friends but used an alternative method of speech. For example, during the sign-making party before a football game, Debbie was there with her sign language interpreter. This party was a FutureLIFE-organized event with around 50 guests during Imagine University Family Weekend. FutureLIFE students, parents, guardians, siblings, FutureLIFE staff, and friends were in attendance. The interpreter went with Debbie wherever she wanted in the party room and facilitated that communication. Debbie often signaled that she wanted to talk with someone by touching their hand or shoulder. Once the person she wanted to talk to gave Debbie their attention, often through eye contact, she would start signing, and the interpreter would start

interpreting. This repeatedly happened with new people throughout the event, as Debbie is very social. There were a lot of smiles and laughter during these encounters.

Although many participants described talking and communicating as essential parts of friendship, there were also moments when too much communication became a problem. During the residential student focus group, the students had the following discussion:

Madelyn: They do not like when I send a good morning, goodnight text. All I'm doing is being really nice to them.

Flynn: It was at ridiculous hours. Who says goodnight at 5 o'clock at night?

Madelyn: I'm not trying to be annoying. I'm just trying to be nice to you guys. See how you're doing. I miss you guys.

Madelyn was referencing a group chat that many of the residential students are part of on a group messaging app. The purpose of the group chat was to keep the residential FutureLIFE students aware of where they could meet for events like dinner and other group activities on campus. It is also a place where students could suggest their own ideas for plans. Madelyn and Flynn's conversation stemmed from an issue that had begun the prior semester. Although Madelyn mentioned her preference for not socializing much, as seen in a previous excerpt, she still cared about the other students. She liked to text them good morning and goodnight texts every day. Not all of the other students enjoyed receiving these daily check-ins from Madelyn. It often caused tension within the group chat, some of which could be seen through the interaction between Madelyn and Flynn during the focus group. So although communication with friends and listening was important to many participants, there were limits to how often everyone thought that should occur.

Characteristics of a Bad Friend. Most participants did not shy away from discussing

the negative aspects of friendship or getting to know people to then realize they were not good friends later. Interestingly, when bad characteristics were mentioned, it was often because a former friend did the "bad" thing, which ruined the friendship.

Dishonesty. Different participants mentioned the characteristic of dishonesty as a sign of being a bad friend. Flynn mentioned a few people with whom he is no longer friends and said, "They have been mean to me and accused me of something that I did not do." This was something that Flynn talked about often, and I was never made aware of the situation (or situations) that Flynn was referencing when talking about being accused of things.

Arthur mentioned honesty during one of our interviews while explaining how they act when making new friends. They said,

Yeah, you can be friends with people you're still getting to know, and I would just say be more careful with that. Because getting to know them doesn't always mean you can see their true colors. So like, if you're friends down the line, and they start being meaner and meaner. Then you got to just be careful on getting to know them because they might also not always be truthful if you're just meeting them.

In this excerpt, Arthur illustrates that friendship grows over time. Whether or not someone is honest is something Arthur finds challenging to discern at the beginning of a friendship. Through these examples, it is clear that honesty is necessary to continuously reflect on throughout a friendship for the participants.

Disrespect. Jerry was another participant who recognized the growing and changing nature of friendship. In his case, though, he looks for how people treat him to decide if they will become or stay his friends. He said,

If they take advantage of me, sorry, you're not going to be my friend. Um, [pause] take

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advantage of me. When I make friends, like, I know it's not going to click right away. But you wait to see if it's, like, going to be good together. And I just say, sorry, it's not gonna work out.

Being taken advantage of or disrespected was not as easily picked up through observations. There were small moments, though, where disrespect was picked up, like when I observed during a FutureLIFE internship seminar. Clark was calling another student a nickname that could have been categorized as disrespectful because the student had told Clark not to use that name previously. In a focus group discussion with Tyler, he gave an example of a time when he felt a friend was not respecting his wishes.

Researcher: Do you ever have issues or problems with your friends?

Tyler: Only sometimes. Like one time, I wanted to sleep. And my friend was in my room. And I told him I really wanted to sleep, and I asked him to leave. But he didn't listen to me and stayed in my room and hung out more.

In this example, Tyler mentioned that his friend, another FutureLIFE student, did not want to leave Tyler's dorm. Instead of listening to Tyler's request for him to leave the room, the other student stayed. His friend's refusal demonstrated disrespect for Tyler's space and time. Disrespect was discussed in different ways by the participants.

Not Making Plans. As mentioned, interaction with another individual is necessary to form a friendship tie (Block, 2015). A few participants discussed the lack of making or sticking to plans as a sign of someone not being a good friend. On this topic, Jerry said,

I've learned that acquaintances are people that are not your real friend… Because you know, you haven't hung out with them in a long time, and they haven't reached out to you. But I get it now. I'm like, yeah, all these people are acquaintances now. So I'll see

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them around campus, and I'll say hello, like, what's up, how was your summer?… I ask

that, but…

Jerry was mainly focused on errors in judgment he had previously made regarding friends

in the past. He highlighted that for him, friends hang out frequently. Other participants also

talked about friends who changed plans at the last minute and how that made them bad friends.

Flynn spoke about how friends do things together, saying, "you can make friends from the

program and outside of the program also. And you can get together. Have brunch, breakfast,

lunch, or dinner. Or do stuff together at night." As Flynn explained, meals were a common place

where I heard about interactions with friends.

A few of the observations that I did were during meals, some with large groups of

FutureLIFE students that were scheduled each week in the campus food court. Another

observation was done with Kent at one of his favorite spots on campus - a different dining hall

inside an academic building. He goes there with his 1:1 mentor in between classes on campus.

On the day I went to observe, Kent's friend, who had graduated from FutureLIFE, came to join.

This friend works on campus and I was told they get together often. When I got to the dining

hall, Kent, his friend, and his mentor, had already eaten. This friend was the other graduated

participant who had consented to participate in this research but never attended the planned focus

group. The group was in the middle of an UNO game when I arrived. This card game, UNO, is

one of Kent's favorite things to do while on campus. I watched them finish that game, and then

they asked me to join the next round. The group told me the game's rules. Kent repeating often

the phrase of "keep the cards clean," because they had just eaten and typically ate while playing

UNO. Kent and his friend told occasional jokes to each other during the game, and the friend

asked me about myself. Together we played a few more games of UNO, and then it was time for

Kent and his mentor to return to class. They talked about when they would get together next and told me I could join them anytime. We all parted ways. It could be seen through the smiles and jokes that the entire group was having a good time. They enjoyed being together and looked forward to doing it again another day. Moments like these exemplified many participants' importance of being around friends and making plans.

Dating and Identity

Throughout the data collection, dating, and romantic relationships were prominent in the participants' lives. Six of the 16 participants disclosed that they were in dating relationships throughout the study. Dating meant different things to different participants. Some of these relationships lasted only days, while others had been going on for years. These relationships included ones with other study participants and other individuals affiliated with the FutureLIFE program who were not participants. None of the romantic relationships disclosed to me were with individuals not affiliated with the FutureLIFE program. However, I am aware of other FutureLIFE students' relationships with outside individuals. During the observations, I witnessed some of these romantic relationships in action, such as kissing in the dining hall, sitting on their partner's lap at an event, and using spoken language that signified closeness of the relationship, like "babe." On a few occasions, I also witnessed platonic friends doing actions akin to romantic relationships, such as kissing.

For individuals who were not in relationships throughout the study, a few mentioned the desire to be in a relationship. This was something mentioned by participants as well as other students who were present throughout different observations. During one observation, a student was lamenting that "everyone else is in a relationship, so I feel like I have to." In another example, Clark chose to add another FutureLIFE student to the intimate circle of his social circle

diagram, declaring that he was "working on it," implying that he hoped for a relationship to begin with this person. Poppy often spoke about a new student she had quickly fallen for because of his physical characteristics and personality being similar to hers. Tyler discussed some difficulty that he had had socializing with females, saying,

> It's easy with the guys, but with girls it's really hard for me. Girls are really nice, but I don't know what to do. That is really hard for me. But overall, I don't care if they have disabilities or not.

Tyler was illustrating through this quote that he thinks he has trouble in some social situations, primarily related to the opposite sex.

Participants discussed previous relationships and how they dealt with losing them and starting new ones. In one interview, the prospect of a new relationship became the entire focus of the discussion for the participant. In other observational data, participants noted their crushes on staff members and how they were unsure how to act. From this data, I understood that dating and romantic relationships were critical to FutureLIFE students and something they devote significant time and thought towards.

From the information I learned during the interviews and saw during the observations, I learned that "dating" means different things to each participant. In the case of Jerry and his girlfriend,

> I do a lot with her. Like go to dinner, she cooks for me at her apartment, we hang out... we listen to music, watch TV, play video games, talk, all the usual stuff a girlfriend would do.

Jerry and his girlfriend see each other often and do many activities together. With Poppy and her hope for a new romance, she talked about her feelings on dating in college and how she

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was moving on from her previous boyfriend.

Poppy: I'm done with him [previous boyfriend]. Now with Knox. [laughing]

Researcher: Oh, ok, but they're [Poppy's parents] not gonna let you date Knox?

Poppy: Um, well, I don't know. Well, we'll give it a try. If that wasn't us, that's fine.

Researcher: Okay. Is that something that is important to you? To be dating someone?

Poppy: Yes. Yeah.

Researcher: Why is that important?

Poppy: Because I'm in college. Like, I learn stuff in the class. I do a lot of homework, and I can see Knox once a month or something like that. Like, I need that.

Poppy has Down syndrome and mentioned in the same interview that "they [her parents] never let me… they do not let me date Knox." Parental permission to date seems intrusive, especially considering that Poppy lives in a dorm on campus. This example with Poppy illustrates that she finds importance in dating as well as other aspects of college life, like academics. Poppy only desires to see a significant other once a month. This differs from Jerry, who discussed seeing his girlfriend often and doing many activities with her. I believe this distinction between dating experiences demonstrates the potential ramifications of k-12 inclusivity differences and societal expectations that have been impressed upon individuals over time. Ableism, especially towards those with a visible intellectual disability like Down syndrome, elicits lower expectations for what dating entails and who can consent to date. Health and relationship education in k-12 is often not required or offered for students with IDD, causing this variance in experiences.

Talking about Sex

Not all participants agree on how someone should talk and act around other people they

potentially want to be in a relationship with or want to be romantically involved with. Flynn and

Clark both were especially concerned about how some individuals acted provocatively at

college. Flynn specifically blamed another student's "inappropriate behavior" on the fact that

they learned about sex in one of the FutureLIFE seminars[24]. Instances of this behavior were

mentioned numerous times.

The seminar mentioned specifically by Flynn as a cause of inappropriate behavior was

one in which students learned health topics that many non-disabled students learn in high school,

such as relationships, pregnancy, STDs, and condoms, for example. Although all the actual

relationships in the data were with other current or former FutureLIFE students, some of the

"inappropriate" moments that Clark and Flynn were worried about included matriculated

students and a FutureLIFE student. In one instance, Flynn described his friend harassing a

lifeguard at the Imagine University pool, constantly asking her if she was single. Flynn stated,

"One of my best friends, and he's a guy. And he is taking advantage of it… He's been in [health

seminar] for like, two years now. And he's taking advantage of with, the whole sex thing." When

I asked him to expand on this, he said,

> "... I think it's like sex songs. And his parents told him to stop, and I've been telling him
>
> to stop… now there's a bunch of people just telling him to stop, but he keeps doing it.
>
> And he's also saying girls are hot, sexy, and cute. But all of us told him to stop, but he's
>
> not stopping."

Flynn was the only participant who brought up the topic of sex explicitly during any of

the interviews and observations. He mentioned how he thought parents should be the ones

---

[24] All Imagine University students can take seminars about sports, advocacy, relationships, and other health topics through the FutureLIFE program. The content of the seminars shifts each semester depending on FutureLIFE student desire, but some are held repeatedly.

teaching about sex. Interestingly though, when asked if he learned about sex before college, Flynn mentioned, "No, I did not. I didn't learn about sex until I got to college. And my parents was preventing me to know about it, and they didn't want me to know about sex." Flynn also mentioned when his parents found a condom he had received from the seminar course and how they laughed at the discovery. I asked Flynn to tell me more about that experience.

Researcher: Right. How did that make you feel that they were laughing?

Flynn: Oh, I felt. I didn't mind.

Researcher: Were they laughing? Just like, why do you think they were laughing?

Flynn: Because I had told mom and dad. I took a seminar called [health seminar]. And they talked about sex.

Researcher: Yeah. Do they not think you ever will do that?

Flynn: No.

Researcher: Do you think that's why they were laughing?

Flynn: Yeah, I think, I don't know.

This discussion with Flynn demonstrates how ableism, especially related to relationships and sex, has impacted him. His parents dismissed Flynn's competence to make choices about his body and infantilized him by laughing at the possibility of him thinking about or having sex, and Flynn exclaimed that he did not mind that they laughed. This nonchalant attitude about his parents' actions demonstrates how ingrained his parents' attitude is within society. Flynn's experience and understanding of sex is one that many disabled individuals have dealt with, especially those who have been termed as having "moderate to profound ID" (Barnard-Brak et al., 2014).

Other Important Relationships for FutureLIFE Students

The participants in this study discussed relationships that ranged from acquaintance to intimate, all of which included disabled and non-disabled individuals at Imagine University. Interactions with these folks often happened throughout the data. There were some important findings related to these other relationships.

Networking Through Relationships

The idea of helping and reciprocity was crucial to more fully understanding the dynamics of the students' relationships and interactions. I often memoed how many relationships the participants had, especially with non-disabled individuals, revolved around the idea that they might need something later. This was especially true when thinking about future jobs. Numerous participants talked about how these casual and close friends that they have now will eventually be able to help them find a job.

Jerry and Naranj both spoke about their professors as members of their networking circles. Jerry mentioned that "I'll probably become close with my PR professor. Because he wants to become closer to everyone in the class. But that's what professors want; professors want to help people get a job." Naranj stays in touch with his former professors and often mentions texting and emailing them. He said, "To be honest with you, I still talk to my professors on the phone. And every time I send an audio message, they say, 'I'm so happy to hear from you.'" Arthur spoke about professors briefly, stating, "I'm more social with the professors than I am with the students." After discovering this during our interviews, Debbie also joked about not realizing she and her former professor shared a love for dance. Chadwick also mentioned how his connection to his teachers was strong.

Jake [Chadwick's support staff]: Write the name of a friend.

Chadwick: [turns back to the whiteboard and starts writing FRIEND]

Researcher: So now write the name of a few of them. Who's a friend here?

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Chadwick: Teacher

Overall, the participants positively interacted with the faculty and professors and enjoyed learning more about them. They wanted to keep connections with those instructors after completing the class. Any difference in how the faculty-student relationship shifted during and after a semester was not explicitly mentioned by any participants. The positive connections the participants in these examples had with faculty and instructors implied that they wanted sustained relationships after classes ended and that many of them had sustained relationships with their former professors.

Support Staff Interactions

Debbie, Kent, and Chadwick all had support individuals in some or all of their interviews and observations. I allowed them to decide if they wanted support during the interviews. During interviews and observations, I noted how the support individuals interacted with the participant and how they may have impacted their social interactions. Considering reciprocity, the support staff are there to support the FutureLIFE student. Even so, it is connected because how the participant responds to the support staff demonstrates if there is any level of reciprocity in their relationship. Specific codes acknowledged the mentor support during data collection, ANSWERING FOR/SPEAKING FOR, CONTRADICTING, HELPING-PHYSICAL, PARTICIPANT RELIANCE ON SUPPORT, PRAISING AND CONFIRMING, AND PROMPTING. Each of these codes was used to analyze any data collected on participants who typically have 1:1 support with them; Debbie, Chadwick, and Kent. I found it especially interesting to see the frequency of participant reliance on the support person. This was often denoted by looking at the support when asked a question. Only a few times throughout the interviews did the support speak for the participant without the participant showing some desire for support. Several factors, including confusion, learned helplessness, and curiosity about the

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support's response, may have been at play in those moments. In some instances where there was a contradiction between the participant and the support, there was an added piece of the participant desiring humor by not telling the truth. This was notated by mischievous laughter after stating something incorrect, such as if they were the oldest sibling but said they were the youngest. In these three cases, the support person was always listed as part of one of the inner circles on the social circle diagram or someone with whom the participant spends much time.

There was one instance where reciprocity was lacking in the relationship between the participant and the support staff. During an observation of Kent's class everyone was put into groups to discuss the playlists former politicians used while running for office. The moment Kent's group got together, his mentor, from an outside agency, exclaimed to the members, "My name is Laura, and this is Kent. We are just here to listen." Kent did not look pleased with that announcement and eventually talked to the group anyway. But only a few quiet words. I later talked with Kent in an interview about his preference during class. Kent adamantly said that if he were given a choice to "listen or participate," he would choose "participate." Kent has tendencies with his speech that are common for some autistic individuals; echolalia, hyperfocus, and minimal words, but does speak. In observations where Kent was with people he seemed comfortable with, he spoke more. Kent's preference for class participation differs from how his mentor wanted him to act. Because the mentor put her view out to the group, that was how the entire group was instructed to view Kent. This illustrates the importance of having supports who listen to and understand the preferences of the student they are working with. By not doing that, Kent's support led to him being seen as an outsider in his class, furthering the ableism and stigma he is up against.

Classmates

An important finding from this research was that many participants did not claim friendship or closeness to the other students in their inclusive Imagine University courses[25]. There were multiple examples of how different participants talked about peers in their classes. Some said they do not engage with the people in their classes. For example, when asked if he talks with people in his classes, Flynn said, "I have not." Clark directed his lack of connection with classmates toward his focus on the courses themselves. He said, "I just say I'm quiet during classes; I just like to focus on lectures and write down the notes." Some participants only mentioned talking with other classmates about course materials. Kent said, "Talk to them about the class. Because we're in the same class." Poppy thought of classmates more as people who could potentially help her with course material, saying, "Talk about homework, subjects, like, 'I need help with that,' like modified things." In the instances of Jerry, Arthur, and Faith, there were clear lines that classmates would not cross in terms of friendship, specifically on the social circle diagrams. Naming classmates as acquaintances or, as Arthur did, separating her friends from her classmates.

> I have close and casual friends. It's with; they're not in my classes cuz, ya know, they're either, they're the same uh. Junior year I believe. One's… a senior now, but, um. They're, they're not in. Clark, I think he said he was like a history or something major. [not the same major as Arthur and not in the same classes]

These different excerpts show that many FutureLIFE students have similar experiences regarding social interactions during Imagine University classes. The participants did not mention these thoughts negatively but as facts of their experiences. The participants mainly consider

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[25] All FutureLIFE students take Imagine University courses as part of their program. They choose a major of interest and take courses typically both within that major and outside of the major, just as matriculated students do. Typically FutureLIFE students are auditing courses.

classmates to be acquaintances rather than friends. Although they have majors through which they are taking courses, they are not interacting with others from their major similarly to their matriculated peers.

This chapter has shown findings from this study related to how individuals with IDD are experiencing social interaction with other individuals on campus. Many more interactions could have been spoken about here. However, they all encompass the same ideas: students with IDD desire to form connections with other individuals just like non-disabled individuals. The examples I have given demonstrate how the stakeholders within and surrounding IPSE programs facilitate and impede success with social interactions. Events and activities that participants attended were designed and created by these stakeholders. In that way, the stakeholders facilitated access to social interaction for IPSE students. In other ways, though, these interactions were only sometimes created with students with IDD in mind; therefore, some aspects of these activities impede access to social interaction. As DSE acknowledges, there is importance in privileging the interests of disabled people. This is true in planning and facilitating events and activities on college campuses, including courses, internships, and social events. Some causes of impeded access have been mentioned in Chapters 4 and 5. These include a lack of intentional grouping in classes, parental directives towards IPSE students related to dating and relationships, and support person interference while on campus. These all have impeded the access and success of participants' social interactions.

Chapter 6: Discovering My Role: Reflections and Discussions of Inclusive Methods

"Are you observing?" – Faith

The previous two chapters have discussed the findings from this work related to IPSE students and their experiences while in IPSE programs. As data was being collected and analyzed, it became apparent that themes were developing related to the social interactions that occur while researching with individuals with IDD. This chapter will explain those methodological findings as they relate to doing research with individuals with IDD.

Researchers have cited the importance of inclusivity, reciprocity, and transparency when doing research with disabled individuals (Seale et al., 2019). Reciprocity during research is one way of ensuring the ordinary of a disabled individual's narrative has the impact they might hope in changing attitudes or transforming systems. Transparency brings the great responsibility to make sure the meaning something has on paper is the same as what the individuals were expecting. There are a few ways transparency can be put in place. In displaying any narrative the participant has brought in (through an interview, observation transcript, etc.), there should be "minimal editing," and as much as possible, their words should be kept in a broader context (Seale et al., 2019). It also needs to be clear in research who is saying or doing what. In some former research, it has seemed like researchers were being dishonest about their roles. To combat this, some researchers have narrated how the projects came to be and how the co-researchers took part (Chapman & McNulty, 2004; Seale et al., 2019).

Similarly, this chapter will explain the transformation of this research project and how the participants impacted what it became, although they were not considered co-researchers for this work. The role of the participants was important because this study was inclusively designed. I will discuss the methodological findings which show the importance of doing

flexible yet consistent qualitative research inclusively with individuals with IDD. In addition, I

have significantly reflected on my impact on the research and its findings within this chapter.

Flexibility and Consistency with Participants with IDD

This study was done with inclusive qualitative research methods. Although there is

research on inclusive research methods, as mentioned in Chapter 3, following through with the

initial research design plan and theoretical intent could only be done with flexibility from myself

and the research participants. The aspects of this study that were most frequently changing

throughout the data collection were the number of data collection events and the interviewing

procedures. As mentioned in Chapter 3, memos were taken throughout this study, and analysis of

that data was a significant factor in realizing these findings.

Quantity of Data Collection Experiences

Getting to the point of "saturation" has been previously mentioned in discussions of

determining when your data collection is complete (Glaser & Strauss, 1967). Nevertheless, how

does one recognize when that point is met? This was an aspect of this research that was often on

my mind. The desired quantity of data collection moments evolved considerably from the design

phase to implementation, the cause of which was two-fold, allowing for participant autonomy

and recognizing the depth of analysis. How I organized my data collection schedule also

impacted how I met a level of consistency with data collection, which allowed me to reach the

eventual close of data collection.

Reflecting on the memos analyzed in this study, I recognized that a significant stressor

within this work was the timeline and working within the participants' schedules. I acted in

specific ways to react and deal with those stressors. The impact of these actions is most explicitly

shown through the adaptations made to the timeline and quantities of data collection throughout

this work. As seen in Tables 5 and 6, there were changes to the timeline.

Table 5.

Initial Data Collection Timeline from Proposal

Phase 1	Phase 2	Phase 3	Phase 4
● Consent Meetings ● Focus Group	● Pre-Observation Interview ● 2 Observations ● Post-Observation Interview	● 2 Observations ● Post-Observation Interview	● 2 Observations ● Post-Observation Interview ● Focus Group

Table 6.

Changes to Data Collection Timeline

Phase 1	Phase 2	~~Phase 3~~	Phase 4 3
● Consent Meetings ● ~~Focus Group~~	● Pre-Observation Interview ● 2 Observations ● Post-Observation Interview ● Focus Group	● ~~2 Observations~~ ● ~~Post-Observation Interview~~	● 2 Observations ● Post-Observation Interview ● ~~Focus Group~~

In all, there were 48 observations completed across the ten core participants. All but one

of these participants had me observe at least four times. Figure 3 shows how often each

participant had me complete a participant observation. Although I initially had a goal of 60

participant observations, I surpassed my amended goal of 40. Figure 4 shows the breakdown of

how many interviews I had with each participant. Although the original goal was 40 interviews,

my amended goal of 30 interviews was almost met, with a total of 26. These reductions were

necessary to keep this work inclusive, with the participants leading the way.

Figure 3.

Participant Observation Quantity

Number of Participant Observations
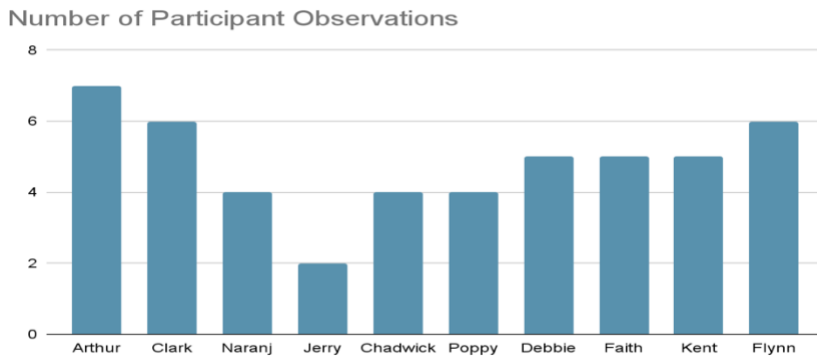
Figure 4.

Participant Interviews Quantity

Number of Participant Interviews
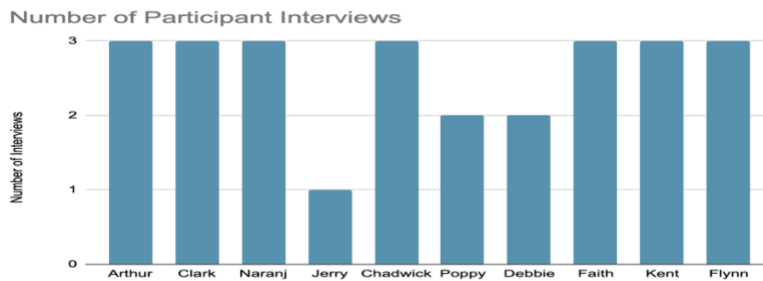
The participant observation goal was constantly re-evaluated throughout the data collection procedures. It was decided to reduce the goal towards the end of December after approximately 15 observations had been completed. The significant factors in reducing the goal and determining if I had enough data were participant autonomy and data depth.

Participant Autonomy. Research has noted that defining and pursuing autonomy can be difficult, especially for individuals with IDD. "For people with intellectual disability, [autonomy] might mean that they lead lives that are consistent with their needs and desires so that their lives reflect what is important to them" (Petner-Arrey & Copeland, 2014, p. 39). I kept this definition in mind while continually reflecting on the research and participants' responsiveness to participate. Pursuing this research line was taking up time in the participants'

lives. Consent to participate, as explained previously, was a constant conversation. It did not end after the initial consent meeting. The participants had their own goals they were trying to accomplish throughout the semester I was doing this research, like looking for new jobs, pursuing new romantic partners, learning new skills, completing coursework, and many other things. There were needs and desires encapsulated within those goals that I had to recognize would take up their time and inhibit their availability for interviews and observations. Many of the participants did seem excited about the research from the beginning. In one early memo from July 10th, 2022, I wrote,

> I am feeling very lucky that this group of students has so far been so willing and excited to do this research. A few of them, Clark, Arthur, and Naranj already thought a lot about where I could observe them. Their trust in me is amazing, but also scary.

This memo was written after only the consent meeting had taken place with those three participants. Initial excitement about participation in this study was sustained throughout the study for these participants. They consistently reminded me when we would meet and would send weekly texts with lists of possible events I could join. Not all participants showed as much initiative related to our interview times and the scheduling of observations. For example, Jerry, who had only one interview and two participant observations, was often unavailable to meet. Communication with Jerry was sometimes tricky as he did not respond when I reached out. Even so, he demonstrated a willingness to participate on his own terms. Communication with Jerry was also done mainly through email and text messages, as seen in Figure 5. Jerry felt comfortable asking to change the time of our initial interview and wanted to ensure he was prepared. However, after our initial interview, communication could have been more consistent.

Utilizing numerous communication forms resulted in one interview with Jerry and two observations.

Figure 5.

Communication with Jerry
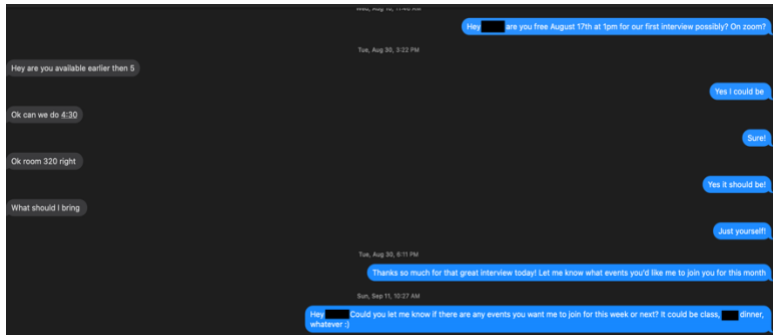
Taylor and Bogdan (1998) discuss five guidelines for establishing rapport with participants in qualitative research. These include paying homage to their routines (doing what the participants do), establishing what you have in common with people (communicating with them), helping people out (recognizing if they have a need you can provide), being humble (try not to challenge participants on their beliefs and keep knowledge gained to yourself), and acting interested (care about what your participants say). One way that I implemented the guideline of "paying homage to their routines" was by asking participants the best methods for communicating with them. I purposefully used that preference throughout the study but continued sending emails (which were not always the preferred method), so there was consistency. With some participants, reminders helped us complete the desired observations and interviews. A memo I wrote during data collection illustrates this decision to give reminders to some of the participants.

> I had been having trouble getting observations set up with Poppy, so I reminded her a
> few times about this event. She had said she was going, and she did end up going. I

was nervous that she would not show up, though.

In this example, Poppy had yet to follow through on making plans for observations. I reminded her more often about things I could observe with her. Once we made a plan, I reminded her of our plan in the days leading up to the observation. With those reminders, I gathered greater knowledge of Poppy's experiences. Although all the participants had consented to participate in the research, they had a say about how much they did. Throughout the study, I reminded the participants of the voluntary nature of the study and its purpose. I also explained any changes I made regarding the study design, like reducing interviews and the number of observations. I did not force any interviews or observations to happen. As Taylor and Bogdan (1998) have said, "In most instances researchers should spend at least several months in a setting regardless of the frequency of their visits" (p. 79). After consent was given, I spent five months in the "field," doing interviews, focus groups, and participant observations. In those months, as I have stated, the participants led me and the research to the topics and events they wanted. They thought methodically about how I could see different events, one explicitly refusing to let me see the same setting twice. In deciding not to extend the study longer than five months, I thought deeply about the depth necessary to develop findings related to my research question.

Depth. The depth of data and how much needed to be gathered is discussed extensively by Taylor and Bogdan (1998), guiding qualitative researchers to recognize that it is challenging to know how much data you will need until you are amidst data collection. This was true in this study as well. I had initial estimates, mentioned previously, of how much data would be necessary. I utilized previous research as a guide, knowing I would want to triangulate data between focus groups, interviews, and participant observations, to collect thick descriptions of participants' social lives during their time at an IPSE. As Glaser and Strauss (1967) have

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discussed, "The theory that emerges from the researcher's collection and analysis of qualitative

data is in one sense equivalent to what he *knows systematically* about his own data" (p. 225).

Recognizing this, I had to systematically think about the data I had already collected at different

points during the study. I knew what data I had by transcribing, re-reading, and coding

iteratively during the five months. I also knew what data was missing. Some of this missing data

were very surface level, like in the example in Figure 6 where I realized I did not ask where

Arthur's off-campus job was.

Figure 6.

Questions to Ask Arthur Next

Other times I noted more profound ideas that I wanted to ask participants about later. For

example, Clark had questions while reviewing the Social Circle Diagram (Figure 7). This, in

addition to responses from other participants about the Social Circle Diagram, led me to a memo

about questioning the diagram with participants in the future.

Figure 7.

Questioning the Social Circle Diagram

R - Okay.

Clark - And can I? Is there anything else besides that. Or is that it?

Researcher - Well, if there's something that you'd like to add, we can make another ring if you want.

Clark - Can I see the top for a minute. So, I could check something?

Commented [KD4]: Maybe in a later interview ask them to change the diagram to fit their life.

I continued to think about what information was already gathered from the participants and what more was needed until I thought I was near the point of "saturation," the point when similar topics are addressed repeatedly by participants, to the point that the data on its own begins to lose value (Glaser & Strauss, 1967; Taylor & Bogdan, 1998). I was looking towards reaching this point related to specific students and the group of participants. In memoing about data missing related to specific students, I noted

It seems that Clark is given opportunities and chooses to take them. Not seeming to question them much. Things like being a peer employee and doing the Special Olympics. I might try to learn more about this. What is he working towards? What are his goals after? Especially since he's a senior, I'm curious how that will play into things.

Learning more about the different participants' goals would help me understand if their social interactions during college were related to those goals. Many of the themes discussed in Chapters 4 and 5 were starting to become repeatedly found during my repeated readings and coding. I noted this group consensus during another memo about class friends, mentioning that,

In almost all of the interviews, it has been mentioned that the IPSE students do not interact with matriculated students very much. In some cases, there is no interaction at all (I.e. no discussions during class, mostly lecture-based, occasional "hi").

I kept track of these topics that were coming up often throughout the iterative processes

of interviewing, observing, transcribing, and coding. As Taylor and Bogdan (1998) have said,

> *The researcher is interested in understanding a broad range of settings or people.* In qualitative research, an "N of 1" can be just as illuminating as a large sample (and very often more so). However, there are instances in which the researcher may want to sacrifice the depth of understanding that comes with focusing intensively on a single setting or person for the breadth that comes with studying a range of places and people. (p. 91).

Within this research, gathering data in a wide range of places and settings was essential. To do this, I initially explained the importance of this to the core participants during consent meetings and interviews when we were discussing where the participant observations would be. As can be seen from Figure 8, there were some aspects of campus life that I could observe more often than others. Any events at which time was split amongst different core participants were only counted once for this diagram. All the events that were split up were in the categories of FutureLIFE Social Activity/ Group Dinner and University Activity/ Sports. I observed social event settings more often than in campus clubs, organizations, and religious events.

Figure 8.

Breakdown of Participant Observation Settings
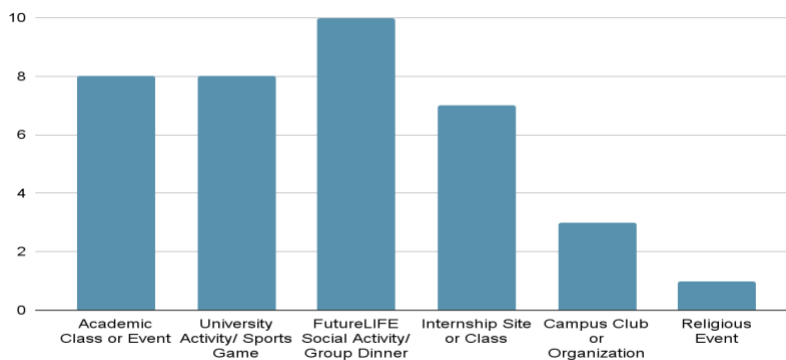
Through conversations with the core participants and brainstorming about their specific

interests, I was able to choose the best options for observations. Some participants went to almost all University Activities and FutureLIFE Social Activities and would only suggest those social events and activities for observations. With my encouragement to think about letting me come to other aspects of their life, I was invited to other events, as seen in Figure 9.

Figure 9

Clark Internship Observation Plan
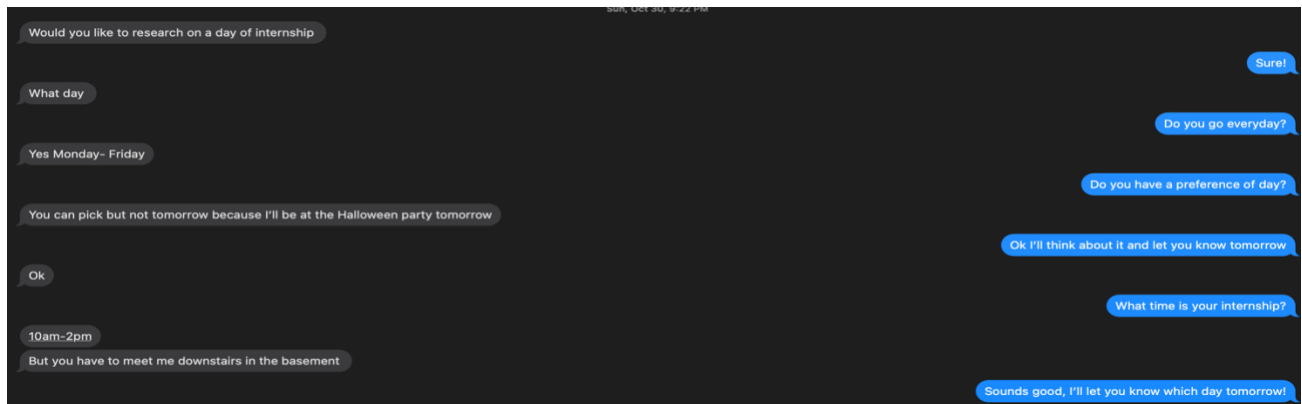
With Clark, for example, I was initially only invited to FutureLIFE and University Social events. In our first interview, he clarified that I was going to the social events because he sent me the entire calendar for the semester, saying, "by the way, did you get the [event] schedule I sent you?" However, towards the end of October, he decided to have me join his internship. Throughout the research, I reminded him and the other core participants that I could observe things like "classes, internships, jobs, and club meetings." Although I gave the participants a choice, reminding them that there were different options helped increase the variety of observation types.

I would have still liked to have more observations done at club/organization meetings and religious organizations, but there was no opportunity. Faith and Naranj were the only participants who mentioned any religious connections on campus, for example. Although I was scheduled to attend a few religious services with Faith, they have yet to happen. Two of these cancellations

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are shown in Figure 10, on the left when the group leader was sick and on the right when I had a family emergency.

Figure 10.

No Bible Study Again
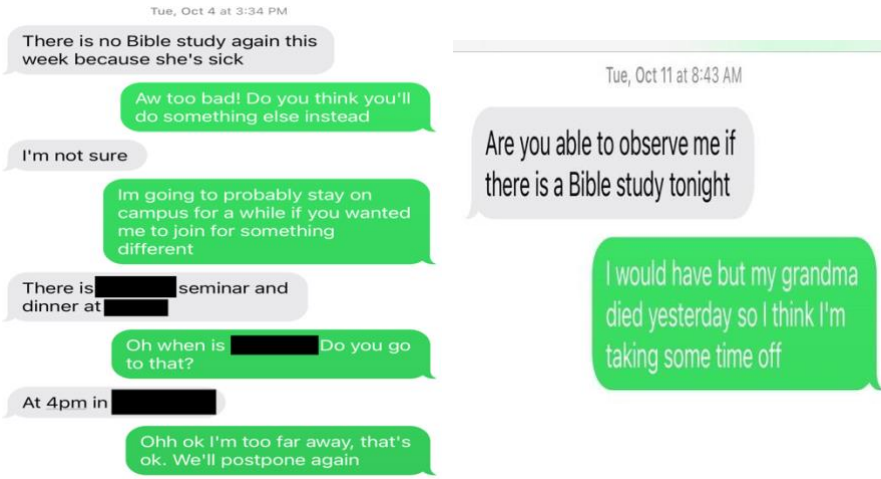
The first time bible study was canceled, we went to a FutureLIFE game night instead. The second and third times, we canceled the observation altogether. Although there were still areas where I only had a few observations, the ones I did have had a good enough amount of detail and information about the experience of those specific students. There did not need to be additional observations done after mid-December. As Holloway and Brown (2012) have said, "At some stage, of course, you need to stop collecting data and to consolidate or collate your existing data" (p. 107). Mid-November was when I began determining if I had enough information to work with across the existing data because the original end date of the research was the end of the Fall semester, in mid-December. Looking at the preliminary codes up to that mid-November point and the iteration of Figure 3 that was completed at that earlier point in time, I knew that I could be finished with a few more observations.

Organization for Consistency. One of the most valuable ways I could keep track of the observations and interviews completed was through a Trello board explicitly created for this

project. Part of this board can be seen in Figure 11.

Figure 11.

Trello Board of Data Collection
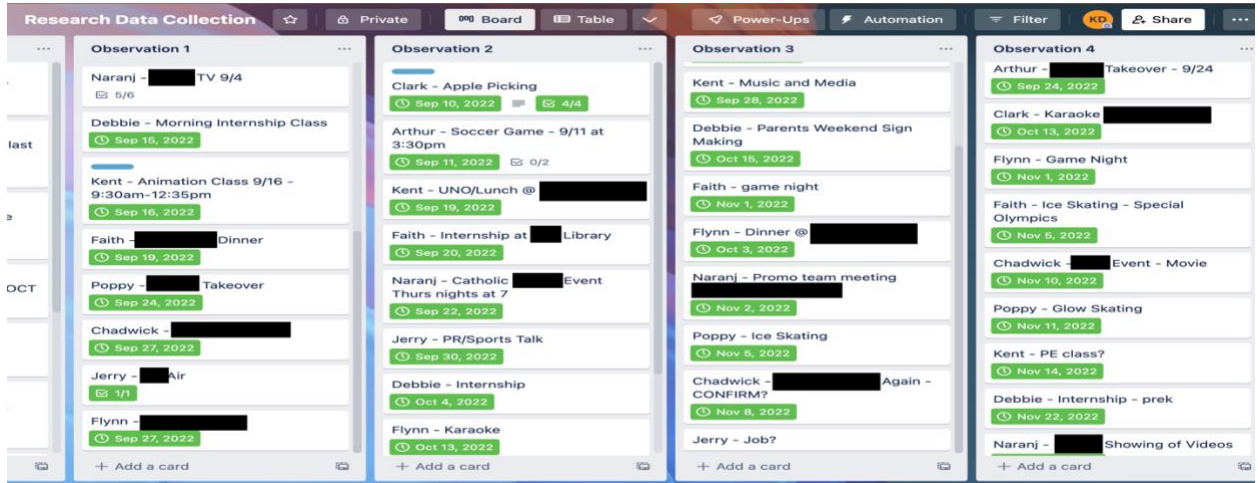
I checked this board almost daily and kept myself consistent by each weekend, double-

checking everything that had happened that week. Typically, I would regroup on Saturdays by

looking through all the communication I had with different participants that week and contacted

them again if I had not heard back in the last few days. I would reach out to confirm any

upcoming observations or interviews for next week. This constant checking of who I had been in

contact with and how many observations allowed me to stay in the moment when I was with the

participants. I did not need to worry about forgetting something that was supposed to happen

later because it was all on the Trello board. In the memo shared previously about reminding

Poppy of our events, I noted how I was worried she would not show up. Missing events often

would have been detrimental to the cyclical iterative process of the methods in this study.

Communicating often and clearly with the participants was essential in getting to the

quantity of data collection that I was able to get to. The Trello app and desktop platform are also

connected to my Outlook calendar, so any observation or interview was also found there and sent

me reminders. Although a seemingly small logistical decision, I could not have completed this work without using this tool.

Universally Designed Interviews

One of my favorite things about this research design was using and transforming interviews throughout the study. The core group of ten participants had at least one interview, some had two, and seven had three interviews. The second and third interviews were confirmatory of previous interviews and more in-depth than the first pre-interview. As I got to know the participants better, I could tailor my questions to our experiences and previous conversations.

Question Design. Determining the best way to ask questions and support qualitative research participants with IDD was a significant aspect of this work. As Wilkinson et al. (2015) have discussed regarding the questions they asked participants,

> …a complex issue was the need to balance the open questions necessary to allow participants to relate their own experiences, with the need to support participants with ID [Intellectual Disability] to understand and answer questions by using concrete concepts, examples, and fixed choice questions. A compromise was reached by using broad questions followed by successive prompts where necessary; however, this balance may not have always been met" (p. 103).

I also used this strategy during my interviews with the core participants and focus groups. Even though I was taught in qualitative methods courses to ask open-ended questions primarily, I believe and have recognized through this study that these rules must be flexible when working with individuals with IDD. The purpose of interviewing throughout this study was to gain insight into the experiences of people with IDD throughout college. Sometimes, the best

way to gain such insight was to reduce the cognitive load using a forced choice paradigm. Bains and Turnbull discussed using this tool during their research with individuals with ID (2021). The art of prompting and giving choices was necessary to dive deeper into some of the participants' discussions and was valuable in my skill set as a researcher. Deciding which choices to give depended on the student and the question I wanted to be answered.

An example was during the final interviews with participants when I wanted to discuss what was important to them during college. Based on the previously discussed topics, I already had ideas, but I wondered how they would choose the "most important" aspect of college. Although I could have asked, "What is the most important part of college and why?" I asked, "What is the most important part of college: Academics, Social Life, Jobs, or Something Else?" Then after they chose an answer, I asked for specific reasons why. Breaking down the question in this way made it more accessible to the participants in this study and ensured that they understood the question I was asking. Although I did break down questions into choices, I also paid attention to the time I gave the participants to think about the questions.

Through the experience of these interviews, I could see how my previous life experiences in teaching and other work with individuals with disabilities set me up for success with this method. I strongly use "wait time" and listening in this research. There were many examples during the interviews where there were pauses. I also gave participants the central questions at least a few hours before the interview, and these actions made the participants more comfortable with the interview experience. I also used these strategies during focus groups. I would wait for participants to think about their answers and prompt them to communicate with one another based on my knowledge about the participants.

Researcher: Okay, awesome. Does anyone want to talk about a different place on campus

that they felt comfortable. Or do we want to move to feeling uncomfortable?

Rosalie: Mmmm

Clover: Uncomfortable.

Researcher: Okay. All right. So, can you think of a place that was like the opposite. A

place where you did not feel comfortable on campus?

Shirley: Ugh, I feel uncomfortable about the [sports facility] because it's very loud.

Researcher: Rosalie, you can respond to that.

Rosalie: Um, really loud. I'm not comfortable with loud noises.

Researcher: So you agree with Shirley?

Rosalie: Yes.

In this example, Rosalie had earlier mentioned her dislike of loud noises and going to the

loud sports facility. When Shirley brought this topic up again, I found agreement among the two

participants concerning campus spaces of comfort and discomfort. Similar to what Taylor and

Bogdan (1998) have said, adapting interview questions led to answers when the more complex or

unfamiliar open-ended questions were causing frustration or confusion. This was one reason the

iterative process of interviews and observations was crucial.

Additional Materials and Supports. Another factor in customizing the interview to the

participant was the supports that would make the interviews accessible to the participants. These

supports included fidgets, other staff, and alternative methods of communication.

Fidgets. As was already mentioned, I provided interview questions ahead of time, and I

also provided fidgets for the in-person interviews. I memoed about this choice when discussing

my first interview with Kent. "This was the second in-person interview, but the first one where I

chose to put out fidgets. I thought that was actually a good move. He ended up using them throughout." After using them during this first interview, I put out fidgets for all in-person interviews. Many of the students did utilize them throughout the interviews.

       Other Staff and Breaks. Three of the sixteen participants wanted their mentor and/or interpreter in the room during the interviews, and one requested a break. These aspects of the interviewing process added complexity to the data in that social interactions were happening during the observations and the interviews. I will speak more about the impact of these individuals throughout this chapter. However, overall, their presence impacted the depth of information I could gather because they had a broad knowledge base about the participants that was greater than mine.

       Alternative Methods of Communication. After contemplating the success and missteps of the first few interviews with many participants, I implemented options for alternative methods of demonstrating knowledge. With Chadwick specifically, I noticed a need for different ways to have him communicate his thoughts. To facilitate this more, I brought paper and markers into the interviews. In some settings, I could also utilize a whiteboard and whiteboard markers to facilitate communication during interviews better. As part of the pre-interview, there was already a visual aspect of the social circle diagram. Figure 12 shows the initial use of the social circle diagram during a zoom pre-interview with Chadwick.

Figure 12.

Social Circle Diagram with Chadwick
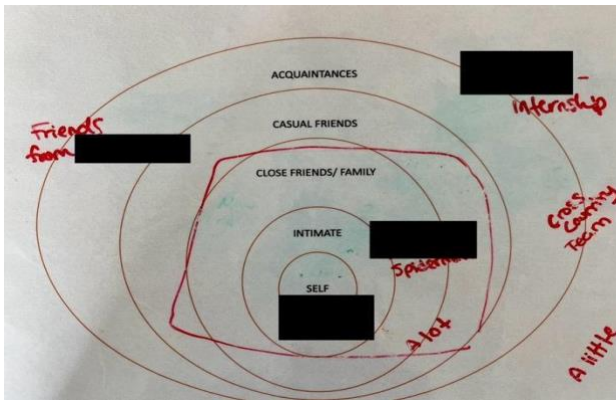
As can be seen, the diagram had to be modified in the context of Chadwick's zoom pre-interview. After some difficulty getting information to fill in the diagram, it became more apparent that Chadwick could better discuss whom he sees a lot and a little rather than the five separate categories. I drew a square in the middle of the diagram and then wrote "a lot" inside that square. Anyone outside of that square was categorized as "a little." Because this pre-interview was done through zoom, I would show the diagram to him through the screen as I drew on it. Zoom was not the best means for this type of communication, so I ensured that the rest of my interviews with Chadwick were done in person. Although this diagram and its discussions were helpful for this work, I needed to expand on the usefulness of visuals in future interviews. Figure 13 shows the drawings and writings that Chadwick completed during our following interview, an in-person interview where I brought in supplies to write on the whiteboard.

Figure 13.

Interview 2 with Chadwick
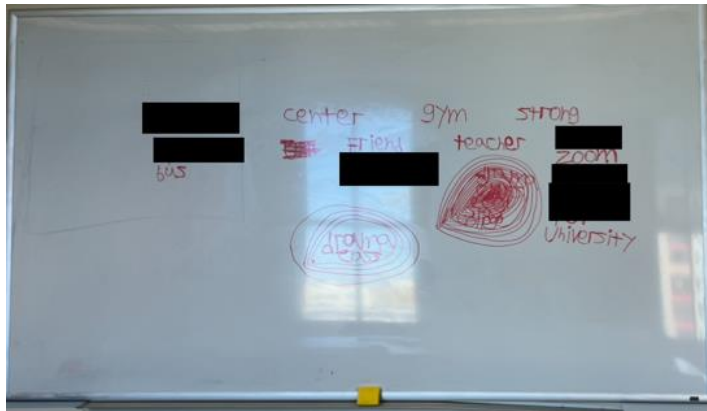
Chadwick was directed to use the whiteboard only if he wanted to. At first, he was answering questions by writing down his answers. Later he chose to draw what his answers were, which can be seen in the circles towards the bottom middle of Figure 13. Jake, the mentor who works with Chadwick, also helped facilitate this moment. The conversation was had while the circles were drawn as follows.

> Researcher: So, what do you like here? Do you want to, Chadwick, do you want to draw me what you like about college?
>
> Chadwick: Yes.
>
> Researcher: Ok, you can use all the colors if you want. Or just red. Draw me what you like about the university or college.
>
> Chadwick: Draw me.
>
> Researcher: Yeah, can you draw a picture?
>
> Chadwick: picture
>
> Researcher: Of what you like. You can draw it underneath, or you can go somewhere else on the board.
>
> Jake: You can use this area here [Jake pointing his hand toward an open area on the board] …

Chadwick: [drawing on the board in the open spot.]

Jake: Good job, Chadwick. What is that?

Chadwick: Draw me?

Researcher: What is that?...

Jake: Oh, what is that though? What did you draw?

Chadwick: Draw.

Jake: What is it? Does it have a name?

Chadwick: Name?

Researcher: Yeah. What do you call that?

Chadwick: Jake.

Researcher: You call that Jake?...

Chadwick: [pointing in the circles he drew on the board]

Researcher: Is that where Jake goes? Are you thinking about like the diagram we looked

at last time?

Chadwick: We, Yes.

R: Yeah. Oh, awesome. And Jake? Where does he go?

Chadwick: Yes.

Researcher: Where would you put him on there?

Chadwick: Drama.

Researcher: Drama. That's your class, right? So you really like Jake and drama class?

Chadwick: Drama.

Researcher: Is that what you're telling me?

Chadwick: Drama class.

Through verbal communication, in addition to the visual drawings and words that Chadwick was putting on the board, I gained more knowledge about what Chadwick likes and does on campus. In this specific conversation, for example, I was able to see that Chadwick likes working with Jake and that he also likes his drama class, which he had mentioned at the beginning of that interview also. I also needed to recognize Chadwick's connection to the social circle diagram from our previous interview. When he drew the image with even more lines inside, he exclaimed that each line was "more Chadwick," signifying that he is an integral part of his own college experience.

During our final interview, I again gave Chadwick the option to use the whiteboard as a tool to communicate. In addition to that, this time, I also utilized the whiteboard as a method of showing some of my questions. I had tried this previously with another participant with paper and a marker because we were in a different room without access to the whiteboard. I designed a question about their preferences to get more information about the participants' experiences during classwork, as seen on the right side of the whiteboard in Figure 14, I drew lecture-style seating. Before erasing it, I had also drawn more table-style seating because Chadwick preferred lecture-style seating. These images were initially used to ask, "which kind of class do you like better?" This was followed up by drawing a circle to signify someone in that classroom. The names of the individuals "in the classroom" were written next to each circle. Using the pictures, I could have the participants design their "dream class" through pictures. This brought out a discussion of where mentors should sit, how they should interact, and how group work would go. Many of those conversations were pivotal in getting to the findings discussed in Chapters 4 and 5. Names that did not relate to anyone in this study were not blacked out in the figure.

Figure 14.

Interview 3 with Chadwick
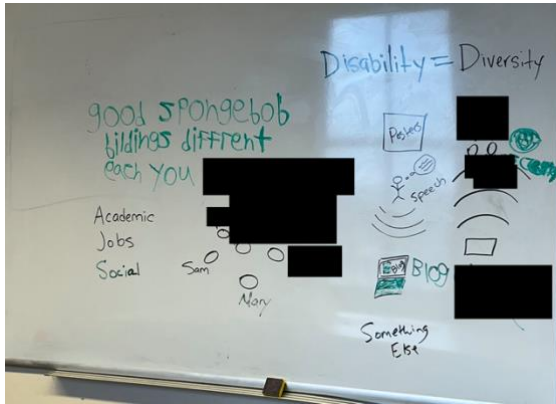
In addition to using the whiteboard to brainstorm questions with participants, I also used it to visually represent answer options for questions. This can also be seen in Figure 14. where I drew images of "posters," "speech," and "blog." This was meant to describe visually the question, "How would you advocate on your college campus about disability?" In this figure, Chadwick pointed towards the blog option and then colored it in to show his answer in another way. I gained more depth from many interviews because I utilized these additional supports.

My Impact on Space

In reference to the phrase "the researcher is the research tool," Holloway and Brown (2012) have said that,

> "the researcher is the research tool means that the study is affected by those who carry out the research, by their background and by the space and time they occupy. Researchers are accountable for their actions; they have responsibility for collecting, analyzing, and interpreting data as well as for interacting and communicating with participants" (Holloway & Brown, 2012, p. 22)

I tried to be cognizant of how I was viewed and my role during the study. I considered how the participants felt and how I could ensure they felt heard and understood. One of the codes I noted in early memos was about the ROLE OF INTERVIEWER. The participants alluded to

my various perceived roles throughout interviews and observations. I could not ignore that the participants and others throughout the observations saw me as an authority figure. I was often seen as someone who could help in difficult situations. However, I was also seen as someone who was not necessarily supposed to be in all the spaces I was in. I did my best to "blend in" while also trying to behave in ways my participants wanted me to. This was not very difficult, but there were moments when the participants explicitly directed or questioned my role.

During one observation at a group dinner, Faith bluntly asked me, "Are you observing?" At that moment, I was conversing with another student who was not a participant because they had asked me a question. Faith questioned the role of an observer, either not remembering that I had mentioned I could participate during the observations or not wanting me to participate. I did ask her if my interaction during the observation was ok with her, to which she said it was fine and did not say much more. Taylor and Bogdan (1998) have said that "People often do not understand participant observation, even when it has been explained to them" (p. 47), so it is likely that perhaps the premise of what I was doing confused Faith. In future observations with Faith, I reminded her she could direct how I act in the space. Even so, she only gave me direction on one occasion when she told me, "I do not like to be followed."

On the other hand, Clark was straightforward in the role he wanted me to play during observations. He would explicitly tell me what I was supposed to do. This is something that Clark does to many people and was a topic of conversation during some of our interviews. Naranj only acted this way once during my interview at a religious service, as discussed in Chapter 5.

I appreciate that students' comfort to "tell me how to act" and to be part of this research continuously throughout the five months was probably related to how I tried to immerse myself

in the community before beginning recruitment. It has been said that "…rapport and trust come slowly in field research" (Taylor & Bogdan, 1998, p. 53). Therefore, I chose to immerse myself in the FutureLIFE community before beginning this work. When recruiting for the study, I already had many connections to students and individuals related to the program. As is necessary during a qualitative inquiry, I was reflective on how my engagement in the space may have impacted my findings. Even so, I made sure I did not premise myself as a focus of the research, only a piece within it. Reflexivity has been critiqued in qualitative research because,

> "some qualitative researchers are prone to place themselves in the foreground rather than focusing on the other person, the participant. Researchers must practice scholarship rather than indulge in excessive self-reflection and autobiographical disclosures" (Holloway & Brown, 2012, p. 23).

The participants in this study were the focus. The ways they interact with the systems surrounding them were the focus. I, as the researcher, was part of those systems and, therefore, could not negate my impact on the work.

Acquiescence Bias

According to research, acquiescence bias is when someone tends to answer a question affirmatively regardless of the content of the question, and often can be connected to the individuals' perception of the person asking the question (Chronbach, 1942; Matikka & Vesala, 1997; Rapley & Antaki, 1996). It has been researched concerning people with IDD previously, finding in many studies an ~30% rate of acquiescence (Matikka & Vesala, 1997; Sigelman et al., 1981). There have been gaps related to who is accepted into these studies, as they have not given students who use alternate forms of communication the option to participate (Matikka & Vesala, 1997; Sigelman et al., 1981). There was a discrete concern in doing this work that the

participants would respond in a way they thought I wanted them to, falling into the category of acquiescence bias. This made me consider how, despite the numerous problems and barriers found throughout the data collection, all participants shared an affinity for their time in the IPSE program. This was not through yes or no answers, except in a few instances, but rather through exclamations they made throughout interviews of the value of IPSE programs. Although they were not yes or no answers, there was still a sense of them speaking about the "positives" rather than the "negatives" in those moments. No previous research has looked specifically at acquiescence bias and its relation to students with IDD in IPSE programs.

Although the positive view many of the participants shared with me about IPSE programs may partly be due to my presence throughout the interviews and observations, I do not think that I, or acquiescence bias, were the main factors in these positive statements. In many cases, the positive perception is something students with IDD are encouraged to feel from parents and other stakeholders when they go to college. Students in IPSE programs currently and previously are often referred to as "pioneers," so they believe this is important and good for them. I do not think this is acquiescence bias but merely a value they reflect in their answers. In many cases, I could tell they recognized their privilege to be in the program and college. They would speak about how they learned about the program and did not realize college was an option before. Debbie and Flynn communicated that they did not realize college was an option until they attended a disability-related conference years ago. When Debbie mentioned the importance of that conference, I asked, "Did you ever think you would go to college until that day?" to which Debbie shook her head left to right, signifying "no." Clark did not realize he could attend college, even though he always wanted to. When I asked if Clark thought he could attend college, he said, "Not with a disability, no. I would have to have a disability college."

I saw some connection between extra support in the room and the positive perceptions discussed. In one case, I purposely requested that a participant come without their support to the final interview if they were comfortable. I did this to see if there was acquiescence because of the support person. I did realize from the discussion during that last interview, and with reflections on the other interviews with this participant, there may be more of a positive outlook that this participant had been coached to have through their many years in Applied Behavior Analysis (ABA)[26] therapy and interactions with support staff, although I cannot say this definitively without gathering more information. During our final interview, I tried to push our questioning deeper because we had built up a good rapport, and his support was not present. After some questions that built upon one another related to campus interactions, I asked a few times explicitly for them to tell me if they had ever heard people make jokes about people with disabilities on campus. I gave examples I had heard from other students to help the participant feel more comfortable saying something negative. I could tell I had gotten to a more sensitive topic when the participant said, "I keep all these thoughts to myself, actually." I debated pushing that conversation further but took that statement as a cue to change the subject to avoid making the participant uncomfortable. This illustrated that although there may be some negative connections this participant could make to campus and the question precisely, he did not want to tell me at that moment.

Many of the positive attributes that the participants spoke about related to FutureLIFE were genuine. Many participants who said these very positive things also said some very critical things. They were often comfortable enough, to be honest about many of their problems. They

---

[26] "Applied Behavior Analysis is a form of behavior modification that relies heavily on external reinforcement, both positive and negative (operant conditioning). ABA is intended to modify or diminish behaviors, as well as increase language, communication, social skills, attention, etc., in children with ASD" (Sandoval-Norton et al., 2019).

had a sense of urgency in their critiques in hopes that I would be able to find solutions. They want things to be better, but they also recognize the positives and privileges of their situation. This is not acquiescence bias but a balanced way of recognizing their current situation.

Tensions of Responsibility

One of the most interesting aspects of my role throughout this study was the ever-changing nature of it throughout data collection. I had intended to take a hands-off approach and see things as a more detached observer. In reality, this was impossible. Classroom setting observations were the only observations where I think my impact was minimal, but there is no real way of knowing. In the more social and events-based observations, I had a much stronger participatory role than anticipated. For example, during one observation at a University evening event [karaoke] with a few participants and other Imagine University students, one participant called me and said another participant's father needed me to call him. Keeping my role as a researcher in mind and recognizing once I arrived there that this was not an emergency, I told the participant [who was not the focus of this observation,] "I'm not going to call anyone's father. You can give him my number if he really needs to talk to me." About 15 minutes later, the father called me. This father asked me to remove his son from the event because he was being "rude to him." I was astonished at the idea of being asked, through the phone, to remove a student from an event. In those moments, I did my best not to reduce the student's dignity, at one point, by refusing to make the student get off the stage when his name was called to sing. Not knowing this parent, I was unsure of how to react in this situation, and I did my best to appease the father while helping the situation end as quickly as possible so that I could return to my observation. Ultimately, I told the student, "Your dad won't hang up the phone with me until you leave. I'm sorry, I think you need to go." I still am worried about the implications of these actions for the

study.

During another observation, a stressed participant confided in me about a text they had just received. A former student was threatening suicide. The participant was angry. I advised them to stay calm and observed as the student showed the text to one of the peer mentors, who was alarmed. Another related text came in from a different IPSE student to the same participant. The mentor looked to me for answers. I gave some suggestions and ultimately called the IPSE director for guidance. At first, in this situation, I did not want to intervene. I wanted to see what would happen if I was not there. When that plan did not work, I returned to my admin/teacher persona. Everyone ended up being fine after the situation, but it was something I did not expect to have to manage during an observation.

Reflecting on these two moments and other less extreme but similar moments has been revealing. I initially thought: *Why do these things happen when I am around? Why are mentors and parents, whom I do not know, asking me for help? What would the participants and mentors do if I was not there?* As Taylor and Bogdan (1998) have said,

> "Fieldwork is characterized by all of the elements of human drama found in social life: conflict, hostility, rivalry, seduction, racial tension, and jealousy. Observers often find themselves in the middle of difficult and sensitive situations in the field" (p. 55).

The experiences at the karaoke and ice skating events made me think about this fieldwork aspect. Through deep reflection, I could discern that this had to do with the rapport I had built with the participants. They know me. They see me doing work with FutureLIFE often. They see me hanging out with students. Some of them have had me as a seminar teacher. All these aspects have made many of the participants and their friends comfortable with me, but also have given them the idea that I have some power. Disability or not, when people are in moments of fear or

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stress, they look for someone they can trust to help and seek out social interaction. This has been discussed in research previously about coping strategies related to adolescents who primarily utilize social support as a coping strategy (Plunkett et al., 2000).

Interestingly, "talking to a school official" was the least utilized coping strategy in that study. If the participants' actions follow the line of Plunkett et al.'s research, then the participants view me more as a social support than a program official. Outside the realm of the study, this trust was continued when participants would text me about friend troubles or would stop me in the hall to discuss an issue they were having with an on-campus club. This was one of the aspects of this research that I memoed about most often, one time saying,

> This student had reached out about an issue with graduated students through text before this interview (but did discuss it during the interview) and asked me to talk to staff at FutureLIFE about it. As a threat was involved, I did mention it to staff but kept the essence of me being in contact with the student for research purposes out of the conversation. I am unsure how I will continue to deal with this in the future, as I don't think it will be an isolated issue.

I had to do my best to separate the things I learned "off the record" and "on the record." Some things ended up being both. Internal reflections about whether or not I should intervene during different situations kept me rethinking every encounter I often had. Ultimately, I built a great rapport with many participants, which many also reflected on during our last interviews.

Flynn: With my best friend, Katie.

Researcher: [slight laugh] Me?

Flynn: I have been seeing you a lot!

Researcher: I've been seeing you a lot, too. It's been fun.

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Flynn: Yeah, it's been fun to get to know you a lot better.

Researcher: Mhmm.

Flynn: Get to spend time with you more.

Researcher -I know. It's been really fun.

Flynn: Yes. Even when you're done with all this, and you graduate, we're still gonna be in contact.

Researcher: Of course. Yes. I look forward to that.

As Taylor and Bogdan said, "when you become intimately involved with people through this kind of research, you can find it difficult, even undesirable, to sever your personal relationships with them" (Taylor & Bogdan, 1998, p. 79). I hope to continue talking with the participants and learning more about them, even after completing this dissertation. As is seen in Flynn's message to me, some did call me a friend, and some still do. Many are still contacting me about meeting up in the new semester. In trying to understand the participants' social interactions and social circles, I became part of them.

Research is an integral part of changing policies and systems, which is true within the realm of IPSE and any other field. Framing this work with DSE led me to incorporate disabled folks throughout all aspects of the work. The implications within this chapter are of great importance, as they can contribute to supporting other researchers in their quest to do inclusive research. Knowing how to listen to individuals with IDD and adapt qualitative research methods to meet their needs best is essential, and these findings explain practical ways that were done within this work.

Chapter 7

Discussion and Conclusion

"There is a profound ambivalence in the position of inclusive researchers. We are committed to

promoting justice and equality and at the same time we are part of the oppressing group…"

(Walmsley & Johnson, 2003, p.88).

Throughout Chapters 4, 5, and 6, I have established the richness and depth of experiences that individuals with IDD have. If all of society were to read this dissertation, the experiences within these pages would elicit a new awareness of the ordinary. Individuals with IDD have experiences, not unlike those without. The participants I had the privilege to collaborate with for this work had many social ties, resulting in many social interactions. Those social interactions paint a picture of life for an IPSE student at FutureLIFE, which illustrate the constant shift of a young adult maneuvering life through a significant transition. Moments enclosed illustrated joy, sadness, and experiences in between. Although IHEs have only started to become retrofitted to support students with IDD, students are making themselves at home. Despite the ableist nature of society, especially on highly competitive college campuses, IPSE students are thriving. The initial quote above encapsulates this ebb and flow of positives and negatives surrounding research, which is mirrored also in IPSE research and practice. In this chapter, I discuss this dichotomy illustrated throughout the findings.

Discussion of Content Findings

In Chapter 2, I mentioned my understanding of inclusion based on the historical shifts in the definition that have occurred over time (Artiles et al., 2006; Farrell, 2000; Will, 1986). I aimed to determine more about the experiences that students with IDD have while in IPSE programs. I created this part of the discussion with the key findings from Chapters 4 and 5 in

mind. It is organized into three main sections: 1) Opportunities for belonging, 2) Ableism on display, and 3) Value of relationships.

Opportunities for Belonging

This study was complex in that I was observing a variety of settings. Each setting related to Imagine University, and the participant chose each setting. Throughout the findings, I described the different settings in which I did observations: Imagine University academic and recreational buildings, FutureLIFE internship sights, Imagine University off-campus events, and Imagine University sports games. I often tried to determine the inclusivity of the various spaces while observing. As was explained in Chapter 2, there are different beliefs about what inclusivity is. I hope for inclusion to surpass just having disabled people given space with non-disabled people; instead, having them take up emotional space and value in spaces if that is what they desire. I cannot define this from my own experiences as a non-disabled person. Instead, I base this definition on the moments of *inclusivity* I witnessed and conversations with participants during interviews and focus groups. In Chapter 2, I described one framework for inclusion in higher education that places togetherness, access and opportunity, and belongingness as necessary "concepts of inclusion" (Bacon & Baglieri, 2021). This framework is based on DSE beliefs and focused on higher education, so I was inquisitive if there would be connections among the themes and findings towards this framework.

Multiple participants inquired about differences between inclusion and belonging. Belongingness was not seen as a part of inclusion but as something more significant than inclusion. Inclusive education research from the UK has recommended that a "state of belonging" become an outcome utilized in understanding the success of inclusive environments (Prince & Hadwin, 2012). Osterman also explained in his review that "belongingness is an extremely important concept" (p.359, 2000). In another qualitative study done by Botha et al.

(2022), aspects of community connectedness for autistic individuals were discovered, two of the categories of which were belongingness and social connectedness. The Botha et al. (2022) study only focused on autistic interaction and autistic identity rather than interactions with those of all disability labels or the general public. It was stated, "In participant's accounts, a sense of belongingness allowed participants to develop a sense of self-worth" (Botha et al., 2022, p. 2159). The observations and interviews throughout this study illustrated moments of belonging. I especially recognized belonging during the many late-night Imagine University events I observed. The participants constantly conversed with peers from FutureLIFE and peers not affiliated with the program. Naranj showcasing his film work was another moment that demonstrated belonging because he got to do something he loved.

The term "inclusion" has been co-opted and transformed into and throughout many different systems (Qvortrup & Qvortrup, 2018). Growing up, these participants were in a variety of what are termed in k-12 as "inclusive" and "non-inclusive" settings, as described in Chapter 2. They know what those settings are and have had that terminology in their minds throughout their lives. Unsurprisingly, many of the participants would separate the idea of inclusion from something else they see and feel, such as belonging. Although there were many examples where belonging was happening, there were also moments in the data where it was not. Participants like Clover mentioned their initial concern of not knowing if they would "fit in." Other students discussed the ways that they are just like everyone else.

Based on the findings in Chapters 4 and 5, I am inclined to work towards a focus on belongingness for people with disabilities and other marginalized identities on college campuses rather than just inclusion. The participants demonstrated through their actions ways to transform colleges and societies to be more inclusive and enhance and encourage the concept of

belongingness. For example, Jerry intended to talk with the administration and advocate for other FutureLIFE students. He wanted to advocate for more opportunities for individuals with IDD to be fully part of campus. Through the participant suggestions and my DSE-framed understanding of the findings, I continue this dissertation discussion with ways to enhance the student social experience during IPSE programming.

As mentioned earlier, participants had a variety of racial backgrounds; White (n=12), Black (n=2), and Asian (n=2). A majority identified as cis-gender and straight, but several individuals identified as non-binary and/or as LGBTQIA+. The way the IPSE program was funded varied widely across the participants, as the participants were from different states, commuter or residential, or utilizing Medicaid Waivers, private pay, or IDEA funding as a dual-enrolled high school student from the local urban school district. I did not ask about the socioeconomic status of each participant. However, I was able to gather basic financial information from those students who disclosed it on their own.

Arthur was one participant who mentioned finances often. Their financial situation was much more precarious than some of the other participants, so they are still commuting as a Junior. Arthur is also a student who identifies as Asian. Chadwick, the participant who is a dual - enrollment student at FutureLIFE, is also a commuter and identifies as Black. It was discussed how Chadwick missed an evening class due to his status as a dually enrolled student and the fact that he is supposed to leave at 2 p.m. every day. Arthur and Chadwick missed out on specific experiences they desired because of their status as commuters. These two participants both have societally marginalized racial identities. DSE implies recognizing and contextualizing social and political spheres where ableism occurs. I could only contextualize this work by acknowledging intersectional identities and their potential impact on the participants. The conversation of

intersectionality came up with a few participants throughout this work. Naranj, as mentioned in Chapter 2, did not speculate explicitly if he thought his Black identity was impacting how he was being treated and reducing his club-related opportunities. Although some white participants also questioned the opportunities FutureLIFE students had offered them, these were typically much less specific grievances than the issues mentioned by multiply-marginalized participants.

Overall, there were examples within the data of participants being included while they were students at FutureLIFE. Participants discussed the friends they interacted with on campus and let me observe a wide range of activities and events. Despite a few examples, Greek life and study abroad, FutureLIFE students were technically included everywhere on campus. However, there were still many areas of future growth stemming from a lack of belonging on campus. I will discuss these findings and their implications in this chapter.

As was mentioned in Chapter 2, Loreman (2007) had listed pillars that make up inclusive schools, consisting of the following: "Developing positive attitudes, supportive policy and leadership, school and classroom process grounded in research-based practice, flexible curriculum and pedagogy, community involvement, meaningful reflection, and necessary training and resources" (Loreman, 2007, pp. 24-33). These pillars were present throughout the data that was collected in numerous ways, especially concerning the social interaction that participants encountered. I will draw a connection to the most consistent pillars with this data: developing positive attitudes, supportive policy and leadership, and necessary training and resources.

Developing Positive Attitudes. This pillar was consistent with the findings and discussion throughout this dissertation. There is a lack of positive attitudes toward students in IPSE programs with IDD, which strongly impacts their social interaction with other people on campus. Changing attitudes and stigma that are held by disabled and non-disabled folks is

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necessary for reducing barriers to inclusion and belonging in IPSE programs. Course entrance

processes especially impacted FutureLIFE student belonging. Deficit-based attitudes created

policies that encourage or mandate auditing over taking courses for credit (O'Connor et al.,

2012; Rillotta et al., 2020). Jerry and Flynn, for example, both dealt with difficulties getting into

courses they wanted. They also incurred discrimination from their classmates questioning their

placement in the class and/or groups. Clover and Jerry both had a desire to take for-credit

courses with support but without modifications but were not successful in bringing those options

to fruition.

Supportive Policy and Leadership. A few of the participants pointed out that changes

need to start at the top. Although I do not fully agree with this statement because change needs

to come from both directions, there is merit in the understanding that college administration and

federal/state policymakers can make a huge difference. This is especially true considering the

financial cost of attending IPSE programs. It is also important to understand the complex

structure of collaborations that keep IPSE programs going such as those with Vocational

Rehabilitation and community disability service agencies.

Necessary Training and Resources. As suggested by many participants, it is necessary

to make others aware of their presence on campus and the value they bring. This can be done

through training and the availability of resources, which could include human resources, such as

the students themselves. There also was a necessity to implement support for faculty and other

instructors to facilitate inclusive classes best, specifically through intentional grouping and well-

thought-out assignments. Lombardi (2010) discussed the importance of consistent expectations

and assignments for success of students with disabilities in college coursework, which aligns

with this finding.

Ableism on Display

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A large portion of the data discussed in the findings' chapters illustrated ableism. I understand this ableism and societal stigma not just as a fact in the participants' systems but as a barrier to their potential success in higher education spaces and beyond. Each participant has had much success, but there is no doubt that ableism has played some role in interfering with their belonging on campus. There also is a necessary caveat with these participants' success in that many came from backgrounds that could be considered privileged in other traditional ways. For example, many participants came from white middle-class families, allowing them to be in the IPSE space initially. Considering the varying demographics of the participants was critical to this study. Grounded in a DSE framework (Connor et al., 2008) and informed by Disability Justice (Sins Invalid, 2019), there was a necessity to address intersectionality among participants and within IPSE. As mentioned, most of the study participants, similarly to most students in IPSE programs, identify as white. Data on diversity within IPSE programs are not readily available, primarily related to aspects of identity other than race. Through this work, I am drawing attention to this absence in previous research and proposing solutions to reduce the stigma of multiply marginalized individuals in college spaces.

As was mentioned in Chapter 5, there was a difference in the experiences of ableism of those participants who communicate in ways society sees as more "typical" and those who communicate in other ways, demonstrating the power and privilege of typical speech as a method of communication. One participant in this study is considered non-speaking and has a sign language interpreter with her most times to assist with communication. Two other participants would be considered to have speech patterns that differ from what society currently deems "typical." Principle Seven of the Disability Justice Framework focuses on cross-disability solidarity. This is especially important when discussing communication. Behavior can be a way

of communicating, but this is not always understood in society. The participants who communicated in different ways were sometimes devalued by non-disabled peers, disabled peers, and staff throughout the data collected. The excerpts examined within Chapter 4 highlight how internalized ableism, even for participants within the FutureLIFE program, is present. Multiple participants spoke about their preference towards individuals who speak or have no disabilities.

Internalized ableism is shared throughout society because the privilege given to people without disabilities is an undercurrent of all things (Campbell, 2008). Gillespie-Lynch et al. (2020) discuss the neurodiversity movement and cross-disability alliance building, which is especially relevant to this finding. Their article specifically calls out the difficulties that the neurodiversity movement has had with cross-disability alliances and those who "struggle to speak" (Gillespie-Lynch et al., 2020, p. 39). They give two examples of ways to create stronger alliances across neurotypes, which I think would positively impact some IPSE students with biases toward other disabled folks. These ideas included "peer-led support groups" and a "mentorship program created for and with autistic University students." Universities with and without IPSE programs need to consider similar options in their structure to support students and their social interactions better.

Participants who do use AAC were present as participants in this study. They did not share strong opinions about how people treat them concerning their disability. As was mentioned, Debbie was asked if she remembered being ignored by a staff member during internship class, but she did not remember. Ashby and Causton-Theoharis (2012) did a qualitative study about the experiences of individuals who type to communicate who were in inclusive higher education[27] programs similar in some ways to FutureLIFE. One of the

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[27] Terminology of IPSE was yet to be coined at the time of this piece.

significant findings in their work was a better understanding of the social implication of IPSE programs and how individuals who typed to communicates' social inclusion and exclusion in college contrasted with their experiences in k-12 education. Although many of the findings in their study were also present in this dissertation study, there were also areas in which they differed explicitly for the participants who used alternative communication. Ashby and Causton-Theoharis (2012) had one participant in their study who discussed how he was taught to play UNO in k-12 school, which was not dignified for him. In this study, one individual who does not type to communicate but does not verbally communicate in "typical" ways, spoke about how much he loved playing UNO with friends while on his breaks at Imagine University. In comparing these two examples, it is recognized that although the game is the same, the purpose behind the activity is different. Being taught to play games like UNO during a course illustrates wasted academic time. Playing games like UNO with friends during free time is purposeful. Clark's PE class, discussed in Chapter 4, was a space for him and his classmates to learn how to play games also. The games in that course had a purpose because they were teaching teamwork and leadership. Considering the ten-year gap between the two studies, I would consider these differences in student experience to be positive and demonstrative of the growth related to IPSE programming throughout the last ten years. FutureLIFE students are self-directed and choose how they spend their time.

There are still barriers that impede successful social interaction for students who use alternative communication and for all students with IDD. Other participants in the 2012 study highlighted the difficulty of forming social relationships in college. This was found in the excerpts about the participants' lack of friendship with matriculated classmates. Debbie, an individual who uses AAC and signs to communicate, was one exception. Debbie is an IPSE

student majoring in Human and Family Studies, and she listed off many friends from the previous course "study groups." Most of the students she mentioned becoming friends with were in classes related to the School of Education. I assume that the matriculated students in those courses were more aware of disability than the general population of Imagine University. There are no students who use AAC within the residential arm of the FutureLIFE program, although a few residential students have communication needs. This may illustrate a barrier within the campus community and possibly admissions processes that keep students who use AAC away from the residential option.

Ableism amongst the campus community was seen widely throughout the data collection. Jerry highlighted these moments best when he discussed how he had been treated like he was not supposed to be in one of his classes because he was in FutureLIFE or when he described his friends not being friends with him after they found out he had a disability. Clark felt the need to help his matriculated student friend who had just been diagnosed with Autism because people in her life treated her poorly because of her disability.

It is crucial to look at the impact administration of colleges like Imagine University can have to reduce and eliminate the stigma and discrimination seen through the participants' experiences. Looking specifically at the findings from this study about extra-curricular and/or non-academic opportunities, continued barriers impede IPSE student social interactions on college campuses. This was seen in the common complaint that students in this particular IPSE are not members of sororities and fraternities, which are a big part of this University's culture. There have been a few examples across the United States where individuals in IPSE programs have been present in sororities. However, no literature has been about how that was established or any outcomes. The same sentiment can be said about students in IPSE programs studying

abroad through typical University programs. However, there have been national and international travel opportunities for current and former FutureLIFE students through non-typical channels. Researchers should examine these areas where IPSE students are not represented at all or enough to determine why this absence exists. Presuming competence and rejecting deficit perspectives towards disability are essential in making systemic policy changes to allow IPSE students to enter these mostly uncharted territories like fraternities and study abroad programs while at college.

The stigma apparent throughout the many excerpts from the participants in this study can have detrimental effects on the self-esteem and FutureLIFE of the individuals experiencing them. As Ehlert, a self-identified queer, disabled art therapist spoke about in their focus piece on an encounter they had with an art therapist-in-training, oppression from sanism or prejudice against mental illness (Leblanc & Kinsella, 2016) in her field was harmful. The Disability Justice framework was named a form of healing for the focus participant in the piece (Ehlert, 2020). Methods of reducing stigma related to a disability should reflect on and work with methods used in other justice movements, as there is healing power in that. Ideas that participants gave for reducing stigma and explaining to others why they should be valued on college campuses included the following:

- Creating a blog that includes pictures of Chadwick, showing people what he does in college. ~ Chadwick
- Going up to the Chancellor's office or sending them an email about why they need to change their systems. ~ Jerry
- Just talk to them and convince them. Show them the cool side of people with disabilities. ~ Flynn

- Go to local k-12 schools and tell them about disability and college as an option ~ Arthur

- Invite them to our FutureLIFE events and holiday parties ~ Debbie

These are just some examples of how the participants suggest to reduce stigma on campus and in society. It is essential to recognize how each of these suggestions is to be pursued by the disabled individuals themselves. This puts much of the burden on an already marginalized group of people. These suggestions were given by the participants while discussing the stigma and ableism they have experienced. As has been seen in past disability justice movements, there is a necessity for creative thinking and bringing the concerns and ideas of the disabled to the forefront. The fight for the ADA to be signed is one such example of where people with disabilities led the movement, penning the phrase, "nothing about us without us." These participants can create immense change through similar pushes toward the administration, government, and peers. There is a fine line between not interfering with disabled folks taking the lead in fights for their rights and not making them take on all the burden of changing society.

Value of Relationships

As was mentioned in Chapters 5 and 6, there was an interesting way that power was reflected in who the participants were "friends" with. Especially interesting was the participants' affinity for those who technically have leadership roles on campus or within the IPSE program. Flynn even mentioned that a good friend should "[not] let me do things that I should not do," which would typically be a designation of a teacher or a parent. Flynn alternatively thought that this would be a sign of a good friend. Telling his friends what they should not do is also witnessed throughout observations with Flynn, so he is acting similarly to what he expects from friends. This connects to two of Rossetti and Keenan's findings about friendships between

students with and without severe disabilities; "Friendships may look different" and "Friendships include more than help" (p.204-5, 2018). We must recognize that friendships can take on different forms and that what reciprocity looks like in friendship is unique to each situation. Vroman (2019) had similar findings related to friendships. Arthur, an autistic IPSE student with ADHD, often talked about how they would help matriculated Imagine University and FutureLIFE friends with different aspects of their social lives. They even offered to help me with my own social life at times.

Peer relationships were significant, as were faculty relationships. Faculty relationships were significant to the students because they were a connection to the future. Multiple participants talked about how some of their actions and choices about whom they spoke to were related to a desire for future success and employment. Individuals with IDD wanted to network to get a job in the future. The employment rates for this population are abysmal but improve after completing an IPSE program (Lindstrom et al., 2014; ODEP, 2021). The participants in this study know these rates. They see the lack of representation in offices and at other jobs. Being at a college that encourages individuals with IDD to work impacts this understanding. Participants had a sense that by networking with people around them, they would have better chances at employment.

The findings in Chapter 6 related to romantic relationships and student identity were also important. As mentioned, there are variances in how students understand romantic relationships and what "dating" looks like. Some data illustrated that romantic relationships are a significant part of one's free time. Some participants were with their partners often, going on dates and spending time in their dorms. Other participants had mostly phone relationships where they texted or called one another often or occasionally. Others primarily spent time together along with large groups, but did show public displays of affection during those activities. In other

research I have done, I have found research related to romance, sex, dating, and IPSE minimal (Ducett & Soldovieri, 2023). It has been seen through research that there is a lack of education about those topics for individuals with IDD while they are in K-12 education, as Flynn mentioned in our final interview. It was acknowledged that non-IPSE students in college have sex, and a common comment was that people with disabilities should be able to do the same things as everyone else. However, the one participant who spoke about this topic contradicted himself by saying that this was one area that people with disabilities should not learn about because it is uncomfortable. Further details about the implications of these findings are given later in this chapter.

Discussion of Methods Findings

There were several aspects of the methodology that I found interesting. The findings explained in Chapter 6 focus on how my research methods were adapted throughout the study and the reasons why that adaptability was important. In this discussion, I will discuss the following: 1) Participant Rapport; and 2) Universally Designed Research.

Participant Rapport

Getting to know the participants throughout this study was integral to getting the data that I did. The participants had to trust that I would listen to them and honor the information they shared with me. They had to feel comfortable with me joining events with their friends and in their classes. By building rapport, I could better know what questions to ask participants during interviews and focus groups. I knew the dynamics of the folks within a focus group and knew what drama might come up that I might need to redirect. These aspects tied back to the rapport I built from the beginning, even before starting the study. I explained in Chapter 6 how difficult moments arose because of my connection with the participants. Qualitative researchers in the

past have discussed this twofold nature of building a solid rapport with participants (Taylor & Bogdan, 1998).

Participants in this study were comfortable with giving me direction and questioning what I was doing. Many participants also illustrated interest and understanding of the research by reminding me of upcoming observations and interviews. Developing connection with the participants and other FutureLIFE students prior to beginning the research reduced the amount of time it took to build rapport during data collection. I did this study in a short time frame so the pre-data collection immersion time was crucial in completing the work, knowing that rapport building in the field can take a long time (Taylor & Bogdan, 1998). Researchers need to factor in this pre-data collection time as part of the research plan.

My role as a researcher was made more complex because of the rapport built and my presence as an older person within the primarily undergraduate spaces where observations occurred. For example, I was asked to act as an authority and problem solver in multiple occasions, like at karaoke night and at the ice-skating rink event discussed in Chapter 6. These complex situations were not planned, and I felt had to be dealt with at the moment. Knowing the contact information for important administrative individuals related to the research (i.e., the director of FutureLIFE) eased these situations. The director signed the coordinating IRB letter and therefore knew about the research in general terms. I asked for her perspective as to the best plan in both the karaoke and ice-skating situations. Qualitative researchers doing inclusive observational research with individuals with IDD need to be prepared to be unprepared. There will be moments of uncertainty.

Doing research with individuals with IDD, there is suspicion sometimes that acquiescence bias is impacting results (Matikka & Vesala, 1997; Sigelman et al., 1981). It is

important to presume competence in the individuals within the research. The participants in this study illustrated a mixture of both positive and negative experiences during IPSE. I did consider how the data may have been impacted by acquiescence bias. I reflected on how the questions I was asking were being understood based on the needs of the participants and whether the questions would elicit responses based on understanding. I was concerned with misunderstanding that might lead to acquiescence, not with participants thinking they had to give me a certain answer. I created universally designed questions, which will be discussed next, as an important aspect of this.

Universally Designed Research

Some previous research used universally designed research methods, and these studies sometimes had visual reminders or picture cues on consent forms (Vroman, 2019). The option of alternative forms of answering a question, such as on a whiteboard or written on a piece of paper, have also been seen sparingly in previous research. In this work, I utilized these techniques. Some were decided upon from the beginning, like plain language consent forms, questions sent prior to interviews and focus groups, and options for virtual or in-person interviews. Other techniques were decided upon as I got to know the participants and determined more about their needs, such as bringing fidgets into interviews, having the option for drawing or writing answers on paper or a whiteboard, and utilizing forced choices as well as open ended questions. Without building the initial rapport with participants I would not have determined the need to use the techniques not initially planned.

Researchers have been calling for exploration of more ways to include people with IDD in research (Atkinson & Walmsley, 1999; Walmsley & Johnson, 2003; Zarb, 1992). The depth of data that I gathered from a diverse group of participants was possible because I adapted the

research methods to meet their needs. For example, if I waited for Chadwick to answer open ended questions verbally, I would not have gotten the depth of responses that I did from him. This was illustrated in the growth of our interviews from the pre-interview to interview two.

Understanding inclusion and belonging does, in part, include access to space and how space is used. By drawing some of the questions about lecture style versus table style classrooms, rather than just asking them verbally, I was able to better understand how participants experience classroom spaces. I was able to point to the visual as a forced choice of which course the participant preferred, and then expanded upon this by asking them where they prefer to be in that preferred classroom. This again gave participants an opportunity to understand the questions in different ways, which made them more accessible.

In addition to these tactile and question-based methods of universally designing research methods, I also was flexible with the timeline and quantity of data collection. As discussed in Chapter 6, there were reductions made to the ultimate data collection goal. I continuously reevaluated the data collected to determine if the depth desired was achieved. This decision was focused on if there was a diverse amount of data related to the main research question. I worked to get to a "saturation" point within the data (Glaser & Strauss, 1967). Researchers working with individuals with IDD need to honor the participants' commitments and dignity by being flexible with the research schedules (Walmsley & Johnson, 2003). Reflection and analysis of what data is collected are essential to this. This flexibility is possible through a well-thought-out organization of what has and is about to happen in terms of data collection. The Trello board I used throughout this study kept me on track and in the present moment with the participants and similar organizational methods are suggested for future researchers.

Limitations

Although this study was inclusively framed, it was not created as a participatory action research study. Therefore, the calls for action by the participants and the strategies that were suggested are not in production because of this work. I encourage continuing research like this with an additional participatory action with co-researchers to facilitate change with disabled individuals as the designers. Many of the participants from this work have taken part in disability advocacy work around the US, including advocacy for more funding for IPSE programs, demonstrating the importance of creating opportunities for more research and advocacy with individuals with IDD.

Another limitation of this research is the limited information about participants' socioeconomic status and prior school setting history. As was mentioned previously, students who are currently in FutureLIFE fund their education in a variety of different ways. If researchers examined the avenues through which students across the United States fund their IPSE education and how SES impacts that funding, the field of Inclusive Higher Education would be set up to better reduce barriers caused by financial and economic burdens. I also did not ask for information about the participants' previous k-12 schooling experience. This is a limitation because there may be connections between the experiences that students have during IPSE that relate to how inclusive their k-12 classroom setting was.

This qualitative study only examined the experiences of students from one IPSE program. This limits the generalizability possible because programs are wide-ranging in how they were set up and their understanding of inclusion across the country. This study could be expanded by using similar methods with various programs in different areas, such as rural, urban, suburban, and colleges, such as large, small, private, public, community colleges, and trade schools.

The focus group methodology that I used in this study had limitations as well. The greatest limitation was the fact that they took place on Zoom. It was originally designed to be either on Zoom or in-person, but the preference for the participants was Zoom. I chose to use focus groups to have recorded social interactions among participants. This would have been enhanced if those social interactions were more natural in an in-person setting.

Implications

There are many implications for this research. Although the setting of this work was specific to an institution of higher education, particularly an IPSE program, the implications span more comprehensively than just that setting. I will discuss implications for the following areas: 1) Higher Education, 2) K-12 education, and 3) Research.

Implications for Higher Education

Of most significant importance, this work demonstrated that students in IPSE programs have positive experiences. Critiques were mentioned, but overall, the participants enjoyed themselves at college. IPSE programs must continuously re-evaluate their procedures and discuss students' experiences with them. An accreditation process is being created that will be crucial in this. Programs cannot reproduce the status quo as the world and society continuously change. With overall positive feelings about IPSE programs from the participants in this study and other previous studies, expanding the number of IPSE programs across the country and internationally is necessary. Students with IDD can now shop around for colleges, but there is still a lot of room for further growth.

The participants in this work illustrated their drive to make a change by discussing issues around them. Some of the participants had participated in disability-related advocacy work. There need to be additional opportunities for IPSE students to become leaders across campuses

and worldwide in disability-related and non-disability-related ways. It was shown that the participants have many interests and do not need to silo themselves only to pursue advocacy in one way. IPSE leaders and IHE administrators need to advertise opportunities and ensure that no institutional policies act as barriers to them applying for leadership positions just because of their enrollment in an IPSE.

Ableism, including internal ableism, was a large part of the findings in this work. To combat this, IPSE programs and IHEs need to bolster the representation of disabled folks on their campuses highly. I do not mean tokenizing IPSE students; I mean having a diverse mix of disabled and non-disabled folks and people with other identity markers in media rollouts. Enhancing how students on campus learn about disability. This could be through a first-year seminar for all first-year students that examines disability history and critically discusses ableism.

Policy should be changed to reduce ableism on college campuses. Specifically, policies that mandate and/or encourage students in IPSE programs to only audit coursework. These policies vary but are often related to funding for coursework on the University, State, and Federal levels. There should be an option for auditing but it should be a choice. When a student from an IPSE does choose to audit or take a course for credit, they should be able to enroll in the course just like any other matriculated student. If the IPSE student has met the prerequisites for the course (i.e. has taken the 101 courses before the 301 courses, if mandated for enrollment), they should be able to enroll. The only gatekeeper should be the University system already in place for all matriculated students. It should not be the faculty deciding whether an IPSE student can enroll. One specific policy that could impact this aspect of course access is the nature of getting only audited coursework paid for through Medicaid Waivers. If the policy shifted to

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allow Medicaid Waivers to also fund credit-bearing courses for students with IDD, students would benefit from having a more accessible option of taking courses for credit. If these changes were made, students could decide on a mixture of credit and audit for their schedule, if they want. Strategic plans and University Diversity, Equity, Inclusion, and Accessibility (DEIA) plans also need to be created with IPSE students in mind. These plans should include aspects related to making physical spaces more accessible to physical, sensory, emotional, and social needs. For example, setting aside funds for sensory-friendly spaces on campus and mandating flexibility with club meetings. These changes would reduce ableism because they would illustrate to the campus community that students from IPSE programs are equal parts of the community, not guests. Changing these overarching policies sets a precedent for faculty and staff at a University, that they need to be thinking inclusively.

There needs to be training based on DSE tenets for organizations and services on college campuses. All officers and/or staff members must be updated on the language and best practices for creating inclusive environments where all students belong. These trainings must be done regularly (i.e., each year or semester), so any new ideas can be shared and disability is not forgotten. It was found that some organizations were not treating their IPSE student members with dignity, and training like this could help. Mentors and support staff for the IPSE students should also receive similar training. This could have reduced the likelihood of Kent's support telling his class group that he was just there to listen. Lastly, in terms of training, faculty members, instructors, and TAs also need to know how to best support students with all disabilities, including IDD, in their classrooms. Teaching faculty about disability studies, presumption of competence, dignity of risk, and UDL would all be essential aspects of this type of training.

Higher education policies need to be amended or created to create accessible avenues in areas that are not yet accessible for IPSE students. In the context of FutureLIFE, one of those aspects was Greek life. Often the college or university has some oversight over Greek life's policies, and they should use this power to create accessible avenues for FutureLIFE students to participate. The other primary example discussed by participants from FutureLIFE was studying abroad programs. I suggest that IHEs hire a specific Accessibility Coordinator in their study abroad offices who can ensure people with all types of disabilities are being accommodated correctly and are given the option to study abroad.

IPSE programs need to recognize the importance of peer interaction for their students and should continue to help those interactions grow. It was illustrated that peer interaction in classes was not often as crucial to students. Although FutureLIFE students have a major, they do not interact with their major. IPSE programs need to coordinate with the different schools where their students are majoring and ensure they are meaningfully connected with that school. For example, if an IPSE student is majoring in art, they should attend the Freshman orientation for art majors and attend art club meetings, if those are things that art club majors do. In the case of FutureLIFE, each student has their own FutureLIFE staff member as an advisor. Adding an advisor to the student's actual major would be beneficial. Not only would this change in program structure connect the IPSE student with a faculty member within their major, but it would also connect them socially with students who have similar interests. This would lead to stronger inclusive class social connections with other matriculated students. An intentional look at how IPSE students are included on campus is essential in reducing ableism.

Considering the dual-enrollment program that Chadwick was part of, there are some specific ways that his experience could have been improved. The most impactful barrier to

Chadwick's social interaction on campus was the fact that he typically had to leave or did not have support easily after 2 p.m. each weekday. This was attributed to the fact that this program was funded through the local public school district and thus, all the staff who worked with students in this particular subset of FutureLIFE were contractually only working until 2 p.m. The local school district bus picks up all the students in that program from campus at the same time. To remediate some of these issues, the University should make a policy and procedure shift. The University should work with the school district to determine a new financial avenue that allows the funds to be used from the IDEA budget but with all staffing, transportation, and procedures created through the University system. This would also give the University and IPSE program the power to train the staff in more disability studies-focused ways rather than hoping the school district is training them in that way, which does not seem to be the case in this study.

Related to the findings about romantic relationships, IPSE programs need to find a way to explain the importance of learning about relationships and sex to students and possibly parents/guardians. It should not just be a stand-alone lesson at the beginning of the semester, and it also should be disabled and queer-friendly. In the best-case scenario, these seminars could be IHE-wide or for all new students at the University. Individuals with IDD are at much higher risk than those without disabilities of being sexually assaulted or harmed by relationship violence, and they do not regularly learn these topics (Grove, 2018). IPSE programs and stakeholders must also ensure that all students on campus have access to dating and relationship-related services that are accessible in more ways than just physical accessibility. For example, any office that deals with the aftermath of a sexual assault should have a room next to the waiting room in case the individual needs a screen reader or mentor to read their forms with them. These forms related to Title IX and sexual assault get very personal, so a private room is necessary.

Implications for K-12 Education

There are two main implications for k-12 education related to this work. Many participants explained that they only realized college was an option for them in late high school, if not after graduating high school. K-12 schools must know that IPSE programs exist so that the students and parents understand their options. Preparing to go to college throughout k-12 school often looks very different than preparing to go to a day habilitation program or sheltered workshops. Day habilitation and sheltered workshops are segregated options for individuals with disabilities during adulthood. These segregated options are problematic and there have been "calls from disabilities rights advocates to move away from sheltered work and day programmes for adults with ID toward appropriate experiences" (Wintle, 2014, p. 195). Teachers, parents, and guardians during childhood do not always have high expectations for their students with IDD, and that leads to these segregated settings being a common outcome in childhood and adulthood (Migliore & Butterworth, 2008; Zollers et al., 1999). IPSE programs need to be reaching out to the k-12 teachers, staff, and families with accessible information about options and stories of success from current and former students. For the options to be given accessibly, they need to be in plain language and offered in different languages. This is especially true as it relates to financing an IPSE education, so parents and guardians recognize that there are ways to make it affordable. Access to this information is important for all levels of k-12 education, not just high school. The earlier families understand that college is an option, the higher their expectations will be for their student with IDD.

The findings also implicate k-12 institutions to teach in different ways than are common currently. For example, sex education and healthy relationships should be taught to all students, including those with IDD. Schools need to be set up inclusively to ensure students with IDD in health classes with their general education peers and in all other classes. This inclusive mindset

needs to be exemplified from the district administration. They need to reduce and eliminate segregated classrooms while also giving teachers and paraprofessionals the proper support so the inclusion initiatives are successful. Inclusion has been seen to improve outcomes in both k-12 and higher education, for students with IDD. If students are in inclusive settings throughout k-12 schooling, they should have greater success in an inclusive college environment than if they were in segregated k-12 schooling. CoP's, which were discussed in Chapter 2, could be an important way of bringing k-12 teachers and IPSE professionals into discussion about inclusive options for transition.

Implications for Research

There are many implications from this work for future research. In these implications, I have considered the gaps in the research based on my literature review and findings. These implications are separated into two sections: 1) Implications for IPSE Research; and 2) Implications for Research with Individuals with IDD.

Implications for IPSE Research. It is crucial to consider feelings of belonging as an outcome of future IPSE research, perhaps longitudinally over time to determine how feelings of belonging shift and what impacts those shifts. There were multiple findings related to inclusive courses at IHEs. Future research should determine the variety of ways that colleges let IPSE students into courses. In the cases where professors give permission, it would be interesting to also look at how they choose whether to let an IPSE student into the class. Findings related to unintentional grouping were not generalizable, so future observational and interview research should be done with faculty who teach IPSE students to determine best practices and use of UDL.

The importance of looking at demographics and how they impact student experience were mentioned previously. Some demographics that future research should include are race,

LGBTQIA+, SES, former schooling (inclusive or segregated), and communication style. I suggest that researchers qualitatively analyze students' experiences from various identities. Researchers should also quantitatively determine if these factors are significant in impacting admissions into an IPSE or outcomes after IPSE.

Future research should take an in depth look at supports connected to IPSE programs. This should be used to create a model of what supports should look like and standardize the language used related to IPSE supports. The FutureLIFE program has a very complex mix of paid and unpaid supports. Other programs also have complex structures, which makes comparison difficult, even though it is necessary for future program development. There should also be investigation into how people learn about IPSE opportunities, who does not know of their existence, and how that can best be remediated.

Research should also investigate how residential and non-residential programs support their students' social interactions. It was apparent that residential students at FutureLIFE had more supports and opportunities for social interaction than non-residential students. Looking at these differences across different programs will assist with determining new supports for non-residential students. Research should also be conducted to determine how dual-enrollment programs are supporting social interaction, especially when they have limited hours of operation compared to other types of programs. Longitudinal social interaction studies from IPSE acceptance to graduation or farther would be important for the field as well. This could help determine how students' social lives change over time and determine which years of IPSE have more barriers to social interaction. Even though I did have students from sophomore, junior, senior, and graduated years, each student experienced different things. A longitudinal study would make it easier to follow students to determine change over time.

Implications for Research with Individuals with IDD. More research needs to be done about inclusive research methods with individuals with IDD. Researchers should investigate how to best plan for and adapt methods continuously to facilitate Universally Designed Research and how to prepare for unexpected aspects of observation. Research like this should include analysis of reflective memos done throughout data collection to determine how researchers if and how researchers mention aspects of accessibility or unexpected decision-making moments. Researchers doing inclusive research with disabled individuals, especially within a DSE framework, need to publish about their work. Other researchers need to understand the importance of inclusive accessible research, and how to do it.

After participant observation studies researchers should do a follow-up survey or interview study to determine how researcher actions impacted the participants. This could help researchers react to acquiescence bias claims from readers. This would also have been helpful in determining how certain moments, like those at karaoke and the ice-skating rink, made the participants feel about the research and the researcher. Researchers need to understand that they do make an impact, as the quote in the beginning of this chapter explains.

Conclusion

IPSE is a place for individuals with IDD to figure out what they like and want. Just as is true for any student, college is a place to learn and explore new things. The IPSE field has grown so much in the last 15 years, but as these students have shown, there is still more to do. Overwhelmingly, the changes that need to be made are some of the most difficult, such as changing minds and combating societal ableism. Through this work, the participants themselves have demonstrated the value they have and bring to a university setting. I did this study to understand the IPSE student experience and improve it. This work and its potential positive

impact were only possible with the participants. Therefore, I have decided to end this

dissertation with a few words from my last interviews with the participants:

Researcher: What does disability mean to you?

Arthur: Just in general, I would just say, disability is also a different way of learning…

As well as diversity. Because it is. It doesn't say that it's disabled to do this. It just is a

disability. So it means you learn differently.

Flynn: Everyone with disabilities should do everything any typical student also does.

Jerry: Hey buddy. No. We're the same as you. You might be a little smarter than us but

we're not robots. We're not like aliens. Everybody thinks a person with disabilities, like

'Oh, I can't hang out with that non-human. We're humans just the same as you.'

Appendices

List of Appendices

Appendix A - Acronyms and Common Terms

Appendix B - Questionnaire

Appendix C - Consent Form Sample

Appendix D - Semi-structured interview questions

Appendix E - Focus Group Topics

Appendix A

List of Important Acronyms in Order From Dissertation

Acronyms

IPSE - Inclusive Postsecondary Education

IDD - Intellectual and Developmental Disability

IHE - Institutions of Higher Education

IRB - Institutional Review Board

SWD - Students with Disabilities

EAHCA - Education for All Handicapped Children Act

IDEA - Individuals with Disabilities Education Act

IDEIA - Individuals with Disabilities Education Improvement Act

ADA - Americans with Disabilities Act

HEA - Higher Education Act of 1965

HEOA - Higher Education Opportunity Act

CTP - Comprehensive Transition Program

TPSID - Transition and Postsecondary Programs for Students with Intellectual Disabilities

CIE - Competitive Integrated Employment

DSE - Disability Studies in Education

PAR - Participatory Action Research

AAC - Augmentative and Alternative Communication

Common Terms in this Dissertation

FutureLIFE - The IPSE program this research was done with.

Imagine University - The University where this research was conducted.

Syracuse University

Eligibility

What is your name?

What is your email?

Are you currently an ▮▮▮▮▮ student?

What is your age?

○ Younger than 18
○ 18-20
○ 21-25
○ 26-29
○ 30-39
○ 40-49
○ 50 and Older

Do you have a documented Intellectual or Developmental Disability?

○ Yes
○ No
○ Unsure

Are you interested in learning more about how to be part of this study?

○ Yes
○ No

○ Maybe

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Appendix C

Consent and Assent Form Sample

This sample is for Option 3 Participant Consent.

All other participant assent and consent forms were based on this.

Teaching and Leadership

Protocol Title: Exploring the Social Interactions of Students with Intellectual and Developmental Disability During College

Introduction of the Principal Investigator/Key Research Personnel:

Katie Ducett is in school for her doctorate at Syracuse University. She is planning a research study.

Dr. Beth Myers is the Director of the Taishoff Center. She is supervising Katie during this study.

You can contact Katie Ducett at ▉▉▉▉▉▉▉ and Dr. Beth Myers at ▉▉▉▉▉▉▉.

Introduction:

(The paragraph below cannot be changed so you can read it in plain language below it).

The purpose of this form is to provide you with information about participation in a research study and offer you the opportunity to decide whether you wish to participate. You can take as much time as you wish to decide and can ask any questions you may have now, during or after the research is complete. Your participation is voluntary.

What is this form for?

This form gives you information about the study.

- It will help you choose to participate or not to participate.

- Take your time. You can decide today, or you can decide later.

- Katie and Beth can answer your questions about the study. You can ask questions now and you can also ask questions later.

- Participation is voluntary. That means that you do not have to participate if you do not want to.

- Katie will talk to you about this form. If you would like to participate, you can sign this form.

- You don't have to decide today. Tell Katie if you would like to think about it or talk with someone else about it. You can decide later.

- This form is 13 pages long. If you need a break while we go through the form, let Katie know.

- Do you have any questions about the form before we start?

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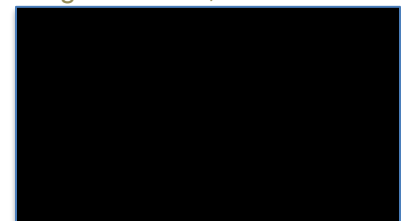
Why are Katie and Beth doing this study?

- Programs like [redacted] are kind of new at colleges.
- Katie and Beth want to know what the social lives of [redacted] students are like.
- Katie and Beth hope this research will help make all IPSE programs better.

What will I do in the study?

There are a few different ways that you can be part of this study. You can choose from these three options.

- **Option 1: Focus Group Only**
    - A focus group is a group talk with Katie and 4 other [redacted] students.
    - This option is explained on a different form. Ask Katie if you want to do this option instead.
- **Option 2: Pre-Interview-Observation-Interview (POI)**
    - Interviews are talks with just you and Katie.
    - Observations are times when Katie will join you for events on campus.
    - Interviews and observations with Katie will happen for a few months.
    - This option is explained on a different form. Ask Katie if you want to do this option instead.
- **Option 3: Focus Group and Pre-Interview-Observation-Interview (POI)**
    - This option includes focus groups, interviews and observations.
    - Focus groups are group talks with Katie and 4 other [redacted] students.
    - There will be two focus groups. One in August 2022 and another in November 2022.
    - Interviews are talks with just you and Katie. Each talk will take about 1 hour. You will have one each month.
    - Observations are times when Katie will join you for events on campus. Katie will join you for at least 2 events each month.
    - Observations and Interviews with Katie will happen for three months.
    - The option to do all of the methods (focus groups, interviews, and observations) is explained this form.

Highlights from Pages 1 and 2 -

- This form tells you about a project Katie and Beth are doing.
- For the project, Katie and Beth need [redacted] students to join.
- This form is just for doing all of the different parts of the project, option 3.

- If you like a different option, please ask Katie for a different form.

What happens in a focus group?

- A focus group is a group talk.

- In the Summer of 2022, there will be a group talk on zoom. You need to use zoom for this meeting. We will help you with this.

- In November or December 2022 there will be a second group talk. You need to come to █████████████ for this group talk.

- Katie will work with you and the other students to find a day and time that works well.

- 42 students might do this study. Only 10-30 will do the group talks.

- In your group talk, there will only be Katie and only 4 other █████ students.

- The talk will last 1.5 hours.

- Katie will send you the questions before you come to the group talk.

- Katie will audio and video record each of the group talks, so she can write down what happened.

- Her notes will help her understand and remember what your group discussed.

How do I act in a Focus Group?

- In the group talks, Katie will ask some questions.

- You can answer the questions if you are comfortable.

- You can listen to other students answer the questions.

- You can ask and answer questions Katie does not ask.

- You can talk to other students in the group.

Highlights from Page 3 –

- If you say yes to be in this study, you can be in 2 group talks.

- One talk will be in the Summer 2022 on Zoom.

- One talk will be in November 2022 in person.

- Katie and 4 other students will be in the group talk.

- Each talk will last 1.5 hours.

- Katie will ask some questions during the group talk.

- You and other students will talk to each other about the questions.

What things will we talk about in the focus group?

- Here are some of the questions that you might talk about in the group talk.

- Katie will send you the actual questions a few days before the group talk.

    - o **First Group - Summer**
        - ▪ What were you hoping to do while you were a student here (at ████████)?
        - ▪ In what kinds of situations are you most comfortable on campus? What about that space or situation made you comfortable?
        - ▪ What are social experiences a student can have on campus here at SU?
    - o **Last Group - November**
        - ▪ What could ████████ change to make social interactions better for you or other ████████ students in the future?
        - ▪ Have you experienced one of these things a student in ████████? Do you think those experiences are common for other ████████ students? Do you think they are common for non ████████ students? Why do you think that?
        - ▪ Is there anything else that you think would be important to share about your social experiences and interactions as ████████ students?

How do I act in a Focus Group?

- In the group talks, Katie will ask some questions.

- You can answer the questions if you are comfortable.

- You can listen to other students answer the questions.

- You can ask and answer questions Katie does not ask.

- You can talk to other students in the group.

Highlights from Page 4 –

- Katie will send you questions before the group talk.

- The questions will be like the ones on this paper.

- The questions are going to be about your social life at college.

- Do you have any questions so far about the study?

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What is POI?

P is a Pre-Interview	O is an Observation	I is an Interview after observations

Why are P,O, and I all part of this option?

- Before observing you, Katie wants to know what you think about your social life.

- Katie wants to make sure that she is able to see what life is like for you on campus during observations.

- Katie also wants to give you the opportunity to talk about what she sees and talk about your social life on campus.

- Each of these parts are important and will help Katie and Beth with this study.

How many other students will be in the study?

- There will be 3-5 students doing only POI, the option on this form.

- There might be 5-7 other students doing POI and focus groups.

- Total, there could be 8-12 participants doing POI.

- Across the entire study, including focus groups also, there could be 18-42 participants.

Highlights from Page 5 –

- P,O, and I are different activities you can do with Katie if you choose this option.

- P is a pre-interview, O is an observation, and I is an interview after the observation.

- If you choose this option, Katie wants you to do all three activities.

- There might be 8-12 other students doing all three activities during the study.

What is a Pre-Interview?

- In August 2022 you will meet with Katie for a one-on-one interview.

- An interview is when Katie will ask you questions about a topic.

- The pre-interview will last 1 hours.

- The pre-interview will be in a conference room, in ███████████████

- Katie will show you the list of questions while you are together.

- She will read you the questions and might ask other questions too.

- This interview will be audio and video recorded.

- Katie will type up what you both said during the interview.

- Katie might ask you these during the pre-interview:
    - Why did you decide to be a student in ████████?
    - Do you describe yourself as a social person?
    - Tell me about the activities you participate in while you are at ████████. What do you like or not like about these activities?

- Katie will show you a diagram called a Social Circle Diagram. She will explain the diagram to you. It looks like this:
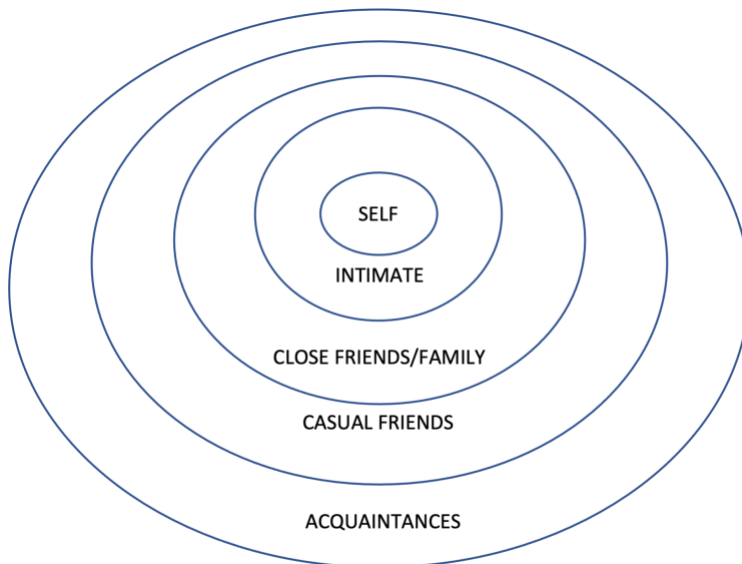
- You will talk with Katie about your friends and other people you see on campus.

- Together you will put the names of people you talked about on the diagram.

- Katie will ask some questions about where and when you see these different people.

- This will help you both decide where Katie should come observe you.

- You will also try to schedule the first few observations with Katie and your next interview.

Highlights of the Pre-Interview

- The pre-interview happens first in the study.
- Katie will ask you questions about your social life on campus.
- There will be a list of questions.
- Katie might ask you questions not on her list.
- You only should answer questions you want to answer.
- Katie will show you a social circle diagram.
- You and Katie will fill out the diagram with people you see on campus.
- You will schedule some observations and other interviews during this interview.

Do you have any questions about the pre-interview?

Next, we will talk about observations!

What is an observation?

- You will have Katie come observe you 6 times, or more if you want.
- Each observation will be about an hour.
- Katie will join in during whatever event you have chosen for her to come.
- She is hoping to see you during many different events and activities on campus during this study.
- Katie will try her best to blend in with whatever activity you invite her to.
- For example, if it is a basketball game, she will cheer and talk with people around you about the game.
- If it is a meal at the dining hall, she will also get something to eat and sit with you and your group.
- Katie will be writing notes on a notebook about what she sees.
- After Katie leaves, she will put all her notes onto a document on the computer. She will talk to you about the notes in the interviews later.

Page 8 of 13

What events will Katie come observe?

Some ideas are -

- o Basketball Games
- o Lunch or Dinner at the Dining Hall
- o Ice Skating on campus
- o Your ███ classes
- o A group project meeting
- o A club or organization meeting or event
- o A game night on campus
- o An ████████████ event

Do you have any other ideas?

What should I do during the observations?

- Katie wants you to do whatever you would normally do, as if she is not there.

- You do not need to pretend or act differently because she is there.

- If you want her to talk to people who are also at the event or activity and tell them why she is there, she will do that.

- If you want her to come to your dorm or somewhere else on campus that is private, she will always tell the other people why she is there.

- She will say something like "*I am here for a research study I am doing about social lives on campus. I will be taking notes sometimes. If I take any notes about you, I won't put your name down. Is this ok?".*

- If they say no, she will leave them out of the notes.

What about pictures?

- Katie will ask you take a few pictures of the event each time she comes to join you. These pictures should help remind you of important parts of the event later.

- Katie wants you to keep the pictures on your phone or camera until your interview that month.

- If you do not have a phone or camera to use for this, Katie and Beth will find you one.

- Katie will make sure you know how to use the camera or phone for pictures.

- There will be no video or audio recordings during any of the observations.

- You can ask Katie to leave the event or activity at any time if you do not want her to stay.

What happens to the notes?

- Katie will take notes of the different events.

- The notes will say things about what you did during the event.

- The notes will also say things about how you and other people were acting.

- After the event is over, Katie will type the notes onto a document.

- She will use this document to help her remember things.

Highlights of the Observation

- You will have Katie come observe you at least 6 times over the three months.

- You will pick different events that show what life is really like for you at █████

- Katie wants you to act like you normally would when she is there.

- Katie will do her best to blend in.

- You will have to take at least 3 pictures at every event to show what the event was like.

Do you have any questions about the observation?

Next, we will talk about the other interviews!

What are the interviews that happen after the observations?

- You will have 3 interviews one on one with Katie, not including the Pre-interview.

- Each interview should last 1 hour, and they will happen once a month.

- Katie will ask some questions and you will both look at the Social Circle Diagram again.

- Most interviews will take place in person in █████ Hall, but if it is easier, some of them can be done on zoom.

- Katie will audio and video record every interview, so she can write down what happened to help her understand what you talked about.

- Katie might ask you these questions during these interviews:
  - Tell me about the social experiences I joined you for to do participant observation in the last few weeks. Did you enjoy those experiences? Why/why not?
  - What do the pictures from these participant observations show? Can you describe them? What were you experiencing or thinking during these moments?
  - During those activities, have there been moments where you felt like you belonged or did not? Why?

Do you have any questions about these interviews?

What happens if I get upset or uncomfortable during the study?

- We do not think there is much risk or bad things that might happen if you do this study.
- You might feel upset or anxious if questions are hard to answer.
- You might feel upset or anxious if questions make you remember hard times you have had.
- Katie can support you or the group if people get upset.
- You might feel uncomfortable having Katie with you during the observations.
- You can leave at any point, and no one will be mad at you.
- Katie will do her best to fit in with the group you are with.
- You can tell Katie to leave at any time or can ask her to do something different at the event.
- If you feel nervous or upset, you can leave the room and come back later.
- If you feel nervous or upset, you can leave the room and not come back.
- Katie will tell you people on campus who can help you if you are feeling sad or upset.

Will other people know I was in the study?

- The other students in the group talk will know you are there.
- The other students in the group talk will know things you say.
- The other students might talk to people after the group talk about things you said.
- Katie will remind everyone to not talk about things people say after they leave.
- Other students might not follow that.
- People might see you go into the room for the last group talk.
- Other people should not know you are in the study unless you ask Katie to tell them during an observation.
- If people see you go into the interview room, they might know you are in a study.
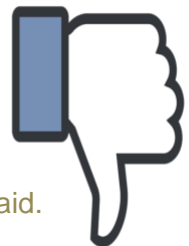
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Highlights from Page 10 –

- Katie and Beth do not think there are a lot of bad things that could happen if you do the study.
- You might feel upset or anxious during group talks, observations, or interviews.
- Other people might know you were in the study.
- Katie and Beth will help you if there are any problems.

What good things might happen if I do the study?

- There are good things that might happen if you do the study.

- Katie and Beth can't promise good things will happen, but they might.

- In the group talks, you might meet new people. They might become new friends.

- In the group talks and interviews, you might learn about some clubs or events that you could join.

- You also might learn more about yourself.

- This research could help make programs like ▮▮▮▮▮ better. You may feel good about being part of making programs better.

- Katie will tell you names of supports you could use on campus at ▮▮▮▮▮▮▮

Will things be kept private if I do the study?
- Katie will make sure things are kept private as much as possible.
- The first group talk will be on Zoom and some of the interviews might be also.
- Katie will use a Zoom that will not let people not from the study in.
- The last group talk and in person interviews will be in a room with the door closed, so other people cannot listen.
- The group talks will have only 4 other students and Katie.
- There is a chance someone will find out you were involved and what you said because there are 4 students in the group talk.
- Everyone in the group talk will be reminded that they should not discuss what people said after they leave.

Will other people be able to see the recordings or notes with my information?
- Katie will audio and video record all the group talks and interviews.
- Katie will put the recording in a safe folder on the computer, so other people cannot see.
- Beth Myers is the only other person who will be able to see the recordings.
- Katie will type up what is said by everyone on the recording and put that in the safe folder only her and Beth can access.
- Katie will remove your name when she types and will give you a fake name. She will let you pick your fake name if you want to.
- Katie will put the words she typed up into a folder in a safe online program called Dedoose. Only Katie and Beth will be able to open this folder in the online program.
- Katie will turn any paper notes or diagrams into something digital, in the safe folder. She will make sure any real names or not on them.
- Katie will then destroy any paper notes.

- The different things Katie puts in the safe folders will be deleted after 5 years.

Highlights from Page 11 –

- Good things might happen if you do this study.

- Katie and Beth will follow steps so other people do not find out you are in the study.

- You will be asked not to talk about the group talks after they are over.

What else should I know?

- If Katie and Beth want to do another study with the things they get from this study, they can, if your real name is not on it.

- If another researcher wants to do another study with the things from this study, they can, if your real name is not on it.

  o We do not need to ask you again to use these things.

  o All information Katie and Beth put in the safe folder will be there for 5 years.

  o After 5 years, Katie and Beth will delete the folder.

- Katie will not tell other people about things you say, unless you talk about being hurt by someone who did something against the law.

Will I be audio and video recorded?
- Yes, you will be audio and video recorded during the group talk.
- Katie will put the recording in a safe folder only Katie and Beth can open.

Will I get anything for doing the study?
- You will receive one $10 gift card for doing a group talk or pre-interview, whichever is first..
- You also will be entered to win a $25 gift card in a raffle.
- If you enter a raffle, it does not mean you win. Only some people will win the raffle.
- You get an entry into the raffle each time you participate.
- If you do the option on this form, you can participate at least 12 times.
- You can enter the raffle after doing the first focus group or pre-interview.
- You can enter the raffle again after doing any other interview, observation, and the last group talk.
- Raffle winners will be chosen in December 2022.
- For every entry into the raffle, your odds of winning are 1 in 200.
- You will receive the $10 gift card and entries into the raffle even if you leave the study before it is done.

Highlights from Page 12 –

- You will be audio and video recorded if you do a group talk or interview.

- You will get a $10 gift card for doing one of the focus groups.

- You also get to enter a raffle and might win another $25.

- The next page is where you can sign if you want to do the study.

What are my rights if I participate?

(The bullets below cannot be changed, so you can read it in plain language below them).
- Your participation is voluntary.
    o *You do not have to participate if you do not want to.*

- You may skip and/or refuse to answer any question for any reason.
    o *You can choose to not answer any question you do not want to answer.*

- You are free to withdraw from this research study at any time without penalty.
    o *You can decide to stop doing this study whenever you want. No one will be mad at you.*

Who can I talk to if I have questions?

- If you have a question, are worried about something, or want more information, you may contact Dr. Beth Myers at ▮▮▮▮▮▮▮ or Katie Ducett at ▮▮▮▮▮▮▮.
- If you have questions or concerns about your rights as a research participant, you may contact the Syracuse University Institutional Review Board at (315) 443-3013.
- You do not need to sign this now. Let Katie know if you are ready to say yes or no.

All of my questions have been answered, I am 18 years of age or older, and by signing this consent form, I agree to participate in this research study. I have received a copy of this form for my personal records.

I understand that the group talks and interviews I participate in will be audio and video recorded. By agreeing with this form, I am saying I am ok with being recorded.

Do you have any questions?

Are you 18 years of age or older?

Do you understand that any focus groups will be audio and video recorded?

Do you agree to participate?

How can I provide you with a copy of this consent script?

Appendix D

Semi-structured Interview Questions

Pre-Observation Interview Questions

Title:

Exploring the Social Interactions of Students with Intellectual and Developmental Disability During College

Who's Doing this Study? Contact us if you have questions!

Principal Investigator: Dr. Beth Myers   Phone: ███████   Email: bemyers@syr.edu

Key Researcher: Katie Ducett   Phone: ███████   Email: kducett@syr.edu

We are trying to answer this research question:

In what ways do students with Intellectual and Development Disability experience social interaction during their time as students in an Inclusive Postsecondary Education program?

What is this interview for?

We want to know what you have experienced as an ████████ student.

The questions we are asking you during the interview will help us understand more about your experience.

This paper has a list of most of the questions we will talk through.

Your answers are important and will help us make ████████ and other programs better!

How does the interview work?

You are getting these questions a few days before the interview.

If you want, look over them or have someone help you look over them before the interview.

If you want Katie to read the questions to you during the interview, she will.

If you want Katie to rephrase the question, she will. Just let her know!

If you do not want to answer a question, just tell Katie and she will move on to the next question.

Because this is the first time you've participated so far, we will send you a $10 gift card.

Where should she send it?
Demographic Questions:

You are unique, and these questions will help us understand more about you.

If you are not comfortable answering any of these questions, just let Katie know.

1. How old are you?

2. What is your race and/or ethnicity?

    a. For example, do you identify as white, Black, African American,

        Hispanic, or Asian?

3. What gender do you identify as?

    a. For example, do you identify as female, male, nonbinary, or

        something else?

4. What is your sexual orientation?

    a. For example, do you identify as gay, straight, lesbian, bisexual, or

        something else?

5. How long have you been a student in █████████?

    a. Do you remember what year you started at █████████?

    b. Are you a freshman, sophomore, junior, senior, or something else?

Social Life Questions:

1. Would you describe yourself as a social person? Why or Why not?

2. Can you tell me about your social network?*

   a. Who do you spend time with while at ███████

   b. Where do you spend time with them?

*We're going to also create a social circle diagram about these questions.

3. Tell me about meeting new people and how you make friends.

Explaining the Social Circle Diagram

This diagram shows how close you are to other people in your life.

The closer you are to the person, the closer they should be to the SELF circle.

INTIMATE –

People you are extremely close with. For example, a boyfriend, girlfriend, or partner.

CLOSE FRIENDS/FAMILY –

People you are very close with. You might see them a lot or go to them for advice.

For example, a best friend, a roommate, a sibling, or a parent.

CASUAL FRIENDS

People you might see often or have good conversations with, but you may not be very close to.

For example, someone you hang out with occasionally, staff, or someone from a club you are both in.

ACQUAINTANCES

People you are around but might not know.

For example, classmates, people you see in the dining hall, staff, or professors.

We'll circle any people who are usually working when you see them.

████ Questions:

1. Why did you decide to be a student at ████?

2. Tell me about the activities you participate in while you are at and outside of

   ████

   a. What do you like or not like about these activities?

   b. How did you decide to participate in them?

   c. What interactions do you have with others at these activities?

   d. Have you felt like you belonged at these activities? Why or why not?

3. Have you felt prepared for the social experiences you have had on campus?

   Why/why not?

4. Is there any way ████ could help you with social experiences on

   campus?

5. Is there anything else you think is important for me to know about your

   social experiences in ████?

Interview Questions – Post-Observation

Protocol Title: Social Lives at College: Experiences of Students with Intellectual and Developmental Disabilities

Principal Investigator/Key Research Personnel:

Principal Investigator: Dr. Beth Myers   Phone: ███████   Email: bemyers@syr.edu

Key Researcher: Katie Ducett   Phone: ███████   Email: kducett@syr.edu

Below is a list of questions I am interested in hearing your responses to. Remember, the purpose of this study is to learn about your social experiences while being a student in ███████ **want to know what impact your social experiences have had on your overall life as a college student. Your answers are important and will help us make decisions about the best ways to meet the needs of our students.**

You may take as much time as you need to read over these questions before we begin. If you would like to have the questions read to you, I will do so as many times as you need. I will give you time to think about your answers. If you do not want to answer any question, please just tell me. We will move on. If you want to stop the interview at any time, let me know. No one will be angry or upset. Your participation is voluntary.

Questions:

1. Tell me about the social experiences I joined you for to do participant observation in the last few weeks.

2. Did you enjoy those experiences? Why/Why not?

3. What do the pictures from these participant observations show? Can you describe them? What were you experiencing or thinking during these moments?

4. Did you feel included or like you belonged during those experiences? Why/why not?

5. Why did you think those events/experiences would be important for me to join?

6. Were there any other experiences in the last month you want to tell me about, that I was not present for? What do you like or not like about these activities? How did you decide to participate in them?

7. During those activities, have there been moments where you felt like you belonged or did not? Why?

8. Is there any way ███████ could help you with social experiences on campus?

9. Can you tell me about your social network? Has it changed at all since our last meeting? Would you add or move anyone around on the diagram? **We are going to talk through a Social Circle Diagram [Appendix 3b], on which you will think about the people you spend time with each day, and we will write them down on the diagram.**

10. Where do you interact with the people we just discussed? **Let's brainstorm where you would like me to come and join you for participant observations. We should pick some of the spaces you just mentioned, so I can see your experiences with people from different rings on the diagram.**

11. Is there anything else you think is important for me to know about your social experiences in ███████

Interview Social Circle Diagram

Protocol Title: Social Lives at College: Experiences of Students with Intellectual and Developmental Disabilities

Principal Investigator/Key Research Personnel:

Principal Investigator: Dr. Beth Myers   Phone: (315) 443-4058   Email: bemyers@syr.edu

Key Researcher: Katie Ducett   Phone: (315) 415-8711   Email: kducett@syr.edu

Below is a diagram we are going to revisit throughout this study. I am interested in discussing your social network, or the people you interact with regularly while you are in ███████ On the diagram, we are going to write down people you interact with who fall under different categories.

From these people, we are going to think about where you see them, and choose where you want me to do my participant observations. I am hoping to do participant observations of you in experiences with people from different rings on this circle.

SELF

INTIMAT
–

CLOSE FRIENDS/FAMILY

CASUAL FRIENDS

ACQUAINTANCES
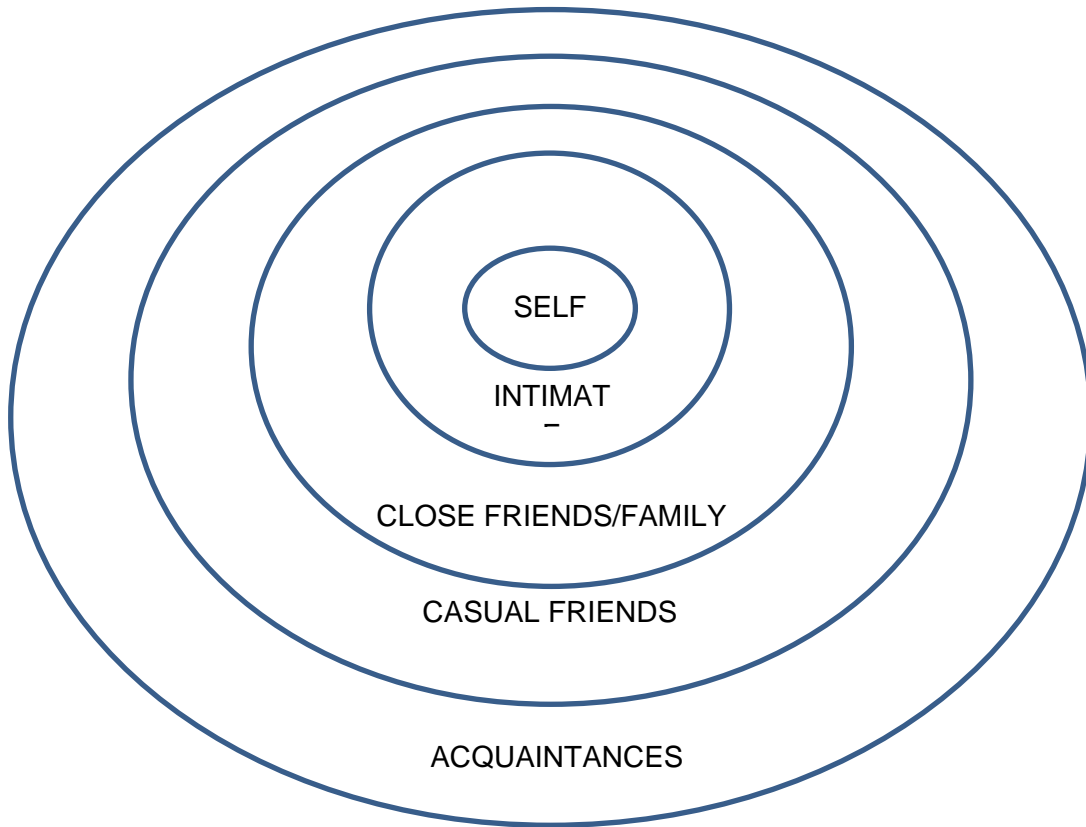
Appendix E

Focus Group Topics

Focus Group 1 Discussion Questions

Protocol Title: Social Lives at College: Experiences of Students with Intellectual and Developmental Disability

Principal Investigator/Key Research Personnel:
If you have questions, please let us know.

Principal Investigator: Dr. Beth Myers   Phone: (315) 443-4058   Email: bemyers@syr.edu

Key Researcher: Katie Ducett   Phone: (315) 415-8711   Email: kducett@syr.edu

How will the focus group work?

- We will meet on zoom as a group!
- We will talk about the questions listed here.
- The questions are about your social experiences when you were an ▮▮▮▮▮▮ student.
- Your answers are important and will help make programs like ▮▮▮▮▮▮ better in the future!
- **REMEMBER – You are not supposed to talk about who is in the group OR what people said after the talk is over.**

Questions:

1. Why did you want to come to ▮▮▮▮▮▮ What were you hoping to do while you were a student here?

2. In what kinds of situations are you most comfortable on campus? What about that space or situation made you comfortable?

3. In what kinds of situations have you been uncomfortable on campus? What about that space or situation made you uncomfortable?

4. What are social experiences a student can have on campus here at ▮▮▮▮▮▮

5. Is there anything about the experience of an ▮▮▮▮▮▮ student that is different from the experience other students have at ▮▮▮▮▮▮

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and inclusion: How an inclusive culture supports inclusive education. *Qualitative studies in Education, 12*(2), 157-74.

Katie Ducett

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EDUCATION

Ph.D.   **Special Education, Syracuse University**, In Progress – Anticipated Spring 2023
              Advisor: Dr. Christine Ashby
              Dissertation (In Progress):
              Exploring the Social Interactions of Students with Intellectual and Developmental Disability During College
              Committee: Dr. Beth Myers (Chair), Dr. Christine Ashby, Dr. Mike Gill, and Dr. George Theoharis
C.A.S.   **Disability Studies, Syracuse University,** 2022
CUT   **Certificate of University Teaching**, **Syracuse University,** 2022
M.A.Ed.   **Literacy Education (6-12), Nazareth College**, 2017
              Advisor: Dr. Naomi Erdmann
B.S.   **Chemistry, Nazareth College,** 2015
              Advisor: Dr. Kelly Hutchinson

Teaching Certificates

Literacy Specialist Grades 5-12: NYS Initial Certification

Chemistry Education Grades 6-12: NYS Initial Certification (Expired 1/21)

Special Education Generalist Grades 6-12: NYS Initial Certification (Expired 1/21)

PUBLISHED MANUSCRIPTS

Cartier, M., Snyder, S., & **Ducett, K.** (In Press). Don't Forget About Me! Creating Accessible, Equitable, and Inclusive Methods During Your Creative Writing Instruction. In S. Howe and K. Wright (Eds.), *Moving Words: Digital and Multimodal Creative Writing Pedagogies.* Lexington Books/Rowman & Littlefield.

Ducett, K. & Miller, J. (In Press). Hi, I'm Jake Miller! In M. Gill and B. Myers (Eds.), *Narrating Higher Education: Intellectual Disability.* University of Minnesota Press. https://doi.org/10.5749/9781452969268

MANUSCRIPTS IN REVIEW

Ducett, K. & Myers, B. (In Review). Building a Life: Examining the Advocacy and Social Experiences of Students with IDD in Inclusive Postsecondary Education. *International Review of Research in Developmental Disabilities.*

Ducett, K. & Soldovieri, S. (In Review) Sexual Assault Research as an Ableized Social Practice: A Critical Review of Research on Sexual Assault and Higher Education. *Journal of Women and Gender in Higher Education.*

Ducett, K., Shults, B., Myers, B., & Cartier, M. (In Review) Transition Planning Into Employment: Supporting Students with Intellectual Disability in Communication. *Journal of Postsecondary Education and Disability.*

MANUSCRIPTS IN PROGRESS

Ducett, K. & Myers, B. (In Progress) Postsecondary Education Program Admissions Requirements: Analysis of the Systemic Barriers Created by IPSE Program Admissions Requirements.

Ducett, K. & Ashby, C. (In Progress) Working to Work: How individuals with disabilities use their resources to obtain competitive employment.
CONFERENCE PRESENTATIONS

Ducett, K. & Myers, B. (2023, April). *Inclusive Postsecondary Admissions: Analysis of Systemic Barriers for Students with Intellectual and Developmental Disability* [Paper Session]. AERA National Conference, Chicago, IL, United States.

Ducett, K., Shults, B., Myers, B., & Cartier, M. (2023, April). *Transition Planning into Employment: Supporting Students with Intellectual Disability in Communication* [Paper Session]. AERA National Conference, Chicago, IL, United States.

Ducett, K. & Soldovieri, S. (2023, April). *A Critical Review of Research on Sexual Assault in Higher Education* [Roundtable]. AERA National Conference, Chicago, IL, United States.

Ducett, K. (2022, December). *Exploring Students' Social Interactions During Inclusive Postsecondary Education* [Conference session]. TASH National Conference, Phoenix, AZ, United States.

Soldovieri, S. & **Ducett, K.** (2022, December). *A Critical Review of Sexual Assault on Inclusive College Campuses* [Conference session]. TASH National Conference, Phoenix, AZ, United States.

Ducett, K. & Myers, B. (2022, October 20). *Inclusive Postsecondary Education Program Admissions: Analysis of Systemic Barriers for Students with Intellectual and Developmental Disability* [Conference session]. State of the Art Conference, Syracuse, NY, United States.

Shults, B. & Ducett, K. (2022, June 14). *Supporting Students in Communication of Employment Wants and Needs* [Conference session]. Association of People Supporting Employment First National Conference, Denver, CO, United States.

Myers, B., **Ducett, K.,** Nunez, M., Gleason, M., & Wilson, T. (2022, May 18). *Intersectional Identities and Barriers to Postsecondary Opportunities for Students with I/DD* [Conference panel]. AHRC Nassau DEI Conference, Virtual.

Ducett, K. (2022, February). *Disability Studies in Teacher Preparation* [Conference session]. Doctoral Student Peer Support Association Winter Conference, University of Rochester, Virtual.

Ducett, K. & Shults, B. (2021, December). *Overcoming Communication Barriers in Inclusive Postsecondary Employment Programs* [Poster presentation]. TASH National Conference, Virtual.

Smith, P. & **Ducett, K.** (2021, May). *Co-Teaching Across Difference* [Conference session]. FPP Annual Conference, Virtual.

Ducett, K., Cartier, M., & Borowski, N. (2021). *Navigating Special Education Services During Covid-19: What Works and What Needs Work* [Conference session]. Society for Disability Studies, The Ohio State University, Virtual.

HONORS / AWARDS
Outstanding TA Award (April 2022) – Awarded to Teaching Assistants (TAs) who have made distinguished contributions to Syracuse University by demonstrating excellence in significant instructional

capacities, such as classroom teaching, leading recitation or discussion sections, or assisting senior faculty members with high-enrollment courses.

Spector/Warren Fellowship (May 2021) – An experience offered to education related students who are interested in issues of prejudice and racism. Students engage with scholars who research the Holocaust as well as survivors.

Award for Excellence in Literacy Education (2017) – Awarded to a graduate student who excelled in training to become a literacy specialist.

Sister Jamesetta Slattery Award (2017) - Awarded for demonstrated excellence in academic performance, commitment to lifelong learning, and dedication to community service.

TEACHING EXPERIENCE
Instructor of Record
Syracuse University: Department
of Teaching and Leadership
SPE 324: Differentiation for Inclusive Education (Spring 2022)

- Designed course content and lead class facilitation utilizing best practices of teaching, including Differentiation, Universal Design for Learning and Culturally Relevant Pedagogy, while continuously encouraging my students to use these strategies in their own teaching.
- Supervised a teaching assistant and provided training to him in procedures of grading and course technologies, demonstrating strong teamwork and collaborative skills.
- Demonstrated care and patience by meeting with undergraduate students regularly throughout the field placement portion of this course, to support them in their growing practical knowledge of teaching.
- Provided instruction based in accreditation standards and regularly met collaboratively with other education faculty to discuss course connections to these standards.

DSP 614: Critical Issues in Dis/Ability and Inclusion (Fall 2021)

- Adapted the set course curriculum to best meet the needs of students from varying identities as well as experiential backgrounds, as students in this master's level course came from a variety of fields (Audiology, Disability Studies, Law, Physical Education, Elementary Education, and more).
- Utilized numerous technologies to give students the opportunity to engage with the content through a virtual but synchronous medium.
- Co-taught with and supervised my teaching assistant while giving them opportunities to help collaboratively plan different course activities.
- Delivered extensive feedback to students for various written and creative assignments to ensure their understanding of the course content.

EDU 201/202: Field Experience (Spring 2020)

- Supervised students in the field at a local elementary school fulfilling education requirements by reading with pre-k and elementary school students.
- Redesigned the course amid the switch to virtual during the beginning of the Covid-19 pandemic.

- Graded student work throughout the entirety of the course and provided feedback in relation to their written work and teaching.

Instructor of Record
Nazareth College of Rochester:
School of Education
Strategies for Teaching Literacy in the Content Areas (Summer 2022)

- Used critical thinking skills to plan two content literacy strategies courses for six-week sessions in the summer, ensuring they were practical and demonstrating necessary theoretical knowledge of pedagogy and being culturally responsive.
- Established a hybrid course with both synchronous and asynchronous course materials and activities by using extensive time management and organizational skills.
- Encouraged active reflection throughout each week of the course by giving reflection prompts and allowing students the opportunity to be metacognitive about their own learning, reading, and teaching.

Nazareth College of Rochester:
Department of Chemistry

General Chemistry Lab (Spring 2017-Fall 2018)

- Supervised undergraduate students while leading them through a variety of chemistry experiments in an introductory practical lab course.
- Used my research skills and chemistry knowledge to support the students in the creative creation of their project-based final projects. For example, analyzing different detergents for their cleaning ability in relation to their chemical makeup.
- Graded lab reports and gave substantial feedback and assistance so students could improve their scientific inquiry skills and chemistry knowledge.

Teaching Assistant

SPE 311: Perspectives on Disabilities
(Fall 2022)

- Assisted the primary faculty with the planning and teaching of a course which gives an overview of a variety of disability categories, ensuring the highlighting of first-person perspectives and enhancing the understanding of disability pride.
- Supported undergraduate students, primarily from teacher preparation programs, in their understanding of the theoretical foundations of disability and the connections to practice in k-12 classrooms.
- Graded student work and provided extensive feedback, to best enhance student learning and provoke greater engagement with content.

SPE 705: Practicum in Psychoeducational Evaluation and Planning for Exceptional Children
(Summer 2021)

- Assisted the primary faculty with analysis of various psychoeducational assessments that our students executed with two k-12 students.

- Collaborated with the faculty and graduate level students in this course to create a complete psychoeducational evaluation to be sent to the two focus students' educational teams, demonstrating strong communication skills.
- Supported the primary faculty with technical support by assisting with the video technology needed to record the graduate students' examination experiences.

Block 2 Courses: (Fall 2020 – Spring 2021)
SPE 324: Differentiation for Inclusive Education and EED 328: Block 2 Field Experience

- Assisted with the facilitation of a virtual class for undergraduate elementary education students by engaging students in introductory icebreakers each class, leading discussion of topics such as IEP processes and disability categories, as well as creating much of the technological materials such as Jamboards and Padlets.
- Collaborated with other program faculty to re-design the field experience into a course on anti-racist pedagogy, due to the COVID-19 pandemic eliminating the ability to have a real field experience at the time.
- Graded student work promptly and with attention to detail, providing substantial feedback to students on ways to improve and where their strengths were.

EDU 203: Introduction to Inclusive Schooling (Fall 2019)

- Collaboratively created engaging course materials to then utilize during weekly discussion sections for undergraduate students pursuing education related fields, typically during their freshman year.
- Assisted the primary course faculty with the lecture section of this course by leading small group activities throughout the semester and assisting with classroom management.
- Provided substantial feedback on the extensive written work required in this course and graded summative assessments in a timely manner. Grading included collaboration with the co-teaching assistant to ensure it was fair and equitable across our three separate course sections.

Lawrence B. Taishoff Center for Inclusive Higher Education
Syracuse University

This center facilitates the creation and teaching of optional courses for students in the InclusiveU program, based on student interests.
Student Leadership Conference Seminar (Spring & Fall 2022)
- Co-taught this course to students in the Inclusive Higher Education program at Syracuse University as a means of gathering input to enhance conference planning and to support the students in creating their own conference proposals.

Health Matters Seminar (Spring 2022)
- Taught students in the Inclusive Higher Education program at Syracuse University about different aspects of health and wellness. Co-taught and co-planned with an individual with an intellectual disability who was a former student in the program.

Digital Citizenship Seminar (Spring 2021)
Co-taught this course to students in the Inclusive Higher Education program at Syracuse University to support their growth in the topics of digital medias and safety as citizens of the digital world.
Classroom Teacher
Rochester City School District (Fall 2017-Spring 2019)
Reading Teacher

- Taught students in grades one through six about reading-related topics, ranging from decoding to comprehension. Our building utilized the Fountas and Pinnell LLI kits for reading intervention.
- Collaborated with my students' classroom teachers to determine the best methods to work with them, as well as to determine potential times for push-in services.
- Led extra-curricular activities to engage students outside of the classroom, including a lunchtime book club and running club.
- Participated on the leadership committee where I added to discussions about best practices for the building in relation to literacy instruction as well as student and family engagement.
- Advocated for students best interests during IEP and RTI meetings regularly.

GRANTS

Ducett, K., School of Education Grad Student Travel Grant, Syracuse University. (2022). **Requested: $400** Approved..

Myers, B. (PI), **Ducett, K** (Co-PI), The Joan N. Burstyn Endowed Fund for Collaborative Research in Education, Syracuse University. (2022-2023). **Requested: $2,500**. Declined.

GRANT WRITING SUPPORT

I wrote and edited large federal grants along with teams of faculty and doctoral students. This included immense research on topics such as inclusion in k-12 schools, multi-tiered systems of support, technical assistance best practices and inclusive postsecondary education programs. This also included editing of APA and compilation of citations from the entire team into a bibliography. In working on both Ashby and Myers grants, I delegated grant research and writing among the team of doctoral students.

Ashby, C. (PI), Myers, B. (Co-PI), Cosier, M., Theoharis, G., Alston, K., *STRIDE National Technical Assistance Center: Systemic TA Results for Inclusion of Students with Disabilities in Education.* Office of Special Education and Rehabilitation Services, US Department of Education. (2022-2027). **Requested: $9,909,180.00.** Declined.

Myers, B. (PI), Ashby, C., Myers, R., Morris, M., White, J., Postsecondary Programs for Students with Intellectual Disabilities – National Technical Assistance and Dissemination Center (PPSID - NTAD), US Department of Education. (2021-2024). **Requested: $5,930,514**. Declined.

Myers, B. (PI).. Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID), US Department of Education, Office of Postsecondary Education. (2020-2025). **Requested: $2,500,000**. Declined.

SERVICE TO PROFESSION

MOST: Museum of Science and Technology: Fall 2019-Fall 2020
- Created sensory friendly science activities for use with individuals who visit the museum.
- Encouraged the creation of a museum "walk-through" with descriptions of different areas of the museums and other information, such as their sound level, which was later implemented.

REVIEWER
American Educational Research Association
Excelsior
Journal of Inclusive Postsecondary Education
State Of The Art Conference

TASH National Conference
SERVICE TO SCHOOL OF
EDUCATION
SOE Strategic Planning Sub-Committee on Graduate Student Climate and Recruitment
(Fall 2021)
SOE Graduate Student Council: Co-President (2021-2022)
SOE Graduate Student Council: Social Media and Marketing (2020-2021)
SOE Alumni Event Moderator: Juli Boeheim and Roxi McNabb (Spring 2021)
- Organized and hosted numerous events for the graduate students in the School of Education (IRB Coffee Hour, Grants and Funding Coffee Hour, Weekly Writers Workshop, Health and Wellness Events, etc.)
- Facilitated meetings with the Graduate Student Council to advocate for the needs of the student body.
- Analyzed issues within the realm of graduate student climate and recruitment and then creatively designed solutions to best solve those issues.

Lawrence B. Taishoff Center for
Inclusive Higher Education
State of the Art Conference   2021-Present
SOTA Student Leadership   2020-Present
Conference
- Collaboratively design the agenda and structure for both conferences, which were virtual due to the Covid-19 pandemic in 2020 and 2021. Continued to design accessible and engaging conferences for an in-person conference in October 2022.
- Facilitated frequent committee meetings with other organizers and committee members.
- Recruited and delegated tasks to a staff of volunteers throughout the planning of the conferences as well as during the conferences.
- Organized and led training meetings with volunteers and presenters prior to the conference to ensure comfort with the conference happenings.

Student and Research Support at European SOTA Conference in Salzburg, Austria (October 2022)
Think College Policy Advocates in
Washington, D.C. (Summer 2022)
Created First Year InclusiveU Seminar Curriculum (Summer 2021 and 2022)
Person Centered Planning Organization (Summer 2021)
Internship Program Orientation Curriculum (Summer 2020)

- Implemented knowledge of inclusive higher education programs, pedagogy, and research skills to enhance programming for the Taishoff Center and InclusiveU.
- Designed curriculum and Blackboard pages for the directors of InclusiveU to ensure that their first-year seminar and fourth-year internship seminars were engaging and clear.
- Expanded my knowledge of IPSE programs by assisting students in various settings, such as in a film class, and during an advocacy conference in Washington, D.C.
- Advocated on Capitol Hill with staff and students from the Taishoff Center, meeting with the staff members for NY senators and congress people, such as Senators Schumer and Gillibrand and Representatives Morelle and Katko.

SERVICE TO PROGRAM
Project Include
Community Event Organizer (2021)
Newsletter Submission (2021)
Newsletter Submission (2022)

- ProjectINCLUDE is a grant that funds special education doctoral students from three different universities; Florida State University, Arizona State University, and Syracuse University.
- As a student under this grant, courses were taken across all three universities and opportunities for collaboration have been pursued.
- Annual newsletters have been created with my input on two different pieces about events the cohort has held and about my journey and future goals. I also took initiative in planning a jeopardy game for the students across the institutions, to assist in creating a stronger community bond digitally.

MEMBERSHIPS / AFFILIATIONS

American Educational Research Association
TASH
Association of People Supporting Employment First

OTHER WORK HISTORY

YMCA of Central New York - January 2020-Present
Aquatics Supervisor, Lifeguard, Swim Instructor, Group Fitness Instructor

Rotary Sunshine Campus - June 2009 - August 2019
Rockwall Team Leader, Program Staff, Cabin Head, Counselor

Heritage Christian Services - January 2015 - June 2018
Direct Support Professional, Community Habilitation

LifePrep@Naz - August 2013 - June 2015
Student Mentor and Job Coach